



End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients

Guidance for health professionals

January 2018

End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients

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For more information contact:

Clinical Excellence Division, Department of Health, GPO Box 48, Brisbane QLD 4001, email CareattheEndofLifeProject@health.qld.gov.au, 07 3328 9148.

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A quick note about standalone resources referred to in these guidelines.

Stand-alone resources developed for this guideline and the [Advance Care Planning Clinical Guidelines](#) are available to download from the [Care at the End of Life website](#). Downloading resources from the website (or by clicking on the pins below) will provide enhanced graphics. It is recommended the handouts be printed in colour, if possible.

Stand-alone resources include:

-  [Decision-making flowcharts to obtain consent \(Section 2.2.2\)](#) (includes emergencies)
-  [Withholding and Withdrawing Life-sustaining Measures – Legal Considerations – 2 page handout \(Appendix 6\)](#)
-  [ACP Quick Guide – possible triggers for initiating advance care planning \(Appendix 7\)](#)
-  [Advance care planning six step process \(Appendix 7\)](#)

Also note that the [Advance care planning clinical guidelines](#) are also available from the [Care at the End of Life website](#).

“The goal of the interdisciplinary team providing end-of-life care should be to deliver care that is appropriate to the needs and condition of the patient, and aligned with their expressed wishes. Opportunities should be sought to identify the patient’s goals and wishes for their future care; offer psychosocial, spiritual, cultural and emotional support; provide treatments that maintain or improve quality of life; and avoid unnecessarily burdensome or unwanted investigations and treatments.”

(Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC, 2015. p.14)

Summary

The primary goal of medical care has always been the preservation of life and health. However, every day decisions must be made about whether or not to withhold or withdraw life-sustaining measures. These decisions are made after careful consideration of the wishes, values and goals of the patient, the balance of benefit and burden from any treatment that is being considered, the likelihood of the various outcomes that might be achieved, and the best interests of the patient. When life-sustaining measures are withheld or withdrawn, the task and the duty of clinicians remains to provide comfort and dignity to the dying person and to support others in doing so. This process requires clinicians to manage discussions that respect patient autonomy while exploring whether a patient’s life should be artificially preserved. Health professionals must be supported as they address the complex balance between the quantity and quality of life within the context of highly technological medicine that runs the risk of preserving a life but with little quality. Respect for life does not mean that all life must be preserved at all costs.

There are difficult clinical, legal and ethical issues to navigate when deciding whether to withhold or withdraw life-sustaining medical treatment. Decision-making about life-sustaining measures is less demanding upon those involved if advance care planning starts early, perhaps even before the patient has become ill. Ideally, this will allow patients to discuss their wishes with their family¹ and friends and to make informed choices about issues such as resuscitation planning so that decisions about treatment and care at the end of life are not made in a crisis.

Good medical practice should guide the clinical assessment and goals of treatment discussed with the patient and/or their substitute decision-maker/s. However, in meeting the standards of good medical practice, doctors are under no obligation to initiate treatments that are not clinically indicated or are known to be ineffective, nor to continue with treatments that have become ineffective.

For patients at the end of life, the potential benefits of medical treatment must be weighed against its potential to be burdensome, which might include pain, suffering, compromise of dignity, and loss of independence. In most situations, assessment of the potential benefits and burdens of treatment is based on various levels of probability rather than absolute certainty. Appropriate actions can also be unclear to attending staff where advance decisions have not been made and documented about resuscitation and decisions are required urgently.

Respecting patients’ choices for end-of-life care begins long before the terminal phase and is an essential component of care for all patients with life-limiting illnesses. While, ultimately, medical decisions will be made by doctors, early, frank and honest communication with the patient and those closest to them will avert many potential problems, and also ensure the patient’s wishes for care at the end of life are respected. When difficult decisions are required about whether to commence or continue, or to withhold or withdraw life-sustaining measures, a range of often conflicting factors may need to be considered. Largely, considerations about life-sustaining measures occupy the core at the intersection of three key domains; clinical, legal and ethical.

¹ Please note: Throughout these guidelines, the word family is often used interchangeably with substitute decision-maker. This is largely for readability purposes, as for the vast majority of cases, the substitute decision-maker will be the next of kin or a close member of the patient’s family. However it is acknowledged that in some cases, the legal substitute decision-maker may or may not be a member of the patient’s family, and will need to be determined in accordance with the law.

Those for whom decisions are about life-sustaining measures are required represent some of our most vulnerable patients and are usually at or nearing the end of their life. Many of these patients also lack capacity for decision-making and rely on those closest to them or legal documents to support them and make decisions on their behalf. All patients, irrespective of age, race, gender, culture or lifestyle, are entitled to the same dignity, compassion and quality of care at the end of life, regardless of whether they have the capacity to make decisions about their health care. Decisions involving life-sustaining measures are most associated with acute emergency situations and careful documentation is required so that all clinicians feel confident and supported in carrying out any written medical directions. However, in the absence of documentation, the standards of good medical practice, which includes obtaining the appropriate consent where there is time to do so, and the patient's best interests prevails.

These guidelines are designed to provide considerations to support decision-making about life-sustaining measures for adults, however guidance for children and young people under the age of 18 is provided in a [separate document](#).

Purpose

The purpose of these guidelines is to support and guide health professionals, administrators, policy-makers, decision-managers and interested parties who encounter the profoundly complex area of decision-making associated with life-sustaining measures. As such, these guidelines should be viewed as a reference document when encountering challenges of decision-making around life-sustaining measures in the Queensland context. 'Life-sustaining measures' is a specific term referred to in what is commonly termed the "guardianship legislation" in Queensland;¹ other jurisdictions nationally and internationally use similar terms, such as life-prolonging or life-limiting measures. Almost always, such measures refer to health care intended to sustain or prolong life and to maintain the operation of vital bodily functions that are temporarily or permanently incapable of functioning independently. In other words, measures that will save a person whose life is under imminent threat. Life-sustaining measures can include, but are not limited to cardiopulmonary resuscitation, assisted ventilation and artificial hydration and nutrition.

These guidelines update the document *Implementation Guidelines End-of-life care: Decision-making for withholding and withdrawing life-sustaining measures from adult patients*, first published internally by Queensland Health in 2009. The changes to this version are not significant and reflect minor amendments to relevant legislation, new case law and updates in conjunction with a scholarly review. While Queensland's guardianship legislation is under review at the time of publication, for the most part, national and state laws largely remain the same. Recent Australian government initiatives and reforms that impact on end-of-life care decisions are now incorporated into these guidelines. Perhaps the most significant change to the earlier guidelines, is that they are now combined into one document, and not two separate parts.

In 2009, this document's predecessor was designed to provide guidance across a spectrum of issues to support health professionals in decision-making around withholding and/or withdrawing life-sustaining measures. The guidelines were also specifically developed as a resource to accompany the statewide implementation of the Acute Resuscitation Plan (ARP), which was endorsed for use in all Queensland Health facilities in 2010. Updating the original document is intended to continue to support our health professionals by offering consistent statewide guidance on decision-making around life-sustaining measures and at the same time preserve the autonomy of the Health and Hospital Services.

While little has changed in the regulatory environment (particularly in terms of guardianship laws), the issues and challenges that surround healthcare delivery for people approaching the end of life are still as profound as they ever were. A number of challenges to the provision of health care for this vulnerable population either remain active or continue to increase:

- the increasing number of elderly Queenslanders, including those with combinations of frailty, significant physical and cognitive disabilities, dementia, multiple chronic illnesses, and functional limitations
- while overall death rates are decreasing in Australia,² living with chronic disease is becoming increasingly common
- growing cultural diversity of the Australian population, which makes it increasingly important for clinicians to approach all patients as individuals, without assumptions about the care choices they might make
- managing community expectations about the inevitability of death and dying in our society, which is sometimes sensationally reported as a failures of the health system
- the unsustainable growth in costs of the current health care delivery system over the past several decades
- systemic problems, including fragmented care delivery, perverse financial incentives, time pressures that limit communication, a lack of service coordination across programs, and the availability of palliative care services to keep pace with the growing demand
- inequities accessing the health system itself, with Aboriginal and Torres Strait Islander populations and those in remote areas at more risk of dying from chronic disease and injury
- the complex tension between legal, clinical and ethical considerations in this area.

To accommodate the profound complexity in this area, these guidelines start from the premise that decision-making in this area is not, and can never be, straight forward. Therefore in many instances, its guidance offers a less direct approach - by posing questions rather than answers, and considerations rather than algorithms or formulas. These guidelines aim to guide reflection, judgement and action in providing good care at or near the end of life and, in particular, to provide legal, clinical and ethical frameworks for making decisions under conditions that are challenging and often psychologically distressing for all involved.

Using this document

It is important to remember that decision-making at the end of life can be very challenging at times, even for the most experienced clinicians. However, a good working understanding of the legal, ethical and clinical issues can go a long way to reducing those difficulties and should be a starting point for all those involved in caring for patients approaching the end of their lives and supporting their families.

This document may be used for a variety of purposes and in a variety of ways. As a reference document that summarises the sometimes complex legal, ethical and clinical issues around decision-making, it is a rich resource for those wishing to achieve a more instructive understanding of the concepts involved. Some clinicians may wish to increase their knowledge relevant to their domain of clinical practice so they can be more effective as they make decisions with their patients. In this setting it is probably best just to work through the document while coming to an understanding of the variety of issues that are addressed. Unfortunately, as this can be a complex and difficult topic involving a multiplicity of intersecting issues, there are no easy “work arounds”.

For those using the document to address the issues raised by particular cases it is suggested that the clinician first of all clarify the questions that they wish to have answered and then undertake a structured exploration of the relevant sections. The [Common Scenarios](#) section below may also be helpful, as it provides guidance for some specific issues involving decisions about life-sustaining measures. The [Table of Contents](#) and the navigation pane on the left hand

side allows the reader to connect by hyperlink to the relevant section without having read through the entire document.

It should also be noted that all staff are subject to the duty of confidentiality outlined in Part 7 of the *Hospital and Health Boards Act 2011* (HHB Act). Accordingly, all staff need to comply with a lawful exception to that duty when discussing patient information with another person. References to discussions with ‘family’ in this document are assumed to be done lawfully. For example, there may be times when it is not lawful to disclose patient information to a family member, and sometimes the patient’s substitute decision-maker will not be a family member. Therefore, it is highly recommended that staff be familiar with the relevant sections of the *Hospital and Health Boards Act 2011* dealing with permitted disclosure of confidential information.³

This use of this document and the information it contains is not a substitute for good communication and open discussion, nor should it compromise the vital importance of establishing good working relationships with patients, families and other clinicians. In some circumstances, it may be appropriate to seek specific legal advice in relation to particular cases.

Ten key messages

While there are many important concepts covered in this document, ten key take-away messages are summarised below. It is important to remember the information below is a brief guide only, and should not be relied upon without further consideration of more detailed information provided elsewhere in this document.

1. Refer to the flowcharts for decision-making about [life sustaining measures](#) for quick guidance. There are two of these: the first is when decisions are required to [PROVIDE](#) life-sustaining medical treatment; the second is for decisions to [WITHHOLD OR WITHDRAW](#) life-sustaining measures. Print them out for easy reference, preferably in colour.
2. Remember, legal follows clinical, not the other way around. Start with the clinical position first – what is [good medical practice](#) and in the patient’s [best interests](#)? Many of the legal aspects turn on the need for consent, so refer to the [consenting regime](#) if more information is needed about the consenting requirements, in particular any [legal documents](#) that maybe required. For quick reference of the main points, print out the [legal considerations sheet](#) (double-sided page) used during education and training sessions.
3. Legal aspects of decision-making also includes whether decisions are required in [emergency situations](#). In some urgent situations, consent is not required to provide life-sustaining measures, nor to withhold and withdraw them. This largely depends upon whether it is known the person without capacity has ‘[objected](#)’ to the healthcare being provided or withheld and/or withdrawn. When there is no guidance as to the patient’s preferences, the doctor must exercise clinical judgement by adhering to the standards of [good medical practice](#), and be willing to defend their decision. If the patient had/has decisional capacity when they made or make any objections (to the [treating doctor](#)), their directions must be followed.
4. Since the introduction of the [Guardianship and Administration Act 2000](#), except in some acute emergency situations, unilateral decisions to withhold and withdraw life-sustaining measures are not lawful. A [collaborative approach](#) is required; one that actively [involves the patient’s support network](#), which will usually include their [legal decision-maker](#). The [Guardianship and Administration Act 2000](#) provides that every person who [lacks capacity](#) has a decision-maker to act on their behalf – the Public Guardian being the decision-maker of last resort.
5. There is a [legal requirement](#) to document the decision-making pathway leading to every decision to withhold and/or withdraw life-sustaining measures. The [Acute Resuscitation Plan \(ARP\) was developed to document this process](#), which includes following the appropriate [consenting pathway](#). Note that medical practitioners can be indemnified if this process is followed in good faith.⁴

6. All documents are not equal. A valid [Advance Health Directive \(AHD\)](#) is the only legal document that “acts as” the person’s decision-maker should they lose capacity. [Doctors may override AHDs](#), but only in specific circumstances. Other enduring documents may also come into play should the patient lose capacity, such as an Enduring Power of Attorney ([EPOA](#)) which appoints a legal [decision-maker](#). An [ARP](#) is a medical order and therefore serves a very different purpose to an AHD. An [ARP](#) is evidence that a clinical decision-making process and [consenting pathway](#) was followed, and is a means by which the doctor directs treatment.
7. The section on [ethical considerations](#) is just that, considerations. It is included to explore concepts that allow for broader [ethical principles](#) to be contemplated. While some of the concepts within the ethical considerations section involve legal elements, such as [euthanasia](#) and [assisted suicide](#), there is no mandate to adopt any particular position on other ethical matters raised in that section.
8. [Resuscitation planning](#) is a subset of the broader [advance care planning](#). Resuscitation planning should result in the completion of an [ARP](#) which directs future treatment. Advance care planning should [commence early](#) in the disease trajectory (if not earlier in life), and outcomes documented appropriately. Patients and their families should be made aware that completing [legal documents](#) is entirely voluntary.
9. Patients with decisional capacity can decide to [refuse medical treatment](#) even if this results in their death or would cause it to happen sooner. It is important to note that no one else needs to agree with them. This is a fundamental right and must not only be [respected, but followed](#).
10. Finally, remember that doctors are under no legal or ethical obligation to offer or attempt treatments that are considered [futile](#); that is, medical treatment that potentially affords no [benefit](#) and would cause the patient [harm](#). It may be necessary to engage in early [collaboration](#) and appropriate [dispute resolution](#) and, particularly when there is ongoing conflict, benefit can be obtained from [suggesting a second opinion](#).

Ten (reasonably) common scenarios

The following represent ten (reasonably) common scenarios where decisions about life-sustaining measures will be required. Links are provided to assist the reader to quickly locate the appropriate section within the document for more in-depth guidance.

1. The decision involves withholding (not providing or continuing) CPR	
a.	Follow the flowchart about withholding and withdrawing life-sustaining measures
b.	Remember, a decision to withhold and/or withdraw life-sustaining measures does not exclude the provision of supportive treatment and care, such as palliative therapies, seizure treatments, management of pain and other distressing symptoms
c.	Decisions about the following will be required:
i.	First, decide what is clinically appropriate for the patient, what is good medical practice and in their best interests ?
ii.	Is this an emergency situation ? If so, UNLESS the patient has objected to cardiopulmonary resuscitation (CPR) being withheld (i.e. they have requested it) consent is not required to withhold CPR (TIP: if time, check the AHD or ARP for evidence the patient has requested CPR as this may equal an objection)
iii.	Determine the patient’s capacity for decision-making (consenting regime <u>only</u> activates when a person loses capacity for decision-making – until then discuss with patient)
iv.	Does the patient have an active ARP ? If so, this can be followed, exercising clinical judgement in the circumstances
v.	Does the patient have an AHD (this effectively acts as their legal decision-maker when capacity is lost; if they have capacity, the AHD does <u>not</u> apply)
vi.	If no AHD and no ARP, who is/are the substitute decision-maker/s ? Work through the list

outlined in the [flowchart](#) to determine who will provide consent if it is needed

- vii. Withhold or withdraw CPR if consistent with [good medical practice](#) and appropriate consent obtained, if required.

2. The decision involves withholding or withdrawing artificial hydration and/or nutrition (e.g. a Percutaneous Endoscopic Gastrostomy (PEG) tube)

- a. First, decide what is clinically appropriate for the patient – what is [good medical practice](#) and in their [best interests](#)
- b. Follow the [flowchart](#) about withholding and withdrawing life-sustaining measures
- c. Remember, a decision to withhold and/or withdraw life-sustaining measures does not exclude the provision of supportive treatment and care, such as palliative therapies, seizure treatments, management of pain and other distressing symptoms
- d. Decisions about the following will be required:
 - i. Determine the person's [capacity for decision-making](#) (consenting regime only activates when a person loses capacity for decision-making – until then discuss with patient)
 - ii. [Consent is required in EVERY case](#) to withhold or withdraw artificial hydration and/or nutrition, irrespective of whether it is an [emergency](#) (rarely an emergency in this context)
 - iii. Does the person have an [AHD](#) (this effectively acts as their legal decision-maker when capacity is lost)
 - iv. If no AHD, who is/are the [substitute decision-maker/s](#)? Work through the list outlined in the [flowchart](#)
 - v. If the patient has decisional capacity they are [entitled to refuse](#) feeding (e.g. to have a PEG or nasogastric tube inserted and this decision must be [followed](#)).

3. The patient is rapidly deteriorating from an irreversible condition, lacks capacity and the family are demanding “everything to be done”

- a. First, decide what is clinically appropriate for the patient – what is [good medical practice](#) and in their [best interests](#)?
- b. This situation will likely require [dispute resolution](#), so it may be useful to involve senior clinician/s as soon as possible
- c. It can be very helpful to clarify what the family understands the patient's goals, wishes and values to be and compare these with what the clinicians believe can be achieved. Arrange [family conferences](#) to enable open consultation with all involved
- d. Follow the [flowchart](#) about withholding and withdrawing life-sustaining measures
- e. Confirm the clinical decision based on [good medical practice](#) and in the [patient's best interests](#)
- f. Decisions about the following will be required:
 - i. Is this an [emergency situation](#)? If so, UNLESS the person is directly known to have [objected](#) to life-sustaining measures being withheld or withdrawn (i.e. they have requested it to the treating doctor), consent is not required to withhold treatment, provided the measures are NOT artificial hydration and/or nutrition – consent is ALWAYS required to withhold and/or withdraw these measures
 - ii. Confirm the person [lacks decision-making capacity](#) at the moment
 - iii. If the patient expressed they wanted “everything to be done” to the treating doctor, consent will be required from the decision-maker/s to withhold life-sustaining measures
 - iv. Does the person have an [AHD](#) (this effectively acts as their legal decision-maker when capacity is lost – it overrides the demands of the family)
 - v. If patient has an AHD, determine that the [AHD is current and valid](#)
 - vi. If no AHD, who is/are the [substitute decision-maker/s](#)? Work through the list outlined in the [flowchart](#) (e.g. it could be someone different from the family)
 - vii. Time-limited trial of treatment may be appropriate if clinically indicated

- viii. Are the decision-makers (family members) acting in accordance with the [General Principles and the Health Care Principle](#)? If not, consider contacting the Public Guardian.
- ix. Activate local [dispute resolution](#) processes as soon as practicable.

4. Should the patient have an [ARP](#)?

- a. If an [emergency situation](#), it's too late to initiate an [ARP](#). Exercise clinical judgement according to the circumstances having decided what is [good medical practice](#) [best interests](#)
- b. Check the [likely triggers to initiate an ARP](#) for the patient
- c. For example, any one or a combination of the following could apply to the patient:
 - i. diagnosis of a life-limiting condition and, on the balance of probabilities, the patient's death is expected within 12 months
 - ii. experienced multiple admissions and/or presentations to ED
 - iii. advancing age accompanied with frailty
 - iv. multiple comorbidities which impact on activities of daily living.
- d. Go to the section for guidance on [how to complete the ARP](#).

5. The patient is [unconscious](#) and requires immediate [ventilation](#) with [intravenous therapy](#) and a [blood transfusion](#).

- a. First, decide what is clinically appropriate for the person – what is [good medical practice](#) and in their [best interests](#)
- b. Follow the flowchart about [PROVIDING](#) life-sustaining measures
- c. Decisions about the following will be required:
 - i. Confirm the person [lacks decision-making capacity](#)
 - ii. Is this an [emergency situation](#)? – i.e. are decisions required immediately?
 - a) If yes, consent IS required if the patient has indicated they do not want ventilators or IV fluids in their [AHD](#) – this is a [treatment refusal and must be respected](#) (this also represents an [objection](#)² to this medical treatment being provided), Note that if the patient has specified 'yes' or 'no' to particular treatment in their AHD, consent is not required. The matter can be dealt with in accordance with the direction in the AHD
 - b) If yes, and no known [objection](#), apply the ventilator and insert IV fluids as this is required to save the patient's life and prevent significant pain and distress (as the patient is unconscious) – consent is NOT required
 - c) If yes, [blood transfusion](#) can be provided UNLESS the treating doctor is aware the patient refuses blood products (e.g. they are known to be a Jehovah's Witness and/or they carry a card refusing blood). Consent will always be required in these cases
 - iii. Determine if the patient has an [Advance Health Directive](#) and if it is valid
 - iv. If no AHD, determine the [substitute decision-maker/s](#). Work through the list outlined in the providing health care [flowchart](#).
- d. **NOTE:** sometimes the decision-making around advance refusals of medical treatment are very complex and can be challenging – as legally this represents an "[objection](#)" to medical treatment being provided. Clinicians will need to check advance refusals (however made) very carefully to determine the most appropriate course of action. Keep in mind that any person with capacity is [entitled to refuse medical treatment](#) (at the moment or in advance) even if this results in their death or would cause it to happen sooner, and no one else agrees with their decision. While in

² Section 63 of the *Guardianship and Administration Act 2000* applies here. Assuming the patient does not have capacity, consent is not required to provide health care if:

1. the health care should be carried out urgently to meet imminent risk to the patient's life or health – unless there has been an objection in an AHD; OR
2. the health care should be carried out urgently to prevent significant pain or distress to the adult and it is not reasonably practicable to get consent from a person who may give it under that *Act* or the *Powers of Attorney Act 1998* – unless the patient objected and certain other criteria do not apply.

Therefore, different criteria in terms of a patient's 'objection method' will apply depending on whether the health care is needed to save the patient's life OR relieve significant pain or distress.

Queensland [doctors can legally override AHDs](#) on a number of special grounds, including (i) the directions in the document to refuse life-sustaining measures fails the test of good medical practice, (ii) the person is not sufficiently ill at the time, or (iii) the directions in the AHD do not apply to the current circumstances, the doctor's decision to administer treatment in these circumstances would still need to be defensible (see below). It is also important to note there is increasing public pressure to change the laws to ensure the right to refuse medical treatment be not only respected, but followed in all circumstances.

6. The treating doctor decides to override a patient's [Advance Health Directive](#)

- a. First, decide what is clinically appropriate for the person – what is [good medical practice](#) and in their [best interests](#)
- b. Refer to the section on [deciding not to follow an AHD](#)
- c. Confirm the person [lacks decision-making capacity](#)
- d. Determine the status of the [AHD](#). Is it current and valid? Do the directions in the AHD apply to the current circumstances? Does the patient have a terminal condition and expected to die within 12 months? Are the directions in the AHD inconsistent with good medical practice"? (Go to the section on [Operation of an AHD](#) for more information
- e. Remember that a person's AHD can contain [objections](#) to both the withholding/withdrawal of life-sustaining measures AND/OR to the provision of life-sustaining measures – the [laws around overriding these directions](#) operates differently under each circumstance
- f. If the AHD is valid in all respects, and the doctor seeks to override the directions on the basis of 'good medical practice', the doctor will need to:
 - i. Determine the [decision-maker/s](#) and the consenting process to be followed
 - ii. Ideally, consult with senior medical staff to confirm this decision
 - iii. Be prepared to stand behind this decision and defend it in a court, if need be
 - iv. Thoroughly document the decision-making process.

7. A patient with decisional capacity refuses all medical treatment, including life-sustaining measures

- a. This is a [valid treatment refusal](#) and must not only be [respected, but followed](#). Note that this is treated differently to an advance refusal in an AHD, [as doctors can elect not to follow an AHD](#) on a number of grounds, including that the directions within the document do not meet the standards of [good medical practice](#) (see above)
- b. If they have not done so already, suggest to the patient to document their treatment refusal in an [AHD](#)
- c. Involve the patient's [decision-maker/s](#) in a sensitive manner, as when the patient loses capacity, they may be called upon for consent
- d. Determine whether other factors may be influencing the patient's decision to refuse treatment, such as clinical depression or a [mental health episode](#)
- e. **NOTE:** this is a very sensitive issue as people are entitled to refuse medical treatment even if no one else agrees with their decision and it would result in their death or cause it to happen sooner – this is a fundamental human right and this decision would be supported by the courts (also, see above scenario).

8. There is a difference of opinion within the healthcare team about whether proposed treatment is futile

- a. First principle of decisions involving [futile medical treatment](#): Doctors are under no moral or legal obligation to offer or attempt medical treatment that could cause harm or would provide no benefit to a patient (i.e. futile)

- b. Decide what is clinically appropriate for the person – what is [good medical practice](#) and in their [best interests](#)
- c. Are there [benefits for the proposed treatment](#)?
- d. Could [harm be potentially caused](#) by the proposed treatment?
- e. Does this matter require involvement of more senior clinicians and/or [dispute resolution](#)?
- f. Is there benefit in offering a time-limited trial of proposed treatment?
- g. Consider obtaining an opinion from another team
- h. The [most senior clinician](#) should ultimately make the decision in collaboration with other members of the healthcare team.

9. A patient with a valid and current ARP has a medical emergency and may benefit from surgery (e.g. for a bowel obstruction)

- a. If the patient has capacity the issue should be discussed with them for their decision
- b. Refer to the section in the document on [planned and unplanned surgery](#)
- c. Does the patient have an [ARP](#), if so check the directions in section 3 – [Resuscitation Management Plan](#) (PROVIDE CPR or DO NOT PROVIDE CPR) and section 4 – [Clinician authorisation](#) (whether there are instructions about the ARP applying during surgery)
- d. Is the matter [urgent](#)? If yes, the ARP is not automatically suspended. Refer to the [table about surgery and the ARP](#) for the specific circumstances
- e. Ideally and if time, arrange discussion with the surgeon, anaesthetist and patient, or if the patient lacks capacity, their [substitute decision-maker](#)
- f. Modify the ARP if need be and, if time, patient can also create or modify their AHD if they have capacity – needs to be done in writing
- g. If there is too little time to engage in broad discussions, surgery is urgent, and the patient does not have capacity, and the substitute decision-maker is unavailable, whether or not resuscitation will be attempted should be a shared decision with the surgical and medical team based on [good medical practice](#) and in the [best interests of the patient](#)

10. A patient with a deteriorating chronic condition is admitted for the third time in a month and there is no ARP nor documented treatment plan

- a. Assess the patient's condition and determine likely prognosis
- b. Decide what is clinically appropriate for the person – what is [good medical practice](#) and in their [best interests](#)
- c. Deterioration represents one of the [triggers to initiate advance care planning](#) and also [resuscitation planning](#)
- d. Determine whether the [patient has decisional capacity](#) – if no capacity will need to discuss goals of care and treatment plan with [substitute decision-maker](#) (remember, the consenting process only activates when the patient loses capacity for decision-making)
- e. Discuss with the patient and/or their substitute decision-maker and [family](#) their [goals for treatment](#)
- f. Prepare an [ARP](#) and care plan for the patient – this [is resuscitation planning](#)
- g. Provide the patient with advance care planning resources and advise patient their wishes for future treatment can be [formalised in an AHD](#) or [EPOA appointed](#).
- h. [Coordinate care with other clinicians](#)
- i. Document the clinical decision-making and consenting process with scheduled review/s and file documents appropriately (NOTE: documenting the decision-making pathway that leads to the decision to withhold or withdraw life-sustaining measures is required by law).⁵

Context

It is beyond dispute that the process of dying has seen dramatic changes. By the end of the twentieth century there were some remarkable success stories relating to trends in mortality. They include a decrease in the mortality rate of 73.7 per cent from 1907 to 2013⁶ and a major increase in life expectancy, now over 80 years (80.4 years for males and 84.6 years for females) from birth.⁷ Also of note are falls in the death rates of:⁸

- 95% for children aged four or younger, including infants
- 96% for infectious diseases
- 85% for stomach cancers and 80% for cervical and uterine cancers
- close to 80% for respiratory diseases.

Yet, Australians are not dying as they would wish, with those with chronic disease experiencing extended periods of deterioration.⁹ People are now more likely to live into old age (two-thirds of Australians now die between the ages of 75 and 95) than they are to face a sudden, unexpected death at a young age through disability, accident or communicable disease.¹⁰ Ninety per cent of all deaths in 2011 in Australia were the result of chronic disease.¹¹ As such, the medicalisation of the dying process has led to greater expectations of the health system to prolong life.

Advances in medicine have also improved the ability to predict a person's mortality through complex prognostic methods and diagnostic testing, with 70 per cent of deaths now capable of being predicted within a certain timeframe.¹² Because there are more people on degenerative disease trajectories than ever before, there are widespread calls to improve the way that people die. Improving care at the end of life is important to ensure that people can die well and are able to participate in any decision-making about their treatment and care to the greatest extent possible. High quality end-of-life services bring together a range of health services, home care, personal support and support for carers, but should always accord with the preferences and circumstances of the dying person.¹³ Good end-of-life care embraces access to timely and supportive advance care planning, and emphasises that effective communication is at the core of harmonious and successful decision-making. There should also be an acknowledgement that for some people accepting that they or their relative will die will be challenging, if not impossible. The grieving process may commence before a person has died and potentially plays an enormous part in how decisions are made. One of the biggest challenges is dealing with the uncertainty of prognosis.

The shift to a focus on quality of life rather than quantity typically occurs late in the disease trajectory. Sometimes this choice to adopt a palliative approach to care is only made after curative medical treatments have been exhausted. The research shows that when good end-of-life services are available, people are more satisfied with care, less likely to be admitted to hospital or visit emergency departments and more likely to die at home or in a place of their choice.¹⁴ Ideally, given the choice, people want to die at home in a situation that meets their physical, social, personal and spiritual needs. However, when the person is faced with increasing deterioration from frailty or advancing disease, dying at home becomes the less likely option, with many referred to residential aged care or other residential community facilities to serve out their final weeks, months and sometimes years. The reality is that dying at home requires a significant supportive network of family, carers and friends:

“...providing end-of-life care in the home is particularly intense for family and friend carers. While managing their own grief and the grief of others, carers will be providing high level physical and emotional support that a patient needs at the end-of-life.”¹⁵

In 2014–15, Australia wide statistics show that 63 per cent of palliative patients died in hospital and 25 per cent were discharged to their place of usual residence.¹⁶ Others were variously discharged to other acute hospitals or residential aged or community facilities. The statistics indicate that while many people would want to die at home surrounded by those who support them, the reality is very different. It has also been reported for a variety of reasons that people

are twice as likely to die at home in countries such as New Zealand, the United States, Ireland and France.¹⁷

Because of these comparisons, it has been observed by some commentators that not enough opportunities are being taken to help people to die well. Palliative care services are widely reported to be insufficient across Australia, and in the last year of life many people experience services that are disconnected, confusing and fragmented, usually having to traverse a complex medical system with referrals to multiple health professionals. Such a potentially distressing end to a life well-lived has caused many to support and plan for what is commonly termed a “good death”.¹⁸ It is within this context that decisions about life-sustaining measures occur, and why it is important that health professionals are aware of the complex interplay of legal, clinical and ethical considerations and welcome the contribution of patients and their families to participate in advance care planning to ensure preferences for end of life care are respected and followed to the greatest extent possible. For further context, [Appendix 1](#) contains a brief snapshot of statistics about death and dying in Queensland and an analysis of how people spend the last six months of their life.

Policy Statement

Queensland Health recognises that there are significant and complex clinical, ethical and legal considerations in making decisions to withhold or withdraw life-sustaining measures, even when an adult patient has the capacity to make the decision themselves. Queensland Health also acknowledges that withholding or withdrawing life-sustaining measures will sometimes be in the best interests of an adult patient who does not have the capacity to make the decision. Commencing or continuing medical treatment that provides no benefit to the patient, is overly burdensome or would cause the patient harm is not considered to be in the patient’s best interests.¹⁹ End-of-life care and palliative support must always be initiated if the decision is to withhold or withdraw active medical treatment.

Adult patients with capacity are entitled to refuse medical treatment, even if no one else agrees with their decision, and the withholding or withdrawal of that treatment results in their death or would cause it to happen sooner. Those without capacity who have previously formalised their end-of-life wishes in an AHD, provided the AHD is valid, represents the patient’s wishes at the time they had capacity. If the patient lacks capacity and no advance decisions are known about life-sustaining measures, the legal consenting pathway must be followed.

The policy in these guidelines applies to adult patients at or approaching the end of life. Guidance for health professionals includes patients with impaired capacity and also those diagnosed with a life-threatening illness or condition whose prognosis is likely to involve discussions about resuscitation planning in the foreseeable future. Ideally, conversations about life-sustaining measures should occur as early as possible in the context of the broader advance care planning.

The emphasis in decision-making for patients at the end of life is on patient-centred care and supported decision-making. This means involving patients in discussions about their end-of-life preferences and values as early as possible to minimise the need to determine their wishes through substitute decision-maker/s when no one knows what they would have wanted. The concept of supported decision-making is central to many of the current discussions regarding the reform of guardianship legislation in Australia and internationally. It covers a wide spectrum of decision making models from informal support involving natural support networks to formally appointed co decision makers and representatives.²⁰

Decisions to withhold or withdraw life-sustaining measures must comply with the standards of good medical practice, be clearly documented, and be based on legal requirements for consent from the patient or their substitute decision-maker/s.

Queensland Health guiding principles for decision-making about life-sustaining measures

Principle 1:	All decision-making must reflect respect for life and the patient's right to know and choose.
Principle 2:	All decision-making must meet the standards of good medical practice.
Principle 3:	All efforts must be made to obtain the appropriate consent through a collaborative approach.
Principle 4:	There must be transparency in and accountability for all decision-making.

Summary of key considerations under the four guiding principles

These guiding principles were endorsed by Queensland Health in 2009 and still remain relevant to contemporary practice across clinical, ethical and legal considerations. Since then, much work has been accomplished that builds upon these principles and provides additional guidance for Hospital and Health Services to optimise care at the end of life for their residents. Through collaborative enterprise, the [Statewide strategy for end of life care](#) (the Strategy) was published in May 2015. The Strategy contains four service directions and associated service actions that “promote service delivery by healthcare professionals and services throughout the health system in response to the level of need, regardless of the professional stream of the carer or the setting of the service delivery provider.” The Strategy recognises ongoing need to address knowledge deficits regarding the existing Queensland legislative framework of care at the end of life and develop system level clinical policies and resources to support safe and high quality service delivery.

Another important national document developed by the Australian Commission on Safety and Quality in Health Care ([National Consensus Statement: essential elements for safe and high-quality end-of-life care](#)), also published in 2015, describes the elements that are essential for delivering safe and high-quality end-of-life care in Australia. In particular, the document sets out suggested practice for the provision of end-of-life care in settings where acute care is provided, including fifteen guiding principles. For completeness, these principles, developed through an extensive national consultation process, are reproduced at [Appendix 2](#). In 2015, a [Charter for care of adult patients at the end of life](#) was also developed by the Queensland Department of Health Clinical Senate. These recent documents have been incorporated into these guidelines, where relevant, and importantly support the following considerations under each principle:

Principle 1: All decision-making must reflect respect for life and the patient's right to know and choose.

- dying is a normal part of life and a human experience, not just a biological or medical event²¹
- for ethical reasons, it is important not to harm patients approaching the end of life by providing burdensome investigations and treatments of no benefit²²
- a primary goal of medical care is preservation of life, however, when life cannot be preserved, the task is to provide comfort and dignity to the dying person, and to support others in doing so
- when considering a patient's best interests, other factors must be considered, such as the patient's culture, values and personal wishes
- every patient, regardless of age, race, gender, culture or lifestyle has the right to dignity and compassion at the end of life
- adults with capacity have a right to refuse medical treatment, even if this is inconsistent with good medical practice, may result in their death, or cause it to happen sooner

- where the patient lacks capacity to make health care decisions, except in acute emergency situations, best efforts to obtain consent and document the decision-making pathway is required before any life-sustaining treatment can be withheld or withdrawn
- life-sustaining measures may not be withheld or withdrawn without consent if the doctor in charge of the patient's care has direct knowledge that the adult objects to the withholding or withdrawal of treatment
- consent must always be obtained to withhold or withdraw artificial hydration and/or nutrition.

Principle 2: All decision-making must meet the standards of good medical practice.

- good medical practice²³ requires doctors and the health care team to adhere to the accepted medical standards, practices and procedures of the medical profession in Australia, and recognises ethical standards by respecting the patient's wishes to the greatest extent possible
- in meeting the standards of good medical practice, doctors are under no obligation to initiate treatments known to be ineffective, nor to continue treatments that have become ineffective – there is no obligation to prolong life at all costs
- in situations where further active treatments may be potentially futile, doctors must consider whether the proposed treatment will be in the best interests of the patient, and to the greatest extent possible benefit the patient and not cause them harm
- in assessing a patient's best interests, decisions should not be based on whether the health care team, or the patient's relatives or carers would wish to have the treatment themselves if they were in that situation
- good medical practice also involves doctors facilitating advance care planning and providing or arranging for appropriate palliative care
- [Appendix 3](#) contains the end-of-life component provided in the Medical Board of Australia's [Good medical practice: a code of conduct for doctors in Australia](#).

Principle 3: All efforts must be made to obtain the appropriate consent through a collaborative approach.

- decision-making about life-sustaining measures should be shared between the treating team and the patient, and substitute decision-makers, families and carers should be involved, in accordance with the patient's expressed wishes as per legal requirements
- families and healthcare professionals have an obligation to work together to make compassionate decisions for patients who lack decision-making capacity, taking into account previously expressed patient wishes where they are known
- good communication is key; discussions with the patient and those closest to them about prognosis and goals of care and expectations is at the core of harmonious and successful decision-making
- some patients may have expressed their future health care wishes in an AHD
- an AHD activates only when an adult no longer has capacity for decision-making about matters covered by the directive
- legally, valid AHDs take precedence over treatment requests made on behalf of the patient by family members, including next of kin
- if consensus cannot be reached about a decision or if the substitute decision-maker/s refuses to comply with the Health Care Principle ([Appendix 4](#)), the matter must be escalated according to local practice, and the Office of the Public Guardian should be consulted to resolve any dispute.

Principle 4: There must be transparency in and accountability for all decision-making.

- as prognosis and response to medical treatment varies between patients, there must be honest and open discussion with patients, substitute decision-maker/s and carers about potential ambiguities and uncertainties
- the treating health care team has responsibilities to provide timely and accurate information regarding the patient's clinical condition, expected disease trajectory, available treatments and likely prognosis in the circumstances
- offer support, expert opinion and advice so that patients (or substitute decision-maker/s, families and carers) can participate in fully informed, shared (or supported) decision-making²⁴
- there is an obligation to observe the Australian Charter of Health Care Rights,²⁵ which describes the rights of those accessing the health system to ensure care and treatment provided for those at the end of life is of high quality and safe
- meticulous documentation of all decision-making about withholding and withdrawing life-sustaining measures is critical and required by law
- where appropriate, patients should be encouraged to formalise their end-of-life wishes by completing AHDs, which is a legal document
- other documentation, such as an Acute Resuscitation Plan (ARP) form does not provide legal consent to withhold or withdraw life-sustaining measures, but can be used to guide the decision-making process.

1.0 Legislative framework

1.1 Introduction

These guidelines provide a basis for making decisions about withholding and withdrawing life-sustaining measures. They are built on a framework of current legal, clinical and ethical considerations. The scope of legal considerations in these guidelines is adult patients at or nearing the end of life. They include guidance for decision-making for adult patients without capacity, as well as for those with capacity. Life-sustaining measures or life-prolonging measures as they are also known are designed to save the life and health of a person and cover a broad spectrum from the highly invasive cardiopulmonary resuscitation and ventilation methods through to the less technically demanding such as antibiotics, insulin and other drug therapies. As for all other medical treatment, there is a consenting pathway for life-sustaining measures to be provided, and people have every right to refuse them, if they have the capacity to do so. However, because of the critical nature of life-sustaining measures, and the fact that the measures are usually required in acute emergency situations and most likely in a hospital setting, the laws in Queensland also set out a consenting regime where decisions are made to provide, withhold or withdraw life-sustaining measures from adult patients who lack capacity for decision-making. This section of the guidelines provides detail around Queensland's legal framework to support clinical and ethical considerations that should factor in all decision-making around life-sustaining measures.

1.2 Queensland legislation

Decisions about life-sustaining measures are clinically and ethically challenging. This is the case in Queensland, in other jurisdictions in Australia, and elsewhere in the world. If an adult has capacity (refer to [Section 1.4](#) for more information) to make decisions about health care, which includes withholding or withdrawing life-sustaining medical treatment, the law is reasonably clear, as it is based on common law principles.²⁶ If a valid AHD is in place, the law is also reasonably clear, as it is a legally binding document made at a time when the person had the capacity to

make such decisions. If a patient has capacity, their wishes for medical treatment must be followed. There is a well-established legal principle in Australia and elsewhere in the world that an adult with capacity can refuse any medical treatment, even if it results in their death or would cause it to occur sooner.

If an AHD is in place, any substitute decision-maker/s appointed under that enduring document (called an attorney) has the power to make decisions on behalf of the adult patient. If an AHD is not in place, a substitute decision-maker/s or the Public Guardian makes decisions on behalf of the patient. The effect of the legislation is that there is always someone to represent the interests of an adult patient who does not have capacity for decision-making about health matters. (Refer to [Section 1.5.1](#) for more information about enduring documents, such as AHDs and EPOAs.)

Uncertainty is amplified when patients do not have the capacity to make decisions about their ongoing medical treatment. In these cases, there are two sources of law relevant in the consenting pathway when deciding whether to withhold or withdraw life-sustaining measures. The first is through common law and the powers of the Supreme Court under its *parens patriae* jurisdiction; the second through three key statutes:

1. *Powers of Attorney Act 1998 (Qld)*
2. *Guardianship and Administration Act 2000 (Qld)*
3. *Criminal Code Act 1899 (Qld)*

The legal processes within these three statutes activate when a patient loses capacity and decisions about life-sustaining measures are required.

The complex interplay of provisions within the three statutes makes it difficult to navigate a clear path and provide a simple, straightforward policy for decision-making in this area. Perhaps for good reasons, decision-making in this profoundly complex area does not easily lend itself to working through a simple algorithm, for example, decision-making about life-sustaining measures operate differently according to the individual circumstances of the case, such as:

- whether an urgent decision is required
- if the patient has capacity
- whether the patient is terminally ill
- if the patient requests treatment or refuses treatment
- whether the patient has set out their decisions in an AHD
- if the AHD is valid
- whether the patient formally appoints a substitute decision-maker/s.

There are many more variables, of course, and hence the calls by a number of legal commentators that the legislative framework in Queensland is complex and in need of review. For example, the law operates differently if the clinical decision is to *provide* life-sustaining measures, rather than *withhold or withdraw* them. Generally, except in the case of an emergency where it is not practicable or reasonable to obtain consent, failure to obtain a patient's consent to health care may result in a criminal charge of assault or civil action for battery. In addition, failure to disclose material risks to a patient may give rise to civil action for negligence. In either case, disciplinary action by Queensland Health may be pursued.²⁷

Under Queensland's legislation, urgent decisions to *commence and continue (provide)* medical treatment to save the life of a patient who lacks capacity can be carried out without consent in most circumstances. However, if the treating doctor knows that the patient objects to the treatment in an AHD, and the patient lacks capacity then all reasonable efforts to obtain consent from a substitute decision-maker should be undertaken, as circumstances permit.²⁸

Urgent decisions to *provide* healthcare to prevent significant pain or distress to a patient who lacks capacity should not be provided without consent unless it is not reasonably practicable to get consent from a substitute decision-maker. Such health care should not be carried out without consent if the treating doctor knows the adult objects to the health care. However, if the treating doctor believes the patient has limited understanding of why the medical treatment is being provided or what the health care involves, and as long as the treatment will cause no distress or temporary distress which is outweighed by the benefit to the patient, objections to *providing* urgent medical treatment (which can include life-sustaining measures) can be overruled. These provisions are particularly relevant in the case of blood transfusions (see [3.2.4 – Blood transfusions](#) for further information).

1.3 Life-sustaining measures

Queensland's legislation²⁹ defines a life-sustaining measure as follows:

1. A life-sustaining measure is health care intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation.
2. Without limiting subsection (1), each of the following is a life-sustaining measure —
 - (a) cardiopulmonary resuscitation;
 - (b) assisted ventilation;
 - (c) artificial nutrition and hydration.
3. A blood transfusion is not a life-sustaining measure.

Other definitions are also relevant for understanding the legislative context around life-sustaining measures, for example the term 'health matter.' The *Guardianship and Administration Act 2000* defines a 'health matter', for an adult as 'a matter relating to health care, other than special health care, of the adult'. The *Powers of Attorney Act 1998* provides a similar definition. Under both Acts, a decision about the withholding or withdrawal of a life-sustaining measure is a 'health matter,' rather than a 'special health matter.' This definition and distinction becomes important when considering the capacity the patient and their substitute decision-maker has for decision-making.

Life-sustaining measures may be withheld or withdrawn without consent *only in exceptional circumstances*, such as acute emergency situations, *and only* where the doctor responsible for the patient's care is not aware that the patient has made it clear that he or she 'wanted everything done' in the event that they lost capacity (in other words, that they have objected to the withholding or withdrawal of medical treatment). It is Queensland Health's policy, however, that for the objection to have effect, the doctor responsible for the adult patient's care should have direct knowledge of the patient's objection to the withholding or withdrawing life-sustaining measures, rather than through, for example, hearsay. (As an example, this could be expressed as, "Mum said she wanted everything done to keep her alive.") This is a very complex part of the law and the circumstances of decision-making must consider other equally important clinical and ethical elements, such as whether the treatment would harm the adult patient and offer no benefit (in other words, commencing or continuing life-sustaining measures would be futile and not in the patient's best interests).

The guardianship legislation also provides for decisions about the withholding or withdrawal of a life-sustaining measure from an adult to be made in accordance with:

- an AHD made while he or she had capacity or,
- with the consent of the person's substitute decision-maker/s.

Because the withholding or withdrawal of a life-sustaining measure is defined as a 'health matter', decision-making about the measures is generally governed by section 66 of the *Guardianship and Administration Act 2000*. That section provides:

66 Adult with impaired capacity — order of priority in dealing with health matter

- (1) If an adult has impaired capacity for a health matter, the matter may only be dealt with under the first of the following subsections to apply.
- (2) If the adult has made an AHD giving a direction about the matter, the matter may only be dealt with under the direction.
- (3) If subsection (2) does not apply and the tribunal has appointed one or more guardians for the matter or made an order about the matter, the matter may only be dealt with by the guardian or guardians or under the order.

[Editor's note—

If, when appointing the guardian or guardians, the tribunal was unaware of the existence of an enduring document giving power for the matter to an attorney, see section 23 (Appointment without knowledge of enduring document), particularly subsection (2).]

- (4) If subsections (2) and (3) do not apply and the adult has made one or more enduring documents appointing one or more attorneys for the matter, the matter may only be dealt with by the attorney or attorneys for the matter appointed by the most recent enduring document.
- (5) If subsections (2) to (4) do not apply, the matter may only be dealt with by the statutory health attorney.
- (6) This section does not apply to a health matter relating to health care that may be carried out without consent under Division 1.

The effect of section 66 is that a person's substitute decision-maker/s may make a decision about the withholding or withdrawal of a life-sustaining measure only if the person does not have a valid and enforceable AHD that gives a direction about the matter. The *Guardianship and Administration Act 2000* also includes a provision that authorises a health provider, in limited circumstances (for example, acute emergencies) to withhold or withdraw a life-sustaining measure without consent (other than artificial nutrition and hydration).

Because the legislation does not limit life-sustaining measures to those expressly identified, other interventions could also qualify under this definition. Drug therapies such as chemotherapy, corticosteroids, antibiotics, renal and liver failure treatments (for example, haemodialysis, peritoneal dialysis, haemofiltration) could all qualify as life-sustaining measures. In certain clinical situations, complex surgical procedures could meet the definition of a life-sustaining measure, as could a blood pressure tablet.

If the effect of the medical treatment is to immediately save the life of the patient, it is likely to be captured by the definition of a life-sustaining measure. For more detail on the life-sustaining measures identified in the definition, refer to [Section 4 – Clinical Considerations](#).

For completeness, it is also helpful to provide the wording in section 66A (*Guardianship and Administration Act 2000*) – When consent to withholding or withdrawal of life-sustaining measures may operate (*that is, when the person does not have an enforceable AHD*):

- (1) This section applies if a matter concerning the withholding or withdrawal of a life-sustaining measure is to be dealt with under section 66(3), (4) or (5).
- (2) A consent to the withholding or withdrawal of a life-sustaining measure for the adult cannot operate unless the adult's health provider reasonably considers the commencement or continuation of the measure for the adult would be inconsistent with good medical practice.

If the patient has a valid enforceable AHD, the operation of directions within that document operates under provisions within the *Powers of Attorney Act 1998* (section 36, particularly 36(2)). These provisions will be discussed in more detail in [Section 1.5.1 – Advance Health Directives](#).

1.3.1 Difference between withholding and withdrawing life-sustaining treatment

While the *Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998* in the provisions concerning life-sustaining measures combines withholding and withdrawing medical

treatment, arguably, the two operate under quite different decision-making paradigms. The clinical decision-making for both circumstances (i.e., to withhold and/or withdraw) is affected by; (i) the level of clinical certainty; and (ii) the timeframe available for decision-making. The lines between the two decisions may converge legally and ethically, but diverge clinically.

The decision to *withhold* medical treatment is largely prospective: that is, whether or not to commence treatment for an event/s yet to take place. This may involve a dimension of uncertainty, because there could be unknowns about the future clinical state of the patient, for example, when and if the patient will suffer a cardiac arrest, necessitating CPR.

The decision to *withdraw* a life-sustaining measure implies that a level of acceptance about the benefits of continuing the measures has been reached, both by the clinicians involved and the family. The decision signifies that a stage has been reached where the evidence points to the fact that the patient undeniably and irrefutably is receiving no benefit from the interventions proposing to be withdrawn. Arguably, the consent processes for withdrawing medical treatment may be less onerous than for withholding medical treatment, most likely because the patient's condition has reached the point that no further improvement is expected.

In some cases, consent may not need to be obtained to *provide* life-sustaining measures (for example, under urgent health care provisions), but consent would be required to *withdraw or withhold* the measures. This may be the source of some confusion for families. One explanation is that decisions to withdraw medical treatment almost always occur in non-urgent clinical situations, where there is time to discuss all of the issues with the patient's family and obtain their consent.

Decisions regarding withholding and withdrawing life-sustaining measures are often difficult and complex, and need to involve close consultation and effective communication with the health care team, the patient and those close to the patient cannot be overstated. How well a doctor can broach this sensitive topic with patient and family correlates to how well the patient and family understand and accept this information and trust that the health care team has the best interests of their relative at the forefront of their treatment plan and goals.

1.4 Capacity

Queensland's legislative framework for withholding and withdrawing life-sustaining measures is triggered by whether an adult has the capacity to make decisions about health matters.

The *Guardianship and Administration Act 2000* (sch 4, dictionary) and *Powers of Attorney Act 1998* (sch 3, dictionary) defines capacity as follows:

Capacity, for a person for a matter, means the person is capable of—

- (a) understanding the nature and effect of decisions about the matter; and
- (b) freely and voluntarily making decisions about the matter; and
- (c) communicating the decisions in some way.

Under the General Principles, (see [Appendix 4](#)) an adult patient is presumed to have capacity.

Queensland Health (Clinical Excellence Division) has published the second edition of the *Guide to Informed Decision-making in Health Care*.³⁰ This document provides comprehensive guidance about health care and consent generally, including for complex consenting issues where there are doubts and uncertainties about a person to give consent, for example for mental health patients and children and young people. The Queensland Law Society has also published a comprehensive handbook on legal capacity.³¹ While the document is designed for Queensland lawyers, it covers important concepts related to the determination of capacity and how this may be applied in various legal situations, such as drawing up enduring documents, and what matters statutory attorneys are able to make substituted decisions about.

1.4.1 Assessing capacity

Capacity assessment is based on the principles and techniques of good clinical assessment, in which the process is tailored to the educational, cultural, psychological, social and sensory characteristics of the person being assessed.³²⁻³⁴ The key to determining capacity lies with adequate communication with the patient. Decisional tools and aids can be helpful to guide the process of assessing capacity, however it is important to note that such tools and aids assist with guiding a conversation with the patient and determining clinical judgement, but are not a substitute. A patient's ability to converse with family or members of the healthcare team about their illness is often a better and more critical indicator of that patient's capacity than any tool, particularly for patients at the end of life. There is no evidence that scores from standard tests of cognitive ability are a reliable indicator of capacity, partly because they are language-based and influenced by education, culture and social milieu. Most measures of cognitive status do not evaluate cognitive functions such as judgment and reasoning, which are relevant to capacity. Assessment may fail to find capacity because:³⁵

- it is not present
- the process used was inadequate
- the person applying the process failed to understand, appreciate or apply the process properly.

On the balance of probabilities, any question as to whether a person lacks capacity to give informed consent will be decided by the doctor responsible for the treatment and care of the adult patient. This is consistent with good medical practice.

Lack of capacity cannot be established merely by reference to age, cultural background, behaviour, appearance or physical condition, as this may lead to unjustified assumptions about a patient's competence or capacity to give informed consent. Despite the widespread use of capacity assessments, there is no consensus on generic criteria for capacity assessment. Moreover, several studies³⁶ have demonstrated difficulties when clinicians tend to rely on informal clinical impressions when assessing a patient's capacity to consent to treatment. Therefore a multi-dimensional approach should be adopted, which could include:

- discussions with the patient's family
- consultation with other health professionals
- communicating with the patient with the support of toolkits, including pictures or flash cards. (These may be available through social workers or community liaison officers).

Capacity depends on the nature of the task for which assessment is required, such as decisions about health matters. How well the patient functions will also require consideration of the nature of the decision to be made as well as the clinical condition of the patient.

Specialists or more senior doctors should be consulted where doubt exists about a patient's capacity.

It is generally held that there are four *functional abilities* used in capacity assessments:³⁷

1. the ability to *express* a choice
2. the ability to *understand* information relevant to treatment decision-making
3. the ability to *appreciate* the significance of that information for one's own situation, especially concerning one's illness and the probable consequences of one's treatment options
4. the ability to use relevant information to *reason* so as to engage in a logical process of *weighing* up the treatment options

A person's status on these abilities is not an all-or-none matter. Rarely can it be said that a patient does or does not possess one of these abilities. Usually a person manifests all of them, but in varying degrees. The issue is whether a person functions sufficiently in these areas to allow a judgement that he or she has capacity to consent to medical treatment.

1.4.2 Competence and capacity

Although the terms 'competence' and 'capacity', are often used interchangeably,³⁸ there are important differences between them. 'Competence' and 'incompetence' are legal designations determined by courts and judges, whereas decision-making capacity is clinically determined by clinical assessment.^{39 40} Under Queensland legislation, all adults are legally presumed to have capacity unless determined incompetent judicially. An adult who possesses legal competence, however, may lack the capacity to make specific treatment decisions. Therefore a patient's capacity is determined by a clinician's evaluation rather than by the courts.

Generally, the patient can be regarded as having decision-making capacity if they meet the following five criteria:

1. The patient understands the basic medical situation.
2. The patient understands the nature of the decision being asked of him or her. Understanding includes the following:
 - implications – benefits, risks, what the treatment entails
 - alternatives and their implications, including the implication of no decision
 - being able to retain the information (short-term memory function).
3. The patient is able to use or weigh that information as part of the process of making the decision (for example, asking questions).
4. The patient is able to communicate a decision (for example, by talking, using sign language or any other means).
5. The patient is able to communicate the decision voluntarily (for example, is there an absence of coercion, undue influence or intimidation by the patient's family/decision-maker/s?).

1.4.3 Patients without capacity

Where treatment is able to prolong the patient's life but there are doubts about whether it would provide overall benefit, the health care team and those close to or representing the patient should take account of the patient's wishes, values and preferences in order to assess whether treatment would be in the patient's best interests.⁴¹ Remembering that the guardianship laws are activated when a person loses capacity for decision-making, and appropriate consent will need to be obtained, governed by the circumstances. However, where patients have capacity to make decisions about their own health care, the situation is governed by common law principles. This means that a patient with capacity can refuse medical treatment even if this would result in their death or make it happen sooner.

In assessing best interests in the case of an adult without the capacity to make decisions about health matters on their own behalf, account must be taken of the [Health Care Principle](#) in Schedule 1, Part 2 of the *Powers of Attorney Act 1998* and the following:

- the patient's wishes and the views of those closest to them about what is in the patient's best interests (where the patient has agreed to their involvement)
- views of culturally appropriate people close to the patient

- beliefs and values that would be likely to influence the decision if the patient had capacity
- clinical judgements about the efficacy of the proposed medical treatment
- likelihood of the patient experiencing severe intractable pain or suffering
- level of awareness patients have of their existence and surroundings and their ability to interact with others, and demonstrate self-directed action in any capacity
- likelihood and extent of any degree of improvement in the patient's condition if treatment is provided
- whether the invasiveness of the treatment is justified in the circumstances
- likelihood of the patient experiencing increasing levels of disability and/or lack of function and dependence
- views of the patient's significant others (such as spouses, children and friends), as to what the patient would see as beneficial
- views of any duly appointed health care attorney or patient advocate
- that decisions must be made on an individual basis and that no unjustifiable discrimination occurs
- that all patients are entitled to the same quality of care, and that those who lack capacity should not be excluded from potentially beneficial treatment options solely by reason of their lack of capacity
- that decisions must not be based on whether the health care team, or the patient's relatives or carers, would wish to have the treatment themselves in that situation
- that decisions about best interests must not be motivated by a desire to bring about the patient's death.

This list is by no means exhaustive and can include written statements made by the patient before capacity was lost. In some cases the patient might like to have their families make statements on their behalf.

1.4.4 Patients with borderline or fluctuating capacity

Where patients have borderline or fluctuating capacity, it can be difficult to assess if the individual can make valid decisions on very serious issues. For example, a patient may be capable of making decisions about daily life, such as where they live or what they wear, but may not be able to understand the implications of proposed medical interventions or medications. Psychiatric evaluation of a patient's capacity for decision-making about health matters may be considered where consensus cannot be reached within the health care team. If a person appears to have impaired capacity, health professionals should determine whether reversible factors are present.

The following provides examples of medical conditions that may impact on capacity.

Medical conditions which may impact on capacity include:

- Delirium
- Infection e.g. pneumonia, UTI, influenza, herpes zoster
- Disturbances in fluid/electrolyte balance e.g. renal disease, dehydration, malnutrition
- Adverse effects of medication
- Adverse effects of substance abuse e.g. drug overdose, alcoholic poisoning
- Mental health issues e.g. depression, psychosis
- Dementia
- Endocrine disorders e.g. diabetes, hypothyroidism, hyperthyroidism
- Cardiovascular disease, hypertension
- COPD
- Obstructive sleep apnoea
- Chronic pain

(Etchells et al 1996, Gregory et al 2007, Applebaum 2007)

1.4.5 Capacity is domain-specific and decision-specific

The concept of global or binary capacity, that is, people are considered either capable or incapable for all decisions, is no longer held. This is because a declaration of impaired capacity removes a fundamental freedom and right to make choices and begins to erode a sense of a person's individuality and character. A person is only declared to have impaired capacity when it has been firmly established that they lack the ability to make decisions or are at serious health risk as a result of this determination. It is recognised that people may have capacity in one domain but lack capacity in another. It is rare for a person not to have capacity for any decisions, unless they are unconscious or have a severe cognitive disability. A person may be capable of making simple decisions but incapable of making complex decisions, for example:

1. deciding what to wear but unable to manage medication
2. simple grocery purchases but unable to handle banking activities
3. regular appointments with a hairdresser but unable to attend to personal hygiene
4. a decision regarding having the flu vaccine but unable to consent to surgery.

Capacity assessment focuses on the specific abilities that the person needs to make a decision regarding a specific matter or situation. The clinician responsible will need to assess, or seek an assessment of, the person's capacity for each decision, whenever there is doubt about capacity. This is because a person's capacity can vary in different circumstances, at different times, and about different types of decisions. If the person can make some but not all decisions, then they have a right to make as many decisions as they can. Even if the person couldn't make a certain decision in the past, they might be able to make the same or similar types of decisions in the future.

Every time a decision needs to be made, the assessing clinician should ask the question: 'Does the patient have the capacity to make **this** decision **now**?' If the patient is unable to make a decision about something now, it may be appropriate for the decision to be delayed to a later time when the person may be able to make the decision for themselves. Delaying a decision may give the person the greatest control over their own life. In most situations clinicians will need to arrive at a definitive answer to the specific capacity question at hand. An inherent tension in arriving at this decision is that in many situations capacity may operate as more along a capacity continuum, yet clinicians are required to provide a polar answer. This is represented by the image following:

Clinical Capacity

Has capacity

Diminishing capacity

Lacks capacity

Capacity Assessment

Has capacity

Lacks capacity

Law and good medical practice require that as little interference as possible occurs with a person's right to make autonomous decisions about health matters. Some limits on this right, however, are legally and ethically justified when individuals with mental conditions that impair their decision-making are likely to suffer harm if their choices are followed. However it is important to recognise that not all people suffering from a mental disorder lack the capacity to make decisions about their health care. (For more information, refer to [Special Considerations – Mental health](#))

1.5 Consenting regime

Life-sustaining medical treatment can only be withheld or withdrawn where consent is obtained or where legislative authority is given to make the decision without consent. Where the patient lacks capacity to make health care decisions, except in some acute emergency situations, consent is required before any life-sustaining treatment can be withheld or withdrawn. Known objections by the patient to the provision or withholding of medical treatment can affect the consent provisions. Consent must be obtained through the following, in order:

1. The patient's valid AHD. If none, then:
2. Guardian/s appointed by the Tribunal or Order of the Tribunal.⁴² If none, then:
3. Attorney/s appointed under most recent enduring document. If none, then:
4. A statutory health attorney/s. If none, then;
5. The Public Guardian.

1.5.1 Enduring documents

Advance Health Directives

An AHD in Queensland, or advance care directive as it is sometimes known (or living will in other countries such as the UK and US), is a formal document in which an adult provides direction about current and future health matters, and in which they can nominate one or more people to make decisions on their behalf if they become unable. There are provisions in both the *Powers of Attorney Act 1998* and the *Guardianship and Administration Act 2000* that set out how Advance Health Directives operate generally,⁴³ and more specifically to address decisions to withhold or withdraw life-sustaining measures.

Operation of an Advance Health Directive

Since the directions to withhold or withdraw life-sustaining measures is fundamental to the operation of an Advance Health Directive, the relevant section of the *Powers of Attorney Act 1998* (Qld) is reproduced below:⁴⁴

- (1) A direction in an advance health directive—
 - (a) operates only while the principal has impaired capacity for the matter covered by the direction; and
 - (b) is as effective as if—
 - (i) the principal gave the direction when decisions about the matter needed to be made; and
 - (ii) the principal then had capacity for the matter.

- (2) A direction to withhold or withdraw a life-sustaining measure cannot operate unless—
- (a) 1 of the following applies—
 - (i) the principal has a terminal illness or condition that is incurable or irreversible and as a result of which, in the opinion of a doctor treating the principal and another doctor, the principal may reasonably be expected to die within 1 year;
 - (ii) the principal is in a persistent vegetative state, that is, the principal has a condition involving severe and irreversible brain damage which, however, allows some or all of the principal's vital bodily functions to continue, including, for example, heart beat or breathing;
 - (iii) the principal is permanently unconscious, that is, the principal has a condition involving brain damage so severe that there is no reasonable prospect of the principal regaining consciousness;

Note—This is sometimes referred to as 'a coma'.

 - (iv) the principal has an illness or injury of such severity that there is no reasonable prospect that the principal will recover to the extent that the principal's life can be sustained without the continued application of life-sustaining measures; and
- (b) for a direction to withhold or withdraw artificial nutrition or artificial hydration—the commencement or continuation of the measure would be inconsistent with good medical practice; and
- (c) the principal has no reasonable prospect of regaining capacity for health matters.
- (3) An attorney's power for a health matter under an advance health directive is exercisable during any or every period the principal has impaired capacity for the matter and not otherwise.
- Note—However, the priority of an attorney's power for a health matter is decided by the Guardianship and Administration Act 2000, section 66 (Adult with impaired capacity—order of priority in dealing with health matter).*
- (4) While power for a health matter is exercisable under an advance health directive, the directive gives the attorney for the matter power to do, for the principal, anything in relation to the matter the principal could lawfully do if the principal had capacity for the matter.
- (5) However, the power given is subject to the terms of the advance health directive and this Act.
- (6) A person dealing with the attorney may ask for evidence, for example, a medical certificate, to establish that the principal has impaired capacity for the matter.

Directions for treatment refusals in an Advance Health Directive

A valid AHD that refuses a particular life-sustaining treatment has the same force at law as a contemporaneous decision.

Many AHDs do in fact refuse medical treatments. Health care professionals are required to follow a valid AHD and apply the refusals for treatment to the particular circumstances, with some important provisos. Even though there are provisions in the law that set out how AHDs operate, there are tensions and debate as to how these provisions are applied. For example, under Queensland law, doctors are excused from following the directions in an Advance Health Directive if they have 'reasonable grounds' to believe the direction/s are inconsistent with good medical practice. This adds a significant layer of complexity to the decision-making about life-sustaining measures. More than a decade ago a legal paper raised the matter of advance refusals and made the following observation:

An excuse based on good medical practice seriously weakens the essence of advance directives: the ability of an adult to choose the treatment that he or she wishes to refuse, even if others may disagree. It also undermines the primacy that the common law has given to the right to self-determination or autonomy. The practical effect of the excuse is that an adult cannot be confident that his or her advance directive will be followed if it is not considered good medical practice for treatment to be withheld or withdrawn. The authors are of the view that the excuse should be repealed and that, in this context, the common law position reflects a more appropriate balance between the right to self-determination or autonomy, and the sanctity of life.⁴⁵

As highlighted by legal commentators, if a patient has an AHD, treatment refusals can be potentially overturned on good medical practice grounds, whereas under common law the principle of patient autonomy remains paramount.⁴⁶ The complexity of the law aside, if a patient regains capacity, even for a short time, their wishes for refusing life-sustaining measures must be

followed. If a patient decides they do not wish to receive life-sustaining treatments, this should be carefully documented in the medical record and discussed as soon as practicably possible with their substitute decision-maker/s and, where appropriate, those closest to the patient.

It should also be noted that if a patient regains capacity and decides to refuse treatment, even if this is contradictory to their AHD, the later decision to refuse medical treatment overrides. This is because an Advance Health Directive activates only when a patient loses capacity. If the patient regains capacity, they should be encouraged to review the directions in their AHD if their choices have changed since the directive was first created.

The singling out of artificial hydration and/or nutrition for special mention must be carefully noted.⁴⁷ This provision effectively means that directions in an AHD about withholding or withdrawing artificial hydration and/or nutrition may be followed *only if* the commencement or continuation of measures would be inconsistent with good medical practice. In other words, the provision of artificial hydration or nutrition must be of no benefit to the patient and any attempt to administer these measures would be clinically futile. The [Public Guardian website](#) contains further information for the public about AHDs and how they should be completed.

Only if it is considered clinically futile to commence or continue artificial hydration and/or nutrition may these measures be withheld or withdrawn in accordance with the patient's Advance Health Directive.

Powers of Attorney

A power of attorney is a legal document that enables a person to formally appoint another person/s to make financial and/or personal decisions on their behalf. Personal decisions relate to care and welfare including decisions about health care matters. Financial decisions relate to the management of finances, such as selling of property, investments, taxation and pension payment arrangements. There are two types of powers of attorney; general power of attorney, and enduring power of attorney (EPOA). A general power of attorney is used to appoint someone to make financial decisions on a person's behalf for a specific period or event, such as going overseas and needing property to be sold in their absence. It is used while a person can still make their own decisions and ends when capacity is lost.

An EPOA is used to appoint someone to make financial and personal decisions on behalf of a person if they become unable to make their own decisions, e.g. failing cognitive health or loss of capacity to make decisions about health matters. 'Enduring' means that the power continues even if the person giving it loses the capacity to make decisions. The EPOA has two different forms; a short form and a long form. The short form is used if a person wishes to appoint the same attorney/s for both financial matters and personal matters (including health care). It can be used to appoint an attorney (or attorneys) for financial matters only or for personal matters (including health care) only. The long form EPOA can be used by a person if they wish to appoint an attorney for personal matters (including health care) and a different attorney/s for financial matters.

The Public Guardian can be appointed to make decisions on behalf of a person under an enduring power of attorney.

Enduring powers of attorney documents can be limited by the person creating them. For example, certain decisions may be excluded from being made by the person appointed. Therefore, it is always prudent to check the document to ascertain the detail of the powers given to the person appointed under the enduring documents.

Links to all enduring documents including AHDs, EPOAs and revocation forms can be found on the Department of [Justice and Attorney General website](#). An [Enduring Power of Attorney Factsheet](#) can also be found on the Public Guardian website.

1.5.2 Common law health directives

While AHDs formalise the statutory approach by documenting health care decisions to come into effect at a time when a person no longer has capacity for decision-making, informal directives or common law health directives as they are known, are also recognised. However, the legal complexities in this area mean that common law health directives are not legally binding in Queensland.⁴⁸ Yet, a common law health directive can still inform the decision-making process in consideration of and balancing all other relevant factors. Since common law health directives cannot legally be used for consent like a valid AHD, the legal consenting pathway must be followed for a person without capacity, particularly where the decisions involve life-sustaining measures. To remove all risk, for a person who lacks capacity, it is recommended that the consenting pathway under the guardianship laws be followed, even if a common law direction exists. Further information about the legal status of common law health directives can be found on QUT's [End of Life Law](#) website.

Why do common law directives exist? As an extension of the right of self-determination, the common law recognises the right of every competent adult to indicate in advance whether or not he or she consents to or refuses particular medical treatment.⁴⁹ Essentially, a common law health directive is one that does not meet the formal requirements of Queensland's statutory scheme.⁵⁰ Any person can create a common law health directive and it can be in any form, such as a letter, recalled conversation or video. A common law directive can therefore be oral, such as a conversation or discussion between family members, whereby a person makes clear choices about medical treatment in the event they lose capacity for decision-making. This means that the conversation or discussions held between the patient and his or her substitute decision-maker/s will need to be recalled (by those who took part in the discussion) at the time the decisions are required.

The legal status of common law directives in Queensland aside, common law directives still must satisfy a number of criteria for them to be valid at the time decisions are required. For example, it will need to be established that the person making the common law directive had capacity at the time they made the directive and that their decisions were made voluntarily and not under duress. A common law directive made by a person with capacity can refuse any medical treatment and there is no legal requirement for proof that the person had sufficient information to make their decisions. Common law directives will not apply if a person's circumstances have changed to the extent that their earlier decisions do not apply to their current clinical situation. Also, common law directives do not apply if they are uncertain or ambiguous or based on incorrect information and assumptions, such as a person believing a certain antibiotic would kill them, when there is no evidence of this. While a person can request all forms of medical treatment in their common law directive, including that which is not clinically indicated, doctors are under *no legal or ethical obligation* to provide treatment that they believe to be futile, in other words, medical treatment that offers no benefit and would cause the patient harm.

Understanding the complex interplay and the differences between statutory AHDs and common law advance directives is challenging. What makes this area of the law so complex and open to different interpretations? Under section 39 of the *Powers of Attorney Act 1998* (one of the acts which govern the operation of AHDs) it states:

This Act does not affect common law recognition of instructions about health care given by an adult that are not given in an advance health directive.

While this has every appearance of preserving the common law, there is the view that the common law with respect to AHDs no longer applies due to the later drafting of the *Guardianship and Administration Act 2000* (Qld) (particularly section 66), which states:

'If an adult has impaired capacity for a health matter, the matter may only be dealt with under the first of the following subsections to apply'.

The relevant subsections do not include specific reference to common law advance directives. As such, many legal commentators in this area contend that the common law in relation to advance directives does not apply in Queensland.⁵¹ In other words, this is likely to have the effect that in Queensland, only *statutory* Advance Directives are legally binding. While this may be the case,

not following, or even ignoring, common law directives comes with significant caution for the health professional; just because common law directives are not 'legally binding', ignoring them, however made, could lead to liabilities under civil or criminal laws. As with any common law directive, the directions and sentiments expressed (orally, in writing, or in another way) must be taken into account at the time decisions are needed. If the patient lacks capacity for decision-making, just as for the valid statutory AHD, the valid and applicable common law directive activates and will need to be followed to the extent that to do so is not inconsistent with the legislation. In other words, the legislation in respect of when consent is not required and the application of AHDs will take precedence. (Also see section [1.5.5 – Deciding not to follow an Advance Health Directive](#)).

Nevertheless, the recognition of common law directives in addition to a statutory scheme providing for AHDs creates uncertainty and a two-tiered system where different laws apply to the two types of advance directives without any real justification for those differences.⁵² Further, if an adult who has capacity expresses a view about his or her end-of-life health care, but the view is not expressed in a way that complies with the requirements for the making of a statutory AHD, a health provider would need to decide whether the adult patient's previously expressed view (for example, written in a letter or expressed to members of the family) satisfies the common law test. This may be difficult to determine in practice, and the requirement for decision-makers to act in accordance with, and represent, the patient's best interests should be taken into account. At the time decisions are required, a Court would expect substitute decision-makers to act in accordance with the General Principles and the Health Care Principle (statutory regime) in communicating the common law directive to the health care team. It should be noted that the law in this area is uncertain and untested in this regard.

It should also be noted that for many people, the common law approach to advance care planning is more acceptable for many reasons. For example, where families are very close and have common and shared objectives about future health care needs, the need to formalise wishes may not seem necessary. In addition, the length and complexity of the prescribed form in Queensland may be a deterrent to completing it. Since statutory AHDs potentially have a different status to common law directives, law reform is being sought in this area.

At common law, an advance directive can operate only if it is valid. The courts scrutinise the circumstances of each case very carefully to ensure that the adult possessed the requisite competence and that undue influence had not been exercised. Further, the courts go to great lengths to satisfy themselves that a previously given directive is valid, still represents the views of the adult and that the directive was intended by the adult to govern the medical situation that ultimately arose. Once satisfied of these matters, there is no further limitation on when a directive to refuse a life-sustaining measure will operate. It is irrelevant that the adult would have lived for an extended time or even made a full recovery if the life-sustaining measure were given, or that the adult was not suffering from any illness or disease at the time a decision had to be made about treatment. The directive binds a health professional to the extent that it would be unlawful for that professional to provide the treatment that has been refused.⁵³

1.5.3 Tensions in the debate

As with many matters involving difficult health care choices, there are controversies and tensions in the debate about whether statutory or common law directives can truly represent an adult's wishes for care at the end of life. Partly this has to do with the directions not being contemporaneous at the time the decisions are needed, and partly to do with the administration processes that go towards verifying the directives are valid. Yet community support in favour of people having the ability to make health care decisions in anticipation of a future time when they lose capacity is often reported positively by the media.

Research also indicates that there is support for enabling adults to make statutory or informal advance directives in relation to end-of-life care:

Advance care planning (ACP) enhances patient participation in care and there is evidence that it leads to better outcomes for both patients and families and assists health professionals in decision-making. It is part of good medical practice and governments have repeatedly stated their desire to

promote its uptake by patients and acceptance by health professionals. Yet ambitions to enhance implementation and uptake of ACP have not been realized.⁵⁴

As previously mentioned, there are barriers to the making of advance directives. However, while the uptake of making AHDs is slowly increasing, it is still not as prevalent as earlier predictions provided. Recent research suggests that fourteen per cent of the Australian population has an advance directive and Queenslanders (and people from South Australia) are more likely to have an AHD than those from other states.⁵⁵

However, it should also be noted that the use of AHDs in relation to the withholding and withdrawal of life-sustaining measures has also been criticised. Given the irreversible consequences involved, there is a view that advance directives (statutory or informal) are potentially an inadequate tool to reflect accurately the wishes of an adult at the time when the measures are to be withheld or withdrawn. One of the tensions is the perception that advance directives are open to abuse, with vulnerable persons potentially being coerced into completing AHDs to refuse life-sustaining measures. It has also been suggested that this pressure may be in the form of direct coercion from a person close to the individual, and may also be in the form of 'social' pressure:

For people with disability, the social pressure not to be a 'burden' can be great and, in the absence of other protective measures, which guard against both overt duress on an individual and the more general social coercion, people with disability may believe they have an obligation to die.⁵⁶

This view raises ethical concerns about the appropriateness of justifying the use of advance directives for the withholding or withdrawal of life-sustaining measures in terms of patient autonomy. Other suggested problems with using AHDs for decisions in relation to life-sustaining measures include:^{57 58}

- the low numbers of people who actually execute advance directives
- the reality that often people are 'not provided with enough information about illnesses and treatments to make prospective life-or-death decisions about them'
- evidence suggesting that people can change their treatment preferences over short periods of time
- directions in the advance directive potentially being misinterpreted because of lack of specificity (for example, "I don't want heroics".)
- the problems of locating and interpreting the document at the time it is needed.

On the other side of the debate, while acknowledging these concerns, some observers are of the view that the right to make an advance directive should be retained.⁵⁹

The fact that most people have not made an advance directive does not mean that they do not want the *right* to make one. Many of the important civil rights in Australia are never exercised by the majority of the population but they are fundamental rights which Australians expect to have access to if needed, for example, rights to trial, rights to freedom of movement and rights to protest. The right to make an advance directive is also a fundamental right and for that reason it is worthy of our respect.⁶⁰

Advance directives about withholding and withdrawal of life-sustaining measures are recognised as an important component of advance care planning generally, in which informed discussions about treatment preferences for end-of-life care can take place between patients, family and health professionals. People who formalise their wishes in advance directives often do so to relieve family members of the potential burden of life-or-death decision-making on their behalf in the event that they later lose capacity. However, people who have an AHD may also have very strong feelings about participating in their treatment and care at the end of life.

1.5.4 Consent under an Advance Health Directive

In Queensland, an AHD is a legally recognised expression of a person's wishes in relation to future health care decisions. Under the law, an AHD must be:⁶¹

1. A written document; and

2. Signed by the adult patient (or by an 'eligible signer' on the adult's behalf); and
3. Signed and dated by an 'eligible witness' and certified that the document was signed in their presence and the adult appeared to them to have capacity; and
4. Signed and dated by a doctor (not the witness) and certified that the adult appeared to the doctor to have capacity to make the AHD.

The health care team is entitled to sight the original or certified copy of the AHD.

It is the responsibility of the person making an AHD to make sure the decisions in their document will be drawn to the attention of health care professionals when it is needed at a future time. Certified copies of the AHD may be held at the hospital where the patient is being treated, in the medical records of the patient's general practitioner, in the possession of a close relative, or at the person's own residence. Some people may also carry a card or wear a bracelet with information to this effect.

An Advance Health Directive 'activates' only when a person loses capacity for decision-making; it is not applicable in the situation where the patient has or regains capacity.

If a patient regains capacity for decision-making, the AHD ceases to have effect. A person with capacity, if they wish, can also revoke previous directions, but they must do so in writing.

An AHD should not be relied upon in any of the following circumstances:

- the document is obviously defective (such as pages missing, not signed, dated or witnessed)
- there is doubt about the directions themselves (for example, terminology or treatment pathology, for example 'I don't want heroics')
- the directions are uncertain or inconsistent with good medical practice
- the proposed treatment is not the treatment specified in the Advance Health Directive
- the circumstances are different from those that have been set out in the advance decision
- the person withdrew the decision while they still had capacity to do so
- personal or medical circumstances have changed to the extent that the direction to withhold or withdraw life-sustaining measures is no longer appropriate
- the person has done something that clearly goes against the advance decision which suggests they have changed their mind (this must be discussed with the patient to the extent possible).

It is also important to establish that the person making the AHD was 18 or older when they made their decision and that they had capacity to do so.

If the AHD is considered not to be valid, the statutory consent process must be followed, that is, using the patient's substitute decision-maker/s to make decisions on their behalf.

If it is established that the AHD is valid, the directions must not only be respected, but followed,³ as it is a legally binding document, acting as the patient's decision-maker/s when they lose capacity. Since the effect of the document is of the adult patient making health care decisions while they had capacity, they are entitled to refuse any medical treatment. Legally, valid AHDs take precedence over treatment requests made on behalf of the patient by family members.⁶²

The treating medical team must always start from the assumption that the person had the capacity to make the advance decision/s, but even in emergency situations, as far as practicably possible,⁶³ medical staff must ensure that the AHD is a valid document.

To be applicable, directions in an AHD must apply to the situation in question and in the current circumstances. However it should be noted that objections to certain forms of treatment can be

³ Note that there are some exceptional situations where medical officers can choose not to follow the directions in an Advance Health Directive. See following section 1.5.5 for more detail.

made at a previous time, and must also be taken into consideration in the decision-making process. Health care professionals must first determine if the person still has capacity to accept or refuse treatment at the relevant time. If they have capacity, they can refuse treatment at this point, or they can change their decision and accept treatment. In deciding whether an advance decision applies to the proposed treatment, the doctor responsible for the patient's care must consider:

- the date of the AHD, the patient's clinical circumstances and whether the advance decisions relate to those circumstances; and
- whether there have been any changes in the patient's personal life (for example, the person is pregnant and this was not anticipated at the time of the advance decision) that might affect the validity of the advance decision; and
- whether there have been any developments in medical treatment that the person did not foresee (for example, new medications, treatments or therapies); and
- if any prior objections to health treatment have been made in any capacity. These objections must be taken into consideration in all decision-making about providing or not providing medical treatment; and
- whether a patient may have included in their AHD that they consent to withholding or withdrawal of life-sustaining measures despite the objection at the time this is occurring. This must be respected.

Note also that under the legislation, AHDs do not have a time-limit, despite the recommendation on the prescribed form the document should be reviewed every two years. Revoking an AHD 'may' be done in writing while the person still has capacity. There is no specific or prescribed form for revoking an AHD as there is for an Enduring Power of Attorney.

It is Queensland Health's policy that certified copies of AHDs are permitted in certain circumstances. Clinical and administrative personnel may certify a photocopy or facsimile of an original AHD to keep on the patient's records.⁶⁴ This may also be useful when transferring patients between facilities. However it should be recognised that this does carry an element of risk. For example, the patient may revoke the copied AHD and make a new one some months later and neglect to inform the hospital when they are admitted. Despite this, it is acknowledged that in many circumstances when immediate decisions are required, file copies of AHDs may be the best indication of a patient's wishes. Even if the AHD later proves to be 'invalid', it would still comply with common law evidentiary provisions.

1.5.5 Deciding not to follow an Advance Health Directive

If, after careful consideration of all the circumstances, a doctor decides not to follow a patient's AHD, a second opinion must be sought from another senior doctor or consultant. Meticulous and thorough record-keeping will be required in these circumstances. Utmost care should be taken in this area because, while the law does offer some protections for not following the directions in a valid AHD,⁶⁵ there are risks if doctors choose not to do so.

Generally, doctors are protected in circumstances where:

- they act in reliance on an AHD without knowledge of its invalidity; or
- they act without knowledge of the existence of an AHD; or
- they fail to act in accordance with an AHD that is uncertain, inconsistent with good medical practice or that they otherwise consider is inappropriate due to circumstances changing since the directive was made.

However, the onus of proof of 'uncertainty' would be on the doctor who may be required to defend this position in a court; hence, the need to clearly document these circumstances cannot be overstated.

Therefore, a doctor does not have to follow an AHD if:

- a direction to withhold or withdraw life-sustaining measures is inconsistent with good medical practice; or
- the patient is not sufficiently ill and there are directions to withhold and withdraw life-sustaining measures; or
- a direction is uncertain (although an attorney⁴ may need to be consulted if one was appointed under the AHD); or
- circumstances have changed to the extent that the direction/s does not apply (for example, medical advances mean the direction should not be acted upon).

According to Queensland law, "...in those circumstances a health professional will not be liable for failing to comply with the Directive. The health professional will therefore need some other form of authority to determine treatment, for example, by obtaining consent from the substitute decision-maker to provide or withhold treatment."⁶⁶

1.5.6 Informed consent

The foundation for decision-making about withholding and withdrawing life-sustaining measures can shift depending upon whether or not consent by the patient or their substitute decision-maker is valid. The concept of 'informed consent' differs slightly from consenting provisions discussed earlier as part of the legislative framework (refer to section - [1.5 Consenting Regime](#)). The concept of informed consent has been greatly influenced by medical case law and ethical debate in this area.

Informed consent involves the medical information patients need to know so they can make decisions, sometimes in advance, about health matters.

Decision-making responsibility is also a key feature of discussions about informed consent. Queensland Health's Guide to informed decision-making in healthcare provides useful detailed guidance in this area:⁶⁷

Informed decision-making is the two-way communication process between a patient and one or more health practitioners that is central to patient-centred health care. It reflects the ethical principle that a patient has the right to decide what is appropriate for them, taking into account their personal circumstances, beliefs and priorities. This includes the right to accept or to decline the offer of certain healthcare and to change that decision. In order for a patient to exercise this right to decide, they require the information that is relevant to them.

(...) consent means a person's agreement to the provision of public sector health services. Informed consent means that a patient has received the information relevant to them to make an informed decision and they have given permission for the health care service to be provided. In an ethical sense, the agreement by a patient to receive public sector health services reflects the end point of a process of engagement in which one or more health practitioners have supported the patient to come to an informed decision to agree to the health care offered.

For the patient's informed consent to health care to be valid, certain principles must be fulfilled:

- the patient has the capacity (ability) to make a decision about the specific issue at the specific time, and is not affected by therapeutic or other drugs, or alcohol
- the consent is voluntarily given, and free from manipulation by, or undue influence from, family, medical staff or other social coercive influences
- the discussion between the patient and the health practitioner is transparent, well balanced, and involves two-way communication which is sensitive to the situation the patient is able to

⁴ It should be noted that while the term substitute decision-maker is often used in a collective sense, the technically correct term for a person appointed in an AHD to make decisions on the adult's behalf is an attorney.

clearly understand the information because it is provided in a language or by other means the patient can understand as far as possible, the patient is advised in simple terms of:

- the diagnosis
- recommended health care, including the expected benefits, common side effects and alternative health care options
- the material risks including complications associated with:
 - the recommended health care
 - alternative health care options
 - a decision not to receive the health care offered
 - any significant long term physical, emotional, mental, social, sexual or other expected outcomes
 - the anticipated recovery implications
- the patient has sufficient time to consider and clarify information in order to make an informed decision, taking into account the context of the clinical situation
- the information provided and the consent given relate to the specific health care provided.

There are tensions between what constitutes informed consent for providing medical treatment versus the refusal of medical treatment. The prevailing view is that “the more serious the risk, the greater the level of evidence of capacity that should be sought”.⁶⁸ Some patients may be competent to consent to minor procedures like vaccinations but not competent to consent to major surgery or the prospect of life-sustaining measures being withheld or withdrawn.

Such dilemmas not only create doubt in the process of assessing capacity, it adds to the pressure on doctors making assessments to ensure the patient (and his or her substitute decision-maker) has sufficient information to make an informed decision. There is conflict between the doctor’s duty to do what is considered to be in the patient’s best interests, while also allowing the patient to make decisions that the doctor may feel is “irrational”. Regarding this conflict, however, the law seems to be clear. In a United Kingdom case, the presiding judge stated: “The doctors must not allow their emotional reaction to or strong disagreement with the decision of the patient to cloud their judgment in answering the primary question whether the patient has the mental capacity to make the decision.”⁶⁹

Nevertheless, the intent behind the concept of informed consent is to protect both parties. A patient needs to know what options are available, what the expected outcomes are for each option, and what the success rates and incidence of side-effects are for each option. The treating doctor and attending healthcare team need to know that the patient understands the implications of their decision.

To add to the complexity of issues in applying informed consent principles in this area, some consent can be verbal or implied, and consent need not be in writing to be enforceable. It should be pointed out that the signature on a consent form is not considered to be enough to show the consent is valid and informed. In the event of a dispute about whether a patient had given valid informed consent, a signed consent form needs to be supported by appropriately specific and detailed information, written either on the form or documented in the patient’s clinical record, to provide the best evidence of the communication process followed to obtain the patient’s consent.⁷⁰

The legal and ethical principles that underpin informed consent mean that informed consent is not necessarily required for treatment refusals in an AHD. Competent adults can write medical directions refusing future treatment with no requirement to be informed themselves about the potential consequences of their AHD being applied. A clearly stated refusal of treatment in a valid AHD cannot be ignored on the grounds that the person was not informed about the medical consequences when they wrote it. This is connected to the fundamental right of an adult with decisional capacity to refuse medical treatment even if this results in their death or would cause it to happen sooner.

However, it is important to note that informed consent provisions apply when decisions are made by a substitute decision-maker at the time that health or medical treatment is required, in the same way as they apply when a competent adult decides whether or not to undergo treatment. The treating health care team is obliged to give the substitute decision-maker sufficient information to make that decision in an informed manner. When treatment is indicated, the obligation is on the doctor responsible for the patient's care to inform them or their substitute decision-maker, not on patients and substitute decision-makers to ensure they are informed, for their consent to be valid or their refusal to be binding.

While patients are under no obligation to explain or justify their decision to refuse medical treatment to the health care team, the treating doctor should discuss the implications of the patient's decision in an open and honest manner. This is to ensure the decision is based on accurate information and not on any misunderstanding or misinterpretation of the facts. In these instances, there is a careful balance between pressuring the patient into something they do not wish and ensuring the information provided to the patient is consistent with good medical practice.

If those closest to the patient are involved in these discussions, care must also be taken to ensure the wishes and views of the patient, rather than their family, are followed. Ultimately the doctor in charge of the patient's care will decide what options are clinically appropriate to offer. It would be incumbent upon a doctor and other members of the healthcare team, knowing of the patient's refusal, to ensure the substitute decision-maker/s informed of that treatment refusal.

Offering and informed consent

In non-urgent situations, the legislation requires that consent is obtained in order to withhold life-sustaining measures.⁷¹ This applies to both patients with capacity and patients who lack capacity. For patients without capacity, it is presumed that in non-acute emergency situations, sufficient time is available to locate the patient's substitute decision-maker/s and discuss the patient's end-of-life wishes, or to obtain the patient's AHD, if they have one.

However, the reading of this provision is the cause of some uncertainty and also linked to requirements for informed consent. The most extreme interpretation of these provisions would have doctors offering every conceivable medical treatment in order to obtain consent to withhold it (that is, not to provide it). This has caused implications for the practical application of the legislation that are unlikely to have been intended by Parliament when the withholding and withdrawing life-sustaining measures provisions were introduced in 2001.

Discussing treatment options that in all reasonableness cannot be provided or would be considered potentially futile is counter-productive to an effective doctor/patient relationship. Falsely raising hopes for a dying person and their family by suggesting forms of treatment that would not benefit the patient and have the potential of causing harm is cruel, callous and would not constitute good medical practice.

Offering all possible treatments, including 'extraordinary' measures, may not necessarily benefit the patient and could potentially lead to confusion and unrealistic expectations of recovery. In fact there is no legal or ethical obligation to offer medical treatment that is not clinically indicated (this is discussed further in [section 1.10 – Futile medical treatment](#)). The doctor responsible for the patient's care must use his or her best judgement in applying the standards of good medical practice and proceed with a course of action that provides the maximum benefit to the patient, taking all factors into consideration including balancing the available resources and care needs of other patients.

However, it is recognised that prospective decision-making in the end-of-life arena is fraught with uncertainty. These are not single-dimension, linear decisions; every patient's condition has subtle and not so subtle differences and a patient's disease trajectory and treatment decisions will reflect these differences. Therefore, decisions about what treatments to offer dying patients must be made based on the specific needs of each patient, not on what treatment was offered to another patient of similar age or condition.

It is Queensland Health's policy that the doctor responsible for the patient's care is under no obligation to discuss or offer unrealistic treatments in order to gain consent to withhold them: that is, treatments which, for reasons of good medical practice would be futile, potentially harmful, and offer no benefit to a dying patient.

1.6 Objections to providing or not providing

The matter of objections to provide or not provide medical treatment is a very complex part of the law. *The Guardianship and Administration Act 2000* provides that, in certain circumstances, a doctor may not exercise their power to provide or not provide medical treatment if they know, or ought reasonably to know, that the person objects to the health care ('health care' in this context can mean either actively providing life-sustaining measures or withholding or withdrawing life-sustaining measures).

Section 67 of the *Guardianship and Administration Act 2000* states:

Effect of adult's objection to health care

- (1) Generally, the exercise of power for a health matter or special health matter is ineffective to give consent to health care of an adult if the health provider knows, or ought reasonably to know, the adult objects to the health care.
- (2) However, the exercise of power for a health matter or special health matter is effective to give consent to the health care despite an objection by the adult to the health care if —
 - (a) the adult has minimal or no understanding of one of the following —
 - (i) what the health care involves;
 - (ii) why the health care is required; and
 - (b) the health care is likely to cause the adult —
 - (i) no distress; or
 - (ii) temporary distress that is outweighed by the benefit to the adult of the proposed health care.
- (3) Subsection (2) does not apply to the following health care—
 - (a) removal of tissue for donation;
 - (b) participation in special medical research or experimental health care or approved clinical research.

The term 'object' is defined to mean that the person indicates that he or she does not wish to have the health care, or that the adult previously indicated that he or she did not wish to have the health care if these circumstances arose, and since then he or she has not indicated otherwise. The legislation provides examples of how that objection may be indicated:⁷²

An indication may be given in an enduring power of attorney or advance health directive or in another way, including, for example, orally or by conduct.

If the doctor is aware that the patient objects to certain medical treatment being provided, and decisions are required urgently, the doctor would be required to establish two other factors:

- (i) the patient had minimal understanding of what the health care involves and why the health care is required,⁷³ and
- (ii) providing the health care would cause the patient no distress or only temporary distress that would be outweighed by the benefits of providing the health care.⁷⁴

'Knowing' or awareness in this context would be where the doctor is aware of the patient's objection to certain health care, through:

- directions in a patient's valid AHD, if they have one
- direct knowledge (rather than hearsay, for example, from a family member) from a conversation recently held with the patient
- instructions in the patient's valid 'active' ARP

- the patient's wishes as documented in the progress notes
- another advance care planning document (for example, Statement of Choices (SoC)), if the patient has one.

It is recognised that in acute emergency situations, there is not always time to locate and verify some of the documents mentioned above. In these cases, when critical time is needed to save the life and health of the patient, best efforts must be made to obtain the appropriate legal consent, (or rely on authority in legislation where consent is not required), given the circumstances. Ignoring consent provisions in the legislation has the potential to expose the doctor and other members of the health care team to risk of criminal and civil liability if the clinical decision is to not resuscitate the patient.

If all reasonable attempts to locate the patient's substitute decision-maker/s are unsuccessful, the Public Guardian becomes the decision-maker as a last resort.

A recent legal case in the United Kingdom highlights the need for discussions with a patient's substitute decision-maker.⁷⁵ The High Court ruled in a landmark case that doctors must consult the carers of patients who are mentally incapacitated before placing "do not attempt cardiopulmonary resuscitation" (DNAR) notices on their files.⁷⁶ It is for reasons such as this, that the ARP was designed to reflect a collaborative approach to substitute decision-making under the guardianship legislation.

If all reasonable attempts to locate the patient's substitute decision-maker/s are unsuccessful, the Public Guardian becomes the decision-maker as a last resort. If the patient objects to the withholding of life-sustaining measures, for example, the patient requests the treating doctor to 'do everything possible' or in some way communicates the message 'don't let me die' before losing capacity, then consent from the patient's substitute decision-maker/s would be required if the clinical decision is to *not* provide life-sustaining measures. (See below for further information about the effect of 'objections' for CPR in acute emergency situations.)

While all reasonable efforts to obtain consent should be made, it is recognised that in some acute emergency situations it may be inappropriate to continue to maintain life while attempts are made to obtain consent to withhold or withdraw treatment.

Under the general principle and the health care principles, substitute decision-makers are required to make decisions in the patient's best interests. Also, the decision-making pathway that led to the decision to withhold or withdraw life-sustaining measures from the patient, must be thoroughly documented.⁷⁷

In order for a substitute decision-maker's consent to override a person's objection to health care (which could be either an objection to the withholding or withdrawal of a life-sustaining measure or the provision of a life-sustaining measure), the test in section 67(2) must be satisfied. That is, a doctor must assess the extent of the patient's understanding of the treatment involved and that temporary or no distress will be experienced by the patient.

However, in practical terms, section 67 of the *Guardianship and Administration Act 2000* deals with the effect of an objection that is made other than in an AHD. As explained previously, if a person has made an AHD that contains a relevant direction about the withholding or withdrawal of a life-sustaining measure, the matter may only be dealt with under that direction. In these circumstances, there is no scope for the adult's substitute decision-maker/s to exercise the same powers under the legislation and object on behalf of the person making the directive. As a result, section 67 does not apply to an objection made in an AHD.

Cardiopulmonary Resuscitation (CPR) in acute emergency situations

Effect of objection under section 63A(2) *Guardianship and Administration Act 2000*

Generally, CPR can be withheld from a patient without needing to obtain a substitute decision-maker's consent if the doctor reasonably believes that:

1. the patient has impaired capacity; AND
2. commencing CPR would not be good medical practice; AND
3. the decision to withhold CPR needs to be made immediately.

The only time consent would be required to withhold (not provide) CPR is where the treating doctor knows that the patient objected to withholding CPR. It is Queensland Health's policy that the only way a clinician can "know" a patient objects is if:

- (a) the patient is able to articulate this to the treating doctor or nurse - such as the patient saying "do everything possible" or "don't let me die" at the time of the presentation to the hospital or facility (remembering that verbal statements to this effect which differs from the documented resuscitation plan or any other written advance care planning document should be escalated without delay and preferably resolved before the resuscitation plan needs to be implemented); or
- (b) this is written in a patient's AHD, the patient's chart, the Patient Choices section of the patient's ARP or other advance care planning document (for example, Statement of Choices) as applying to the particular circumstances and such a statement is still valid; or
- (c) the patient's conduct makes it clear they want CPR.

Due to these limitations, a "known" objection to withholding CPR should not arise regularly. A family member or friend saying that the patient would want everything done does not constitute an objection by the patient, as the treating doctor cannot (without more information or a direct indication from the patient themselves) KNOW at the time the decision is to be made if this is true and accurate.

If there is an objection that the doctor knows about, there may be a window of opportunity to obtain the consent required from a substitute decision-maker (including from the Public Guardian) to withhold CPR from the patient. Remembering that the substitute decision-maker must make their decision in the patient's best interests, and there is no obligation to accede to demands for futile medical treatment. However, if the situation arises where the treating doctor is aware of an objection to the withholding of CPR and there is no time to obtain consent, then in what is considered to be very rare circumstances, CPR may need to be commenced, and consent obtained to the withdrawing of this measure.

1.7 Emergency versus non-emergency situations

The legislation distinguishes between the consent requirements for providing and not providing medical treatment and specifically outlines how this works depending upon whether the decision is required immediately, for example in acute emergency situations.⁷⁸ For example, consent is not required to *provide* urgent health care, as long as the doctor is not aware of any objections made by the patient to the treatment to be provided, and:⁷⁹

- (a) the adult has minimal or no understanding of 1 or both of the following—
 - (i) what the health care involves;
 - (ii) why the health care is required; and
- (b) the health care is likely to cause the adult—
 - (i) no distress; or
 - (ii) temporary distress that is outweighed by the benefit to the adult of the health care.

It must also be noted that health care for this section of the *Guardianship and Administration Act 2000* (Urgent health care) does not include *withholding or withdrawal* of a life-sustaining measure, but may include *providing* life-sustaining measures.⁸⁰ In effect, this strengthens the consenting requirements around withholding and withdrawing life-sustaining measures.

1.7.1 Acute emergencies

Acute emergencies are characterised by the urgent need to make treatment decisions to maintain the patient's life and health. They may occur in any clinical setting.

Providing life-sustaining measures in acute emergency situations

Legal consent provisions for administering urgent medical treatment to an adult patient who lacks capacity are not as stringent as they are to withhold or withdraw treatment. In *providing* urgent health care to a patient without capacity, the legislation recognises that it is not always practical to obtain consent in acute emergency situations.⁸¹ Therefore, if there is no time to obtain consent in these crisis situations, the doctor responsible for the treatment and care of the patient must 'reasonably consider':

- whether the patient has impaired capacity; and
- the medical care is needed urgently to save the patient's life; or
- the medical care is needed to prevent significant pain or distress to the patient.

However, there are important provisos about consent and objections even when *providing* health care in urgent situations. Consent is required if the doctor responsible for the patient's care knows the patient objects to the health care in an AHD.⁸² Consent is also required from an adult patient if they have capacity for decision-making, remembering they are entitled to refuse this treatment, even if this would result in their death or cause it to happen sooner and no one else agrees with their decision.

Withholding or withdrawing life-sustaining measures in acute emergency situations

As previously mentioned, withholding or withdrawing life-sustaining measures do not fall within the definition of 'health care' in the section of the *Guardianship and Administration Act 2000* that discusses *providing* urgent health care. As such, *withholding or withdrawing* 'life-sustaining measures' has its own provisions within what is termed 'acute emergency' situations.⁸³ Life-sustaining may be withheld or withdrawn from an adult patient without consent, provided the doctor responsible for the treatment and care of the patient considers:

- the patient does not have capacity to decide about such matters; and
- that providing (commencing or continuing) the life-sustaining measure/s would be inconsistent with good medical practice, in other words providing the measure/s would be futile medical treatment; and
- consistent with the standards of good medical practice, the decision to withhold or withdraw the measure must be taken immediately.

The law does not permit artificial nutrition and hydration to be withheld or withdrawn without consent, even in acute emergencies. As such, these specific measures are not considered life-sustaining measures under this section of the *Guardianship and Administration Act 2000*.⁸⁴

Consent is always required to withhold or withdraw artificial nutrition and hydration.

1.7.2 Non-acute clinical situations

Non-acute situations are included in this section for completeness, and are characterised by more predictable clinical environments where the patient's condition is considered relatively stable and decisions are not required urgently. Patients who lack capacity in non-emergency situations are typically in a ward or other setting, rather than an emergency department or intensive care unit. Examples of this might include a long-term in-patient with end-stage Alzheimer's Disease. In non-acute situations it is presumed sufficient time is available to locate the patient's substitute decision-maker/s and discuss the patient's end-of-life wishes, or to obtain and discuss the patient's AHD, should they have one.

Where no urgent decisions are required and the patient lacks capacity, consent must always be obtained from the patient's substitute decision-maker/s (or through the patient's valid AHD) to withhold or withdraw medical treatment.

In non-acute situations where a patient lacks capacity and their substitute decision-maker/s insists on 'everything to be done', including non-standard forms of treatment and 'extraordinary measures,' that in the considered opinion of the senior doctor responsible would be futile, not in the patient's best interests, and inconsistent with good medical practice, there are essentially two choices, that will be governed by the circumstances:

1. The doctor is not obliged to continue treating the patient, but must as soon as practicable:
 - (a) refer the patient's substitute decision-maker/s to another senior doctor/consultant experienced in that area of medicine for a second opinion;
 - (b) escalate the matter to hospital or facility management, as per local referral process.
2. The matter can be referred to the Office of the Public Guardian for a determination of the case.

In these situations, the focus must always be on the best outcomes for the patient and those closest to them. Dispute resolution processes should be initiated as soon as possible if it is anticipated there may be the potential for escalation of conflict. For further information on communicating with patients and their families, refer to [section 6 - Advance Care Planning](#).

1.8 Good medical practice

As noted above in section 66A(2) of the *Guardianship and Administration Act 2000*, decisions to withhold or withdraw life-sustaining measures should reflect the standards of good medical practice for the patient at that time, circumstances and location, based on thorough clinical assessment. The clinical responsibility for decisions about withholding or withdrawing life-sustaining measures rests with the senior doctor responsible for a patient's care. Accepted ethical principles should also be taken into account when considering what good medical practice is in any particular situation. For more detail, refer to [section 3.1 – Clinical Considerations - Good Medical Practice](#).

However, for patients assessed to have capacity to make decisions about health matters, it is important to recognise they may refuse medical treatment, including the range of life-sustaining measures, even if this would result in their death or cause it to happen sooner. In other words, the decision of a patient who has capacity to refuse medical treatment can be inconsistent with what would be considered good medical practice.⁸⁵ Adult patients with capacity may also make decisions about refusing medical treatment that those closest to them may disagree with. This is a time where the patient's rights must be upheld and an area where the tension between patient autonomy and good medical practice requires careful and sensitive discussions, decision-making and thorough documentation. If life-sustaining measures are withheld or withdrawn, the patient's record must provide details of the decision-making pathway (required under section 66B *Guardianship and Administration Act 2000*).

The *Guardianship and Administration Act 2000* defines good medical practice as that which applies to the Australian medical profession, having regard to recognised ethical and professional standards, practices and procedures. Doctors should consider the professional practice standards that apply to the profession as a whole, and where relevant, practice standards which apply to their specialty. [Appendix 3](#) contains the end-of-life component provided in the Medical Board of Australia's [Good medical practice: a code of conduct for doctors in Australia](#).

1.9 Best interests

The *Guardianship and Administration Act 2000* incorporates the test for best interests in the Health Care Principle⁸⁶ and General Principles⁸⁷ for adult patients without the capacity for decision-making. The *Guardianship and Administration Act 2000* outlines measures to ensure the appropriate use of power by substitute decision-makers, for example their statutory health attorney. These principles ensure that decisions made on behalf of an adult patient without capacity are made in their best interests.

The guardianship legislation activates when a patient no longer has capacity for decision-making about health matters. If the doctor (or other members of the health care team) is convinced the patient's best interests are not being served by their substitute decision-maker who, for example, insists on inappropriate or non-standard treatment, he or she must take the matter further by seeking the opinion of a more experienced doctor or consultant, and/or refer the matter to the Public Guardian.

Assessing whether a treatment is in a patient's best interests crosses the boundary of clinical judgement to include legal and ethical considerations. While there are clinical indicators that test how well a body might be performing, there is no ethical standard for measuring someone's quality of life and for determining what values might be important to them.

It is also highly unlikely we could confidently use the same 'best interests' test between two people of similar conditions, ages and backgrounds. Therefore, it must be acknowledged that the test of best interests will always be subjective and carried out on a case-by-case basis, taking into consideration the full range of factors important to the patient. Almost always, best interests will be difficult to determine for a patient without involving those closest to them.

The decision-making process for withholding and withdrawing life-sustaining measures also requires an assessment of the patient's best interests by reference to the standards of good medical practice. Traditionally, the test of best interests was based on medical considerations rather than personal autonomy which capture the person's goals, wishes and values. Prolonging life at any cost was often seen as in the patient's best interest, because there was always hope that some miraculous medical intervention would save the life and health of the patient. However, such advancements in medicine also make it possible to sustain some essential functions far beyond the irrevocable loss of awareness.

Therefore, the 'traditional' values or codes of practice can no longer be relied upon by doctors for the test of best interests for the patient. Changes in medicine itself, society, the perception of professional roles and public expectations demand that all health care professionals identify, confront and attempt to resolve ethical issues and moral conflict in health care.⁸⁸ It is essential that thorough communication and consultation occurs with the patient and those closest to them, with the patient's consent.

More recently, legal commentators have identified six key themes from the developing body of Supreme Court jurisprudence about life-sustaining treatment decisions for adults who lack capacity: (Refer to [Appendix 5](#) – Supreme Court cases involving life-sustaining measures.)⁸⁹

1. Futile medical treatment is not in a patient's best interests.
2. Treatment that is overly burdensome is not in a patient's best interests, even if the patient is unconscious or unaware of treatment burdens.
3. Courts have generally not engaged expressly in quality-of-life assessments, but they remain relevant for determining best interests when considering the patient's medical condition and prognosis.
4. A patient's wishes and values (gleaned when the patient was competent) are relevant to, but do not determine, his or her best interests. Family members' views may also be relevant where they are reflecting a patient's wishes, and perhaps also when reflecting their own wishes, but these views are not conclusive in determining a patient's best interests.
5. The interests of other people and organisations (including the wider health system) are generally not relevant when determining a patient's best interests.

6. Courts have generally deferred to medical practitioners' opinions about treatment decisions, even when the patient's family has strongly opposed them.

According to the article referenced above, of the then 16 Supreme Court decisions in Australia that concern the withholding or withdrawal of life-sustaining treatment from an adult who lacks capacity, the issue of the patient's best interests was directly relevant in eight cases, most of which involved proposed withdrawal of medical treatment.⁹⁰ The law generally treats withholding and withdrawing treatment as equivalent. Authors of this article contend that, situations involving withdrawal are possibly more likely to lead to family conflict, because decisions to stop treating, as opposed to not offering treatment, are more prone to be construed by families as more causally connected to death. Clinical guidance on these matters agree: "The most challenging decisions in this area are generally about withdrawing or not starting a treatment when it has the potential to prolong the patient's life ... Some members of the healthcare team, or people who are close to the patient, may find it more difficult to contemplate withdrawing a life-prolonging treatment than to decide not to start the treatment in the first place."⁹¹

Based on the Health Care Principle and General Principles (reproduced in [Appendix 4](#)) the following checklist provides some guidance to determine the best interests of a person who lacks capacity for making decisions:

Checklist for test of best interests

1. Do not make assumptions about a person's best interests merely on the basis of their age or appearance, health condition or an aspect of their behaviour.
2. Allow for a person who lacks capacity to make their decisions in other ways, such as by conduct.
3. Try to identify the issues and circumstances relating to the decision that are most relevant to the person lacking capacity.
4. Ensure any decision-making is made in ways which are least restrictive of the person's rights.
5. Consider whether the person is likely to regain capacity and if so whether the decision can wait until such time that the person can make it themselves.
6. Do whatever is possible to enable and encourage the person to participate as fully as possible in making the decision.
7. Seek the views of the person by reference to their past and present values, wishes and feelings, particularly any relevant statements made when the person had capacity in their AHD or other written statements.
8. Seek the views of the person's legal substitute decision-maker, including appointed guardian, attorney appointed in an EPOA.
9. Consideration should also be given to any beliefs and values (faith based, cultural or moral) that would be likely to influence the decision.
10. Consult other people including unpaid carers, close relatives and friends who take an interest in the person's welfare where it is practicable and appropriate in the light of the person's right to confidentiality.
11. In particular try to consult with anyone previously named by the person as someone to be consulted.

1.10 Futile medical treatment

The term ‘futile treatment’ is difficult to define because it is a difficult topic to discuss. The issue is fraught with ethical, medical and legal challenges and this discussion could have been equally placed in the ethical or clinical considerations section in these guidelines. Nevertheless, the decision to withhold or withdraw life-sustaining measures involves considerations about whether the measures are futile, but the term itself is controversial. Some legal commentators agree:⁹²

Despite repeated attempts to define this term in literature spanning the disciplines of law, medicine, nursing and ethics, the concept remains contested and there is no consensus as to the meaning of the term.

A recent study into how clinicians define and use the terms “futility” and “futile treatment” in end of life care concluded that:⁹³

There is an overwhelming preference for a qualitative approach to assessing futility, which inevitably involves variability in clinical decision-making. Patient benefit is at the heart of doctors’ definitions of futility. Determining patient benefit requires discussing with patients and their families their values and goals as well as the burdens and benefits of further treatment.

The Australian Medical Association Position Statement on end-of-life care and advance care planning provides a useful definition of futile treatment as starting point for further discussion:⁹⁴

Treatment that no longer provides a benefit to a patient or treatment where the burdens of treatment outweigh the benefits. Doctors are not required to offer treatment options they consider neither medically beneficial nor clinically appropriate.

There are well-established common law principles that doctors are under no moral or legal obligation to offer or attempt medical treatment that could cause harm or would provide no benefit to a patient.

Such concepts also involve acknowledging that there are limits to what benefits medicine can provide. There are few cases in Australia and New Zealand where a decision to withhold or withdraw treatment has been litigated and where the issue of futile treatment has been raised.⁹⁵ In a notable case, the Court of Appeal concluded that ‘...ultimately, however, a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient’s clinical needs.’⁹⁶ Therefore, competent patients, or those holding authority to act on behalf of incompetent patients, cannot demand treatment that clinicians believe to be futile.⁹⁷ This includes all life-sustaining measures, such as cardiopulmonary resuscitation (CPR), dialysis, ventilation, and in some circumstances, even enteral or intravenous nutrition. Potentially futile medical treatment goes against a patient’s best interests and therefore, at common law, need not be offered. Legal commentators agree that stopping futile treatment does not breach the criminal law, and the courts are more inclined to defer to doctor’s clinical judgement, according to the circumstances of the case.⁹⁸ As Brereton J stated:⁹⁹

No patient has a right to insist on being given any particular treatment. The patient’s right is that the medical practitioner use reasonable professional care in the interests of the patient’s health and wellbeing. A patient is not entitled to insist on being prescribed particular drugs or receiving particular treatment but to that treatment, which the medical practitioner, using reasonable care, judges is best for the patient in the circumstances ... it would not in the present circumstances be necessary for the medical practitioners to resort to the Court for any declaration of the type sought.

Although the decision to withhold or withdraw life-prolonging medical treatment is ultimately a clinical decision, Australian courts are unclear as to what weight should be attached to family’s views.¹⁰⁰ While the patient’s family can offer important insights into the patient’s beliefs and views regarding end of life decisions, the clinician’s duty of care is always to the patient and their best interests, not those of their family.

There are examples of case law where families have challenged the clinical assessment that providing further treatment to their loved one is deemed to be futile.¹⁰¹ Courts are not bound by the views of the medical profession and will reach an independent assessment of what the patient's best interests require.¹⁰² However, the courts have also said, in the context of futility, that the 'decision as to appropriate treatment ... is principally a matter for the expertise of professional medical practitioners'.¹⁰³ If a court concludes that medical treatment is futile and therefore not in a patient's best interests, that treatment need not be continued.

Despite the complexity in defining 'futile treatment', the literature on the subject makes clear between decision-making around potentially futile medical treatment and euthanasia. Withholding or withdrawing life-sustaining futile medical treatment is not done with the intention of killing the patient. It is distinguished from euthanasia and physician-assisted suicide because its primary goal is not to bring about the death of the patient.

There is a heavy presumption in favour of administering life-sustaining medical treatment to a patient where that treatment provides a net benefit to the patient. Modern technology and medical advancements have enabled health care to treat disease and sustain life by artificial means when organ or system failure would otherwise naturally result in death.¹⁰⁴ These technological and medical advances have brought with them new ethical questions. For example, if a medical intervention is found to be technically possible in one case, should it be applied or attempted in all similar cases? Is it the case that everything that can possibly be done should be done? These are not questions that can be easily answered. Everyone, doctors most of all, know there comes a point when a patient is overcome by their disease and medicine is powerless to intervene. The difficulty lies in defining this point with the precision, accuracy and ethical cogency required to guide clinical practice and gain community acceptance.

Withdrawing life-prolonging medical treatment helps the already dying patient to achieve a peaceful and dignified death, so that suffering and death is not unnecessarily prolonged as a result of medical intervention. Once the treatment focus shifts to palliative care, the primary goal is to relieve uncomfortable or unwanted symptoms rather than to cure the disease. The doctor in charge of providing pain relief must do so with the primary purpose of obtaining symptomatic control of the patient's pain, discomfort or distress, and not to cause or hasten the patient's death; even though this may be one of the effects of administering such pain relief. This is known as the 'principle of double-effect', and is readily distinguished from euthanasia or assisted suicide.

Given the problems associated with the term 'futility' or 'futile' and the ethical and medical uncertainty surrounding futility judgements, questions regarding futile medical treatment should not be seen as offering a value-free point of clinical closure but as providing an opportunity to re-examine the goals of treatment and care and to deepen communication between health professionals, patients and their carers.¹⁰⁵

Ultimately, judgements on whether or not a medical treatment is potentially futile are going to be at least partially subjective. Recent procedural approaches to the determination of futility accept that it is not possible to be objective on this issue, and therefore processes (some of them statutory) based on fairness and individual patient's best interests at the end of life should prevail. This is exemplified with the increased focus (legally, ethically and clinically) on advance care planning for patients at the end of life.

Legislative Framework - Summary Points

General

1. The legal processes activate when a patient loses capacity for decision-making and decisions about life-sustaining measures are required.
2. The law operates slightly differently if the clinical decision is to *provide* life-sustaining measures, rather than to *withhold* or *withdraw* them.
3. Life-sustaining measures may be withheld or withdrawn without consent *only in exceptional circumstances* such as acute emergency situations, and only where the doctor responsible for the patient's care is not *directly aware* that he or she objected to the withholding or withdrawal of medical treatment, in other words the patient 'wanted everything done' when capacity is lost.
4. Health professionals have no obligation to provide treatment that is considered futile; that is the medical treatment is not clinically indicated, will provide no benefit to the person, or is not in a person's interests.

Capacity

5. In Queensland, an adult is presumed to have capacity. Lack of capacity cannot be established merely by reference to age, cultural background, behaviour, appearance or physical condition, as this may lead to unjustified assumptions about a patient's competence or capacity to provide informed consent.
6. Capacity is not an 'all-or-none' concept, but depends on the nature of the task for which assessment is required, such as decisions about health matters. Capacity assessments involve more than just judging cognition and weighing objective scores of memory, concentration, attention and orientation. Capacity is also domain specific, and a patient may have decisional capacity in some domains, for example knowing what to eat and wear, and not in others, such as managing medication or driving a vehicle.
7. In cases where patients have borderline or fluctuating capacity, it can be difficult to assess whether the individual can make valid decisions on very serious issues. Second opinions must be obtained where doubt exists about a patient's level of capacity to make decisions about their own health matters.

Substitute Decision-Makers

8. If there is no AHD in place and there is not an acute emergency, consent is required from a patient's substitute decision-maker/s before any life-sustaining measure can be withheld or withdrawn. The doctor responsible for the patient's care must make all reasonable efforts to contact the substitute decision-maker/s if the patient loses capacity, and the substitute decision-maker/s must exercise power in accordance with their appointment and the Health Care Principle (see Glossary).

Consent

9. Life-sustaining medical treatment can only be withheld or withdrawn where consent is obtained or where legal authority is given to make the decision without consent.
10. Where the patient lacks capacity to make health care decisions, except in some acute emergency situations, consent is required before any life-sustaining treatment can be withheld or withdrawn.
11. Consent must be obtained through the following (in order):
 - the patient's valid AHD
 - a guardian appointed by the Tribunal
 - a health attorney under an AHD or EPOA
 - a statutory health attorney/s
 - the Public Guardian.

Legislative framework - Summary Points contd.

Emergency Situations

12. In emergency situations, medical treatment to save the person's life and health (with the exception of blood transfusions) may be withheld or withdrawn from an adult without consent if the doctor in charge of the adult patient's care reasonably considers:
 - that the patient has impaired capacity, and
 - the commencement or continuation of the life-sustaining measure would be inconsistent with good medical practice, and
 - consistent with good medical practice, the decision to withhold or withdraw the life-sustaining measure must be taken immediately.
13. However, life sustaining medical treatment may not be withheld or withdrawn without consent if the doctor in charge of the patient's care knows the adult objects to the withholding or withdrawal of treatment, in other words expresses that they want "everything to be done."
14. Consent must always be obtained to withhold or withdraw artificial hydration and/or nutrition, even in an acute emergency situation.
15. The clinical decision to commence CPR is considered an acute emergency in all cases. While generally consent is not required to withhold CPR in acute emergency situations, there may be limited circumstances where consent may be required not to commence CPR. This is a complex part of the law which says that if the treating doctor 'knows' the patient objects to the withholding or withdrawal of CPR, consent is required from a substitute decision-maker if capacity is lost.
16. There are many complicating factors with such decisions, and it is recognised that it may be inappropriate to continue to maintain life while attempts are made to obtain consent to withhold or withdraw treatment.

Advance Health Directives

17. An Advance Health Directive is a formal document in which an adult provides direction about current and future health matters and may be used to nominate one or more people to make decisions on their behalf should they lose capacity to do so. An AHD can be acted on **only** when the person loses capacity. If the person regains capacity, the AHD cannot be acted on.
18. The health care team is entitled to check the validity of an AHD and to sight the original or a certified copy of it.
19. Valid AHDs take legal precedence over treatment requests made by family members of the patient.
20. If a doctor chooses not to follow a patient's AHD (see [Section 1.5.5](#) for reasons for this), they must seek a second opinion from a senior doctor or consultant, and **must** clearly and meticulously document the circumstances and decision-making process.

Objections

21. Even outside of AHDs, there is scope for a patient to object to the provision or withholding of life-sustaining measures, and scope to override that objection in particular circumstances (see [Section 1.6](#)).

Handout

22. [Appendix 6](#) contains a 2-page printable handout about legislative considerations and withholding and withdrawing life-sustaining measures. It was used extensively in the training and education when implementing the ARP.

2.0 Decision-making framework

2.1 From the healthcare perspective

The decision not to provide life-sustaining medical treatment is a complex, emotionally-charged and confronting issue for the patient, medical team and family alike. When a patient has the capacity to make decisions for themselves, the treating medical team must respect the patient's wishes. Doctors and medical staff have a duty to respect the patient's right to refuse unwanted treatment and health care. This right is based on the well-founded principle of autonomy. Not respecting a patient's right to refuse unwanted medical treatment may be considered assault. Treatment given to a patient without obtaining their consent can potentially give rise to an action in battery (civil assault). It may also give rise to an action for criminal battery (assault) or if a procedure is administered, it may give rise to an action of 'doing bodily harm' or 'doing grievous bodily harm'.

When the patient lacks capacity, then the decision to withdraw medical treatment is ultimately a medical decision made in the best interests of the patient. Doctors need to exercise caution not to transpose their beliefs, values and priorities on to the patient, but rather make a concerted effort to ascertain those of the patient. Determining what will be in the patient's best interests requires careful consideration of medical and ethical factors.

When determining what course of action is in the patient's best interests, the health care team should conduct a formal review of the patient's condition and likely prognosis together with an understanding of their support network, if appropriate. Discussion with family members is particularly important when the patient does not have the capacity to make or communicate decisions, as the family is likely to be aware of previously expressed views the patient may have held regarding end-of-life wishes, or to have an intimate knowledge and understanding of the patient's wants, values and beliefs. Areas of patient care frequently discussed in a formal medical review include prognosis of the patient's condition, the efficacy of current treatment, whether it is justified, and any alternative treatments that may offer a benefit to the patient, including palliative care options.

Consideration should also be given to:

- the likelihood of meaningful recovery
- the patient's length of treatment
- the degree of reported or perceived patient suffering
- whether treatment is achieving its goals
- whether the patient's condition has improved, deteriorated or remained the same
- the nature of treatment required
- the patient's wishes if known
- the adequacy of the patient's care and support network
- the views of family members.

Families and carers usually want to feel involved in elements of patient care. They will also want to feel 'part of the team' in making end-of-life decisions about the patient. Keeping in mind patient confidentiality obligations, it is important that information such as the patient's progress, treatment options and staff opinions be discussed with the family as early as possible in an open, honest and compassionate way. Under the responsibility of the doctor in charge, the multi-disciplinary health care team should aim to reach a consensus with those close to the patient on what treatment and care would be in the best interests of the patient, particularly where decisions are required about whether or not to provide life-sustaining measures.

Holding regular family meetings is an effective way to explore these emotive and sensitive issues, and to gain greater understanding of the patient's wishes regarding life-sustaining medical

treatment, and what values and beliefs are important to them. These meetings will also help to better inform the family and help them come to terms with the patient's likely prognosis. The meetings should commence as early as practicable to avoid crisis-driven decisions when the patient's condition declines.

2.1.1 Support for decision-making

As noted previously, the guardianship laws in Queensland reflect the common law position that a person is presumed to have capacity to make their own decisions.¹⁰⁶ The guardianship laws are also underpinned by general principles that must be applied or complied with by any person who performs a function or exercises power under them (refer to [Appendix 4](#)). The principles govern how a substitute decision-maker should be thinking about how they can best support the person for whom they are responsible. For example, Principle 7 preserves the right of people to be involved in decisions affecting their life to the greatest extent possible and specifies that 'any necessary support' must be provided to enable a person to be involved in their own decision-making.

Read as a whole, the General Principles promote autonomy and respect for an adult and support their full participation and social inclusion. As such, the General Principles impose obligations on the substitute decision-maker to act in a manner that is least restrictive of the adult's autonomy, to provide the adult with decision-making support and seek and take into account their views and wishes. Substitute decision-makers must also act in a way that is consistent with the proper care and protection of the person for whom they are responsible under the legislation, in other words, substitute decision-makers must act in the best interests of the adult. Where tension or conflict arises, between acting in the best interests of an adult and giving expression to an adult's views and wishes, precedence is given to the adult's best interests. Therefore, an appointed decision-maker can only implement a decision that an adult has been supported to make when the substitute decision-maker believes that decision is in the adult's best interests.¹⁰⁷

2.2 Who is involved in decision-making?

Over time, patients are likely to encounter several different health professionals, perhaps in different medical specialties, when planning end-of-life care. The health care team may include medical specialists, surgeons, general practitioners, nurses and allied health workers (such as social workers), patient advocates, chaplains or pastoral care workers in end-of-life care/planning discussions, either directly or in supportive roles.

Individual members of the treating team (such as nursing and allied health staff) may have closer or prolonged involvement with the patient and from this closer association, may be more aware of the patient's values and wishes. Other team members may be more involved in how the patient is psychologically or spiritually coping with illness. Each member may bring valuable perspectives and information to the process of planning care and their collaborative involvement should be actively pursued.

All treatment decisions for patients as they approach the end of life are best made in the context of good quality palliative care. In some cases, however, patients may not wish to discuss future medical treatment options, including resuscitation planning, and they should not be forced to do so. Likewise, if a patient at the end of life does not have capacity, their substitute decision-makers may avoid making any decisions in the hope that the gravity of the situation is not as described and may even improve. In these situations, the senior doctor and or consultant responsible for care of the patient should sensitively establish whether the patient and/or their substitute decision-maker would prefer to have others involved in the decision-making process, such as their GP or other doctor they may know, and possibly including other members of the family.

In circumstances where one team member disagrees with the others, the team as a whole should consider the basis for disagreement and seek the opinions of experts from the same discipline as the disagreeing member. In the event that support for this position cannot be found, it may be appropriate for the dissenting member to withdraw from the treating team.

As in other areas of clinical practice, a health professional may exercise conscientious objection and not participate in a particular practice which is contrary to his or her moral beliefs. Counselling or other psychological support may be appropriate where disagreement occurs about the appropriateness of treatment limitation, particularly for nurses who, in some settings and by their more intimate involvement in the care of dying patients, may be more acutely aware of distress experienced by the patient and those closest to them.

2.2.1 Substitute decision-makers

If an AHD is not in place, and it is not an acute emergency, the law is that in every instance, consent is required from a patient's substitute decision-maker/s before any life-sustaining measure can be withheld or withdrawn. The doctor responsible for the patient's care must make all reasonable efforts to contact the patient's substitute decision-maker/s should the patient not have or lose capacity.

As noted, substitute decision-makers are required to exercise power in accordance with the terms of their appointment and the Health Care Principle (refer to [Appendix 4](#)).¹⁰⁸

If an AHD is not in place, the first of the following substitute decision-makers available to give consent will have authority for the patient's health care decisions:

1. A guardian appointed by the Tribunal or Order of the Tribunal; but if none appointed or made, then:
2. A health attorney appointed under the most recent enduring document (AHD or EPOA); but if none appointed, then:
3. A statutory health attorney, if none is available; then:
4. The Public Guardian.

A guardian is a person appointed by the Tribunal to exercise power on behalf of the adult. A person who demonstrates they have been duly appointed as guardian can give consent to withhold or withdraw medical treatment. The health care team is entitled to ask the guardian to provide proof¹⁰⁹ of their appointment.

Health attorneys can also be appointed under an Enduring Power of Attorney (refer to section [1.5.1 – Enduring documents](#)). However, the health attorney nominated in Enduring Power of Attorney can only exercise decision-making on behalf of the person (usually called 'the principal') should they lose capacity for decision making about health care matters. The health attorney must have accepted their appointment by signing the enduring document. The health care team is entitled to ask the health attorney to provide proof of their appointment.

Statutory health attorney

If a substitute decision-maker is not appointed by the Tribunal or under one of the enduring documents, the next available 'category' is the 'statutory health attorney'. Informally appointed under the *Powers of Attorney Act 1998*,¹¹⁰ this person (or sometimes persons) is generally someone with a close and enduring relationship to the patient, on whose behalf it is appropriate for them to make decisions. A person claiming to be the patient's statutory health attorney can give consent to providing medical treatment or withholding or withdrawing life-sustaining measures.

An adult's statutory health attorney is the first of the following people who is readily available and culturally appropriate:

1. A spouse of the adult if the relationship between the adult and the spouse is close and continuing.
2. A person who is 18 years or more, who has the care of the adult and is not their paid carer. (A person receiving a carer's pension or similar government benefit is not considered a paid carer under the legislation).
3. A person who is 18 years or more and who is a close friend or relation of the adult and is not a paid carer.

If no one is readily available and culturally appropriate to act as attorney the Public Guardian becomes the patient's statutory health attorney. Refer to the fact sheet published by the Office of the Public Guardian in relation to other powers of statutory attorneys.¹¹¹

Consent by statutory health attorneys comes with the same responsibilities as for any other substitute decision-maker empowered to make decisions on behalf of a person who no longer has capacity to make decisions for themselves. Previous mention has been made of this in relation to the requirement for substitute decision-makers to adhere to the General Principles and the Health Care Principle when exercising their powers. The Office of the Public Guardian also provides guidance for those making decisions on behalf of others and sets out the circumstances where statutory health attorneys (for example) would be required to provide consent to medical treatment.

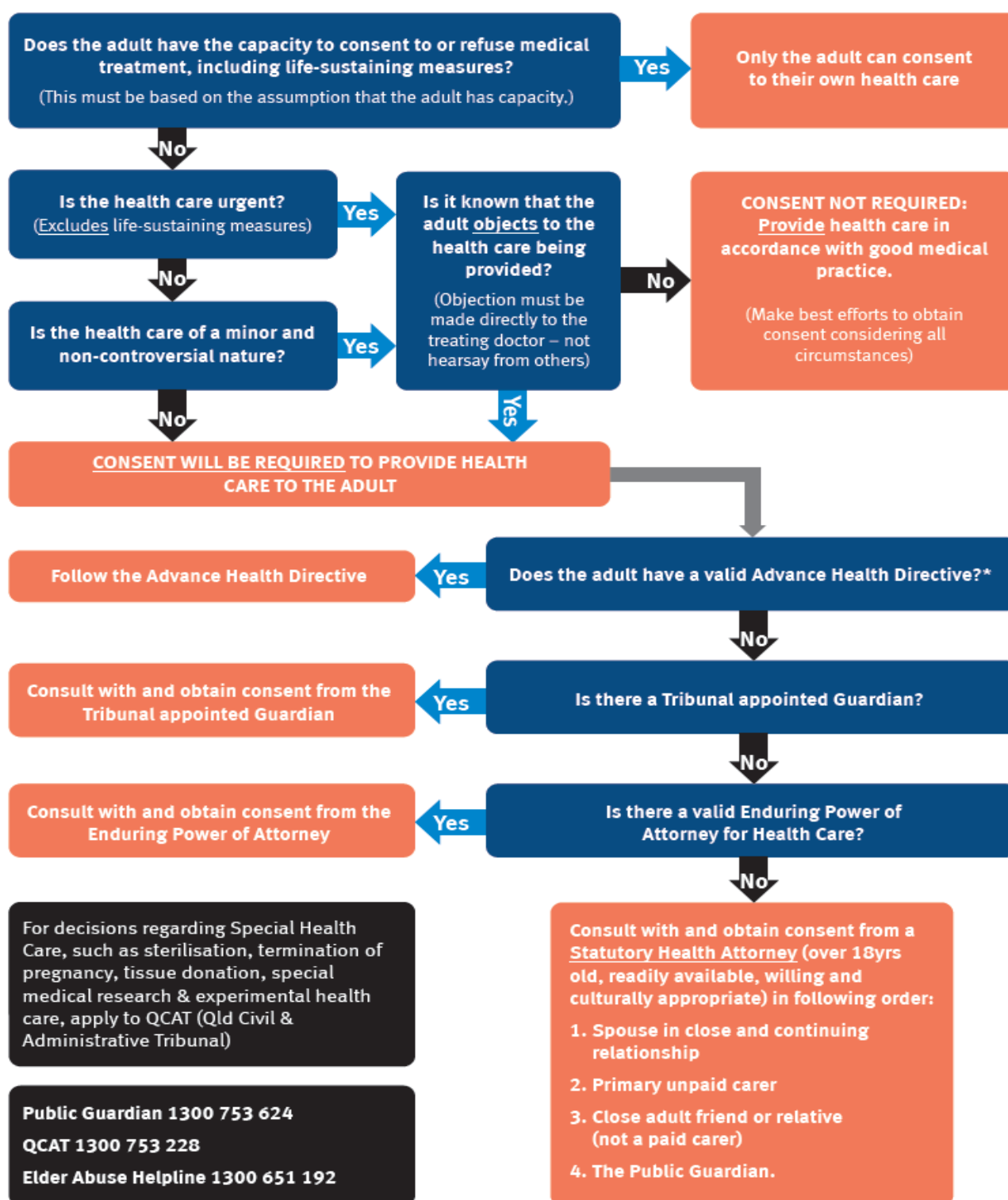
Consent to the withholding or withdrawal of life-sustaining measures cannot operate unless the treating doctor reasonably considers the commencement or continuation of the measure/s for the adult would be inconsistent with good medical practice.¹¹² In other words, consent from a substitute decision-maker/s to withdraw or withhold treatment can only apply where the doctor considers that *providing* that treatment would be medically futile. Or put another way, where the doctor believes providing life-sustaining measures would be consistent with good medical practice, the substitute decision-maker's consent will not be effective to withhold those measures. For example, the Office of the Public Guardian's website states: "If you refuse to consent to the treatment, a health care provider may ask the Public Guardian to intervene if they believe the adult needs the medical treatment and that you are acting against the health care principle." Further, "the Public Guardian is empowered to make the health care decisions if you are acting contrary to the Health Care Principle."¹¹³

2.2.2 Decision-making flowcharts to obtain consent

The following flowcharts were devised to guide the consent process for withholding and withdrawing life-sustaining measures for patients with and without capacity for decision-making. While the flowcharts may guide decision-making, they are indicative only, as decision-making in the end-of-life area is characterised by many variables. The first flowchart provides the consenting pathway in non-acute clinical situations to provide health care (which can include life-sustaining measures); the second flowchart on the page following outlines the decision-making process for consent to withhold or withdraw life-sustaining measures in acute emergencies. Both flowcharts depict the consenting process for decision-making about providing and withholding and withdrawing life-sustaining measures. The second flowchart (decision-making about withholding and/or withdrawing life-sustaining measures from adults) is reproduced from the Acute Resuscitation Plan (ARP) form and has been adapted for these guidelines.

Both flowcharts can also be downloaded as standalone resources from the [Care at the end of life website](https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/patient-safety/end-of-life/guidelines): <https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/patient-safety/end-of-life/guidelines>

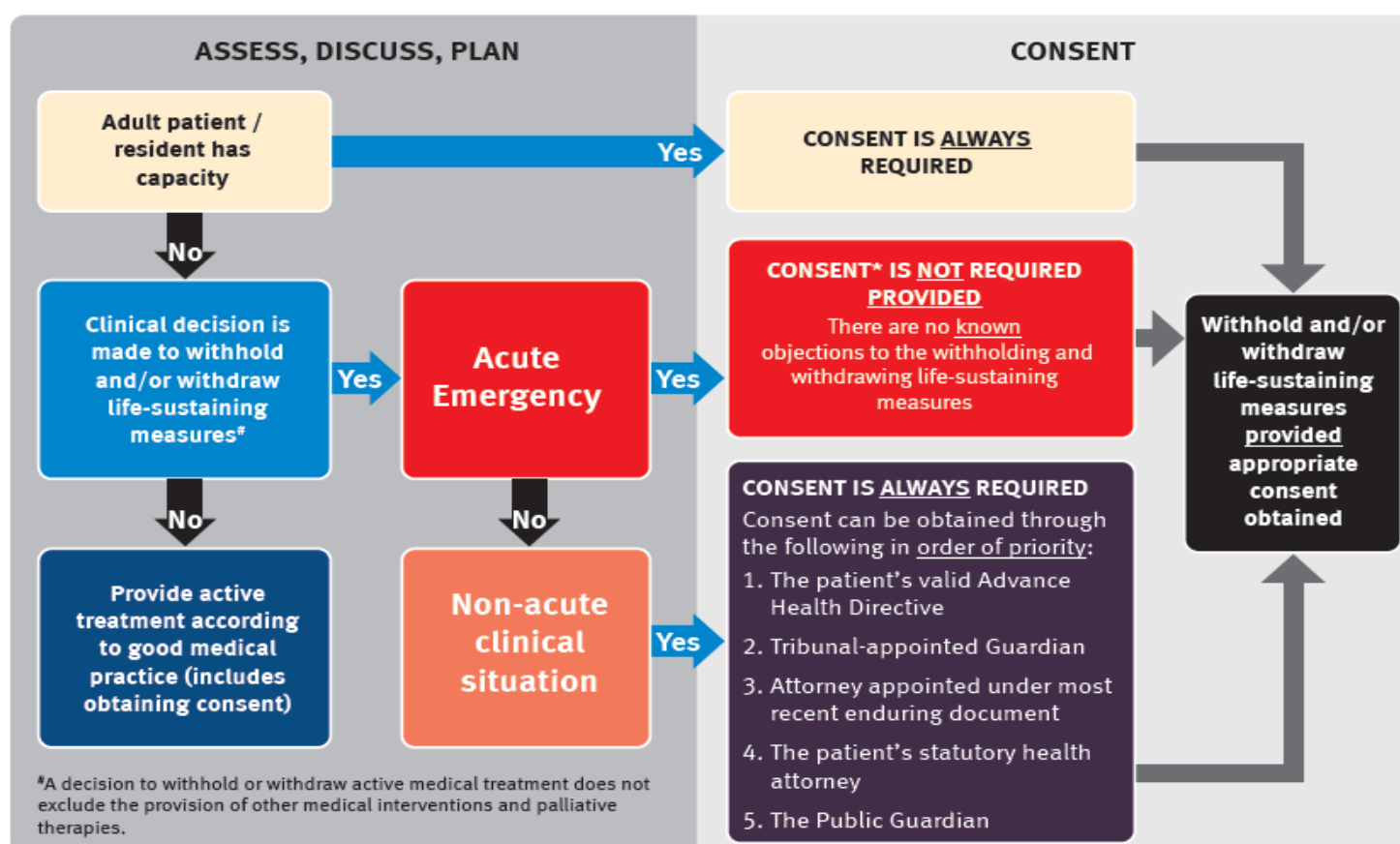
Consent to provide health care to adults



* To be valid, the AHD must be an original or certified copy and apply to the current circumstances. If doubts or uncertainties, consult with the patient's available substitute decision-maker. In these situations, the AHD can still be used to guide the decision-making, but consent will need to be obtained from the appropriate decision-maker. This is particularly important where the adult objects to forms of medical treatment.

Figure 1 - Flowchart – Consent to provide health care for adults with or without capacity for decision-making (includes life-sustaining measures).

Consent to withhold and/or withdraw life-sustaining measures for adults (acute emergency)



*** CONSENT IS ALWAYS REQUIRED IF THE DECISION IS TO WITHHOLD AND/OR WITHDRAW ARTIFICIAL HYDRATION AND/OR NUTRITION IF CONSENT CANNOT BE OBTAINED, OR IF THERE IS A DISPUTE, CONTACT THE PUBLIC GUARDIAN ON 1300 753 624**

Quick facts about consent and life-sustaining measures in acute emergency situations¹

- Emergency situations are characterised by the need for an immediate decision to maintain the life and health of a patient. However, 'artificial' emergencies should not be created to avoid obtaining the appropriate consent.
- The law expects health providers to adhere to 'good medical practice' standards. In meeting these standards, doctors are under no obligation to offer, provide or continue treatments that on balance would have the potential to cause harm and offer no benefit to the patient (i.e. futile).
- Consent ≠ 'contract offer + acceptance' (i.e. offer X treatment in order to obtain consent not to provide it). Consent = conversation about the patient's condition, prognosis, goals and overall treatment plan. Ambivalence is not consent. Ensure overall treatment plan is understood.
- In emergency situations, consent is not generally required unless it is known the patient has objected to the withholding and withdrawing of life-sustaining measures (i.e. "wants everything done"). 'Known' = direct knowledge by the doctor in charge, not hearsay from others.
- If the doctor knows the patient with impaired capacity objected to the withholding and/or withdrawing of life-sustaining measures, best efforts to obtain consent from the patient's substitute decision-maker will need to continue.
- All decision-making must be made in accordance with the standards of good medical practice and in the patient's best interests. Good medical practice will also determine the best approach to obtaining consent.
- Medical treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to obtain consent to withdraw treatment which has been commenced.
- Remember: patients with capacity are entitled to refuse medical treatment even if this results in their death or would cause it to happen sooner.
- There is a legal requirement for all decisions about life-sustaining measures to be accurately and thoroughly documented, including recording outcomes of all consenting discussions.
- The statewide Acute Resuscitation Plan (ARP) form was endorsed and implemented in 2010 and specifically designed to document the decision-making pathway for life-sustaining measures in acute emergencies.
- Provided the ARP is appropriately completed, it also provides clinical authority to act upon directions on the form. Note that medical practitioners can be indemnified if this process is followed in good faith. Even if the directions on an ARP are clear, all attending clinicians must also exercise their clinical judgement.

¹Please note:

This resource is designed primarily for health professionals treating and caring for those at or approaching the end of life. More detailed information can be found in the *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients* or at <https://www.health.qld.gov.au/careatendoflife>

Figure 2 – Flowchart - Process for consent to withhold and/or withdraw life-sustaining measures from adults (acute emergency situations).

2.3 A collaborative approach

Families and health care professionals have an obligation to work together to make compassionate decisions for patients who lack decision-making capacity, taking account of formal decisions or previously expressed patient wishes where they are known. Since the introduction of the *Guardianship and Administration Act* in 2000, end-of-life decision-making formalises a more collaborative approach, involving the patient's family and those closest to them and members of the health care team.

It is important to commit to a collaborative decision-making process involving the patient, their family and/or friends, and the members of the health team. The importance of a cohesive team in providing quality health care is widely recognised and is particularly important when making decisions about whether to withhold or withdraw life-sustaining medical treatment. Seeking agreement within the team about the most appropriate course of action can help to reduce the possibility of subjectivity or bias in cases of uncertainty.

It is also important to make it clear to patients and family members that diagnosis and prognosis are based on probability and past evidence rather than absolute certainty. Although death is a certainty for everyone, many aspects of medicine still remain an imprecise science. Regardless of the prognosis or disease trajectory, a collaborative approach can assist in achieving better outcomes for the most vulnerable patients.

In most situations where a patient is dying, the patient, family and health care team readily come to an agreement on appropriate medical management. However, disagreements can arise regarding treatment limitation decisions, or other aspects of end-of-life care. Most of these disagreements can be prevented by early, sensitive and proactive communication that clarifies goals of treatment, possible outcomes and the patient's values and wishes.

In the event that a disagreement cannot be resolved within what would be considered a reasonable amount of time, the doctor and/or other members of the treating healthcare team must seek a second opinion from a more experienced senior doctor or consultant, or refer the matter to hospital management. In some instances, it may also be appropriate to initiate the ethics committee pathway, as per local arrangements. It should also be remembered that under law, a collaborative approach must also respect the patient's privacy and confidentiality.

2.4 Supported, substitute and shared decision-making

For a number of decades, academics, social commentators and international jurisdictions have called for reform around principles for decision-making on behalf of others.¹¹⁴ It is recognised that the changing view from people with disability being seen as limited 'rightsbearers' to people with the potential for full legal capacity has been a paradigm shift brought about by decades of activism by the disability community.¹¹⁵ More recently, debate in this area has gathered momentum with the concept of guardianship being seen as more of a barrier than an enabler.¹¹⁶ While guardianship has a long history of paternalistic decision-making, the calls for a greater focus on maximising the autonomy of those subject to guardianship are central to many discussions. In contemporary times, the legal response has focussed on substitute decision-making, which most often takes the form of regulated guardianship and administration. In addition, shared decision-making models are gaining momentum, particularly in relation to care at the end of life. A number of other alternative models to substitute decision-making have also emerged internationally.

There is an important distinction between 'substituted' and 'supported' decision-making which was not described in the previous version of these guidelines. In general, the concept of supported decision-making differs from substitute decision-making in that a substitute decision-maker makes a decision on behalf of a person; whereas a supported decision involves the participation of, and ultimately decision by, the person concerned.¹¹⁷ Decision-making supports and arrangements for persons who lack capacity for decision-making take many forms along a spectrum, including:

- informal arrangements—usually involving family members, friends or other supporters
- formal pre-emptive arrangements—anticipating future loss of legal capacity through appointment of a proxy, for example in enduring powers of attorney (financial/property), and AHDs (health/medical)
- formal arrangements—where a court or tribunal appoints a guardian, or a state-appointed trustee or guardian to make decisions on an individual's behalf (guardians and administrators).

In the literature discussing support for people who may require decision-making assistance there is an evident tension in the way that the labels of 'supported decision-making' and 'substituted decision-making' are used. For example, commentators have recognised that supported decision-making remains an ill-defined concept, and that it has "been interpreted as spanning everything from targeted legal powers and authorities through to facilitation of the normal interactions of daily family or social intercourse".¹¹⁸

Nevertheless, the concept of supported decision-making was given impetus by the coming into force of the *Convention on the Rights of Persons with Disabilities* (the Convention) in 2008.¹¹⁹ The Convention has been a significant influence in the movement away from what is seen as paternalistic substitute decision-making towards supporting people with disability to exercise their rights to the best extent of their abilities, including their legal capacity. For example, supported decision-making processes prioritise personal autonomy and recognise that individuals should be empowered with information to make decisions—even bad ones (acknowledging the dignity of risk).

As part of its commitment to supporting patient-centred care and to compliment the work on reducing unnecessary and burdensome health care, the Australian Commission on Safety and Quality in Health care developing a program of work around shared decision-making which it describes as involving:¹²⁰

(...) the integration of a patient's values, goals and concerns with the best available evidence about benefits, risks and uncertainties of treatment, in order to achieve appropriate health care decisions.

It involves clinicians and patients making decisions about the patient's management together.

In partnership with their clinician, patients are encouraged to consider available screening, treatment, or management options and the likely benefits and harms of each, to communicate their preferences, and help select the course of action that best fits these.

The concept of shared decision-making complements a patient-centred approach to health care in which clinicians and patients jointly participate in health care decisions after discussing the options, benefits and harms and consider the patient's values, preferences and circumstances.¹²¹ Informed consent also incorporates the process of shared decision-making¹²² and forms an important part of the Department of Health's approach to quality care at the end of life. (For more information about shared decision-making in advance care planning, refer to the [Advance Care Planning Clinical Guidelines](#).)

The Australian Commission on Safety and Quality in Health Care has released online modules aimed at improving communication of risk.¹²³ The module, [Helping Patients Make Informed Decisions: Communicating benefits and risks](#) promotes shared decision making and risk communication in practice. The module is designed to help clinicians communicate risks and benefits, including complex statistical information, so that their patient can participate more fully in decision making about their health care. While the focus of the module is on general practice in the community, there are important principles about shared decision-making that also apply in the end-of-life population. The Australian Commission on Safety and Quality in Health Care provides helpful information about [shared decision-making](#) on its website.

2.5 Discussion with families

While modern health care has the capacity to prolong life, it cannot do so indefinitely. Therefore, a realistic but compassionate discussion about prognosis, which includes the inevitability of death, is almost always in the best interests of the patient and those closest to them. This should be communicated in an honest and compassionate manner.

It is recommended that the doctor responsible for the overall treatment and care of the patient initiate advance care planning discussions soon after a life-threatening illness or condition is diagnosed. While this may not be possible at the time of diagnosis for a variety of reasons, the discussion about the patient's available and realistic options for end of life care should occur as soon as appropriate. Elements of advance care planning may have already been raised in the context of available treatments, therefore discussing resuscitation planning may be acceptable to the patient and the family as a necessary extension of this discussion.

One of the most important goals of the decision-making process is effective communication, to ensure that patients have access to the necessary information and support to make informed decisions based on a shared decision-making approach.

Multiple studies have demonstrated that treatment at or near the end of life is rarely optimal. Unwanted life-sustaining treatments, sometimes described as 'death-prolonging treatments', are frequently provided and open communication about death and dying is often lacking. Early communication about goals, prognosis and options can improve patient care at or near the end of life by respecting and protecting patients' choices and facilitating pathways toward palliative care.

Sometimes a patient may not wish some family members to be involved in discussions. It is always best to check with the patient and obtain their consent before discussing the patient's condition with their family and/or friends. Some family members may even feel as if they are 'actively killing' their loved one by withdrawing or withholding life-sustaining measures rather than allowing the natural disease process to run its course, and will commonly experience feelings of guilt, anxiety and bereavement. It is important that they receive appropriate care and counselling, before and after the decision has been made to withdraw or withhold life-sustaining measures. In particular, those closest to the patient should be advised that social workers or counsellors are available to help the family through this difficult time.

Patients may also feel under pressure not to 'abandon' the family or 'give up' on life, even though their condition is in its terminal phase. Similarly, some patients may feel like a burden to family, friends and the health care system and wish to withdraw treatment prematurely. Again, communicating openly and honestly with the patient, family and staff is the most effective way to achieve understanding, and to alleviate the 'guilt' associated with dying and/or withdrawing treatment.

2.5.1 Patients with capacity

Where a patient has capacity, their directions for health care must be followed, including withholding and/or withdrawing medical treatment according to their instructions. This is the common law, and people have a right to refuse medical treatment, even if by refusing treatment it will result in their death or make it happen sooner. Where the patient has capacity to make health care decisions and is likely to require life-sustaining treatment, consent procedures should be put in place to ensure their views and decisions are respected when they lose capacity. This may include any combination of the following:

- the doctor or other health professional as appropriate initiating advance care planning discussions with the patient
- the doctor formulating an ARP after discussions with the patient
- the patient appointing a health attorney who represents their interests if they lose capacity

- any member of the health care team encouraging the patient to formalise their end-of-life wishes by completing an AHD.

Discussion about diagnosis, prognosis and preferences for care should be encouraged, but not forced. A patient's wish not to discuss specific treatments or interventions, or the possibility of his or her own death, should always be respected and emotional support provided. In situations where the patient does not want to discuss or decide on resuscitation, the doctor should sensitively establish whether the patient would prefer to have others outside the healthcare team involved in the decision-making process. This may include religious or spiritual advisors, as discussed with the patient, and where the patient does not have capacity, under the advice of the patient's substitute decision-maker.

Where the patient is willing to talk about treatment options, including life-sustaining measures, the discussion should include information about the risks, benefits, side-effects, likelihood of success and anticipated level of improvement if treatment is given, the likely outcome if treatment is withheld, and any other alternatives that might be considered.

Patients' preferences for life-sustaining treatment are not static over time and should be regularly reviewed by the doctor responsible for the patient's care, particularly as the patient's condition deteriorates. Requests for life-sustaining measures are likely to be more certain in the earlier phases of the patient's disease trajectory than towards the end of a person's life.

In cases where a patient requests non-standard forms of treatment that, in the considered opinion of the doctor in charge, is not clinically indicated, would not benefit them and would be against their best interests, the doctor must discuss the implication of these requests with the patient in an open, frank and honest manner. If, after these discussions, the patient still insists on treatment that would, in the doctor's opinion, be inconsistent with good medical practice and offer no benefit to the patient, the doctor must refer the patient to, or obtain advice from, another senior doctor/consultant experienced in that area of medicine as soon as practicable.

If there is any suggestion that the patient is being coerced into requesting treatment that in the considered opinion of the doctor and other members of the health care team is not in their best interests and may cause them harm, they should refer the matter to a senior doctor/consultant or take the case to the hospital's administration or ethics committee, or other appropriate local procedure. In these circumstances, consideration should be given to contacting the Office of the Public Guardian for advice as soon as practicable.

2.5.2 Patients without capacity

Legal, ethical and clinical decision-making can become increasingly complex and challenging where a patient who lacks capacity has not clearly expressed their wishes to family or those closest to them. In this case, doctors and other members of the health care team, as appropriate, must discuss end-of-life issues as early as possible with the patient's substitute decision-maker/s, which in most instances is a close family member.

Sometimes a patient who lacks capacity may have expressed a prior wish that some family members not be involved in discussions about their health care. These wishes must be followed when the patient loses capacity, particularly if formally directed in an AHD.

It is always necessary to follow Queensland Health's obligations regarding confidentiality before discussing a patient's condition with their family or friends.¹²⁴ Confidentiality provisions are also contained within the guardianship legislation about the sharing of personal information, with confidentiality named as one of the general principles.

All discussions should be conducted in an appropriate, comfortable and preferably private setting.

If the doctor or other members of the health team are unfamiliar with members of the family, where practical, time should be spent identifying each family member's relationship to the patient. This provides an opportunity to observe family members interacting with the patient and with each other before approaching those with the statutory decision-making ability.

All requests for continuing treatment should be given careful consideration before making decisions about the appropriateness of treatments. Any request for active treatments should lead to a review of the diagnosis and prognosis and the margins of certainty in each aspect. At the appropriate time, the doctor responsible for the patient's care should explain clearly (if possible in non-technical terms) to the patient and their family why they think the desired trial or treatment is inappropriate.

The question 'Do you want everything done for [name]?' should be avoided. No person could, without enormous guilt, answer "no" on behalf of someone they are close to. Instead, reframe the discussion to address the patient's comfort levels in the context of their prognosis and likelihood of recovery. Discussions about tube-feeding in particular can be charged with guilt that failing to provide artificial hydration and/or nutrition represents denying the patient fluids and starving them to death. The advice of a senior doctor/consultant should be obtained in decisions to withhold or withdraw artificial hydration and/or nutrition.

Discussion of appropriate treatment options with the patient's substitute decision-maker/s should include information about the risks, benefits, side-effects, likelihood of success and anticipated level of improvement if treatment is given, the likely outcome if treatment is withheld and any other alternatives that might be considered.

Within this context, doctors and other health professionals are under no obligation to offer treatments that would provide no benefit to the patient, that is, treatment that would be considered potentially futile. As already discussed, substitute decision-makers have responsibilities under the legislation and are required to act in accordance with the General Principles and the Health Care Principle (refer to [Appendix 4](#)). Where substitute decision-makers are considered not to be complying with either of these, the Public Guardian should be contacted.¹²⁵

2.6 Disputes

Disagreements between the patient and his or her family may arise if the family is not properly informed by the healthcare team about the directions given by the patient. Guided by the patient's best interests, every effort should be made to communicate this information to the family. All requests for continuing treatment should be given careful consideration before decisions about the appropriateness of treatments are made. In a recent article, it was highlighted that almost a quarter of intensive care beds are occupied by patients receiving inappropriate care.¹²⁶ Furthermore, up to a quarter of health budgets are spent on inpatient care during the last 18 months of life without any real prospects of extending overall survival or impacting on quality of life.¹²⁷

Disputes can also arise when the patient and/or their family misinterpret or disagree with the health care team on medical treatment proposed, the prognosis of the patient's condition, and whether or not the medical treatment is in the best interests of the patient. Scott et al (2013) point out that most complaints received from bereaved family members about hospital treatment relate to end-of-life care, mainly perceived failures of communication and preparedness for death. Citing a study from 2011, Scott et al (2013) state that doctors spent a median time of only one minute on do-not-resuscitate discussions with patients after admission.¹²⁸

Families of patients without decision-making capacity who demand continued treatment might have unrealistic expectations about what can be achieved, particularly when the treatment is not considered standard for that condition or when its application would be completely ineffective and would not benefit the patient. More often, a family will ask for 'everything to be done' if they are not ready to accept the patient's inevitable death. This situation may be exacerbated when the family is not engaged early in treatment planning before the onset of the dying process, or where guilt may be associated with fractured or distant relationships within the family.

Also, there may be more than one eligible decision-maker for the decision to withhold or withdraw life-sustaining measures. Negotiation is more difficult where there is disagreement between substitute decision-makers, such as multiple guardians or statutory health attorneys.

Potential disagreement can usually be overcome through sensitive and considered communication between interested parties by focusing upon the known wishes of the patient and their best interests. If the patient has formally documented their wishes in an AHD before loss of decision-making capacity then, legally, these wishes prevail over the demands of the family.

The efforts of the health care team, other health professionals, pastoral care workers, social workers or other counsellors should be directed to supporting family members and helping them to resolve their difficulties in accepting the reality of the patient's impending death. In such circumstances, it is preferable to continue with a trial of treatment until conflict with relatives is resolved. However, time-critical situations pose extremely difficult choices and challenges. Senior doctors/consultants should be involved in all these discussions.

2.6.1 Resolving disputes

One of the challenges in resolving conflict around end-of-life decision-making is articulating the concept of certain death occurring in the near future, despite active measures. Prognosis almost always has certain degrees of certainty attached to it. Prognostic information substantially influences treatment decisions and prognostic estimates of doctors are reasonably accurate^{129 130}
¹³¹ However, there usually comes a time when the disease process is so advanced that the patient's condition is worsening despite the best efforts of the treating healthcare team. The challenge is to predict futility at a time which minimises the patient's and their carers' suffering.

In the case of dispute or disagreement, health professionals must be able to demonstrate a reasonable justification for their decisions, particularly those which deviate from established clinical guidance. Detailed clinical notes should be kept of any guidelines consulted or additional opinions sought. Not all dispute resolution options will be available in all clinical contexts. However, the simple approaches should be taken first in the context of providing the best possible care for the patient and compassion for the family. These include the following:

- **Allow time**

Unless decisions about life-sustaining medical treatment need to be made urgently, allowing families time to come to terms with the impending death of their loved one, and to seek further discussion with family or others providing support, may be sufficient to resolve most issues. Keep the patient and the family involved at all stages of the decision-making.

- **Seek a second opinion**

A request for a second medical opinion may be raised with, or directed to, any member of the health care team at any time. Offering a second opinion in the early stages may also be appropriate if the family are displaying anxieties or uncertainties regarding diagnosis or prognosis. It is the responsibility of the doctor in charge of the patient's care to arrange any second clinical opinion/s and arrange counselling for the family, as appropriate.

- **Consider a time-limited treatment trial**

Where it is in the best interests of the patient, consideration may also be given to a time-limited treatment trial. This may be undertaken to provide more time for the family to come to terms with the decisions required, but may also help to clarify prognostic uncertainty or resolve disagreement about prognosis.

- **Seek assistance with communication and resolution**

Sometimes difficulties with communication and a family's inability to reach final acceptance may mean resolution is not possible within the limitations of the health care team who are required to balance the care needs of many other patients. In these difficult cases, consideration should be given to involving a third, independent party who is sufficiently experienced in these matters. This person may be a senior member of the hospital administration, a senior health professional, or another independent person agreed upon by those involved and who has sufficient seniority and experience to be respected by all parties.

- **Refer the matter to senior hospital administration management**

There may be other local management practices for dispute resolution, such as hospital ethics committees. Such a course of action can be considered given the circumstances of the situation and whether there is time to engage these processes.

If the above steps are clearly not working and the situation becomes intractable, the patient and their family should be given the option of transferring the care of the patient to another facility. These decisions must only be made through the appropriate channels of the hospital's administration and/or ethics committee and after all other efforts have been exhausted.¹³²

Most of the more qualitative descriptions of how to effectively communicate around end-of-life decision-making emphasise a consensual model of shared decision-making and avoid 'who has the legal right to decide' wherever possible. The goal is to establish robust trust and mutual understanding between the family and the health care team. As part of the advance care planning discussion and approach to the overall treatment plan, 'seeking consensus' should be aimed for, rather than 'asking permission'.¹³³ A publication that deals specifically with conflict in intensive care units has distilled some specific points that have emerged from the literature around avoiding conflict at the end of life, which includes:¹³⁴

- Inform families of high-risk patients (e.g. post-cardiac arrest, hypoxic encephalopathy, severe traumatic brain injury) within 24 hours of admission to the ICU of the high possibility of death.
- Avoid euphemisms or medical terminology.
- Emphasise 'intensive caring' as part of the end-of-life process.
- Ensure families have access to patients with as little restriction as possible.
- Advise relatives to look after their own health in this process... "This could be a long distance race, not a 100 metre dash."
- Identify with the patient early... "We never got to know Mrs X, can you tell me a bit about her".
- Emphasise the point that "while we may not be able to always offer a cure, we can promise you that they won't suffer".
- Add that... "I (as the intensivist) cannot afford not to be honest with you (the patient/relative). It may sound blunt but we will always try to reflect exactly what we think the patient's chances are."
- Be active listeners and try to detect early hints of discord which may lead to conflict.

If consensus cannot be reached about a decision or if the substitute decision-maker/s refuses to comply with the Health Care Principle (refer to [Appendix 4](#)), the Public Guardian should be consulted to resolve any dispute. However, the Public Guardian can be referred to only when the patient does not have capacity. Clear documentation of the decision-making process which led to the circumstances, including notes of discussions with family members, will be required in these cases. Further information about advance care planning can be found in the [Advance Care Planning Clinical Guidelines 2017](#).

2.7 Transparency and accountability

Ensuring open and frank communication between the health care team and the family/ substitute decision-maker/s of the patient will limit the situations where doctors are asked to provide what would constitute potentially futile treatment. Decisions to withhold and withdraw life-sustaining

measures made solely on clinical grounds must be strongly justified and thoroughly documented. Careful attention to recording (in charts and progress notes) details of the clinical circumstances and events leading up to the decision to withhold medical treatment is required by law.¹³⁵

The decision-making process must be fully documented and all details included in the patient's medical record, including:

- the patient's condition and the rationale for withholding or withdrawing life-sustaining measures
- documentation of the patient's consent if they have capacity
- the rationale for not obtaining consent in an acute emergency
- matters discussed with the patient's family, close friends and carers
- details of the substitute decision-maker/s and the decisions made by the substitute decision-maker/s
- details of the medical staff involved in the decision-making.

Junior doctors, while encouraged to participate in end-of-life discussions, must be supervised by more senior doctors and/or consultants in decisions to withhold or withdraw life-sustaining measures.

2.7.1 Documentation/process audit post-death

All decisions to withhold or withdraw life-sustaining measures should be reviewed by the senior doctor responsible for the patient's care (and/or consultant if applicable) within five working days post-death. It is recommended that consideration be given to reviewing documents and decision-making by the health care team during any local mortality screening process.

2.8 Protections for health professionals

Health providers are afforded a number of protections under the legislation. When they act in good faith and where the standards of good medical practice have been followed, the legislation recognises this. For example, health providers are protected if they act on a health care decision by a substitute decision-maker and it subsequently emerges that the person does not have the power to make such decisions.¹³⁶ In addition, they are protected if they act in reliance on an AHD without knowledge of its invalidity, or they are not aware that an AHD exists. In these circumstances, health providers may wish to seek indemnity from Queensland Health if they are subjected to civil or criminal liability.

Irrespective of the circumstances, meticulous documentation of all decision-making regarding the withholding and withdrawing of life-sustaining measures is required by law. Remember: good documentation, good defence; poor documentation, poor defence; no documentation, little defence.

While the law does offer protections, if doctors override the directions in an Advance Health Directive, this must be within the context good medical practice and the patient's best interests. Doctors should be aware that they may be required to justify their decision in a court if this is challenged. (Refer to [Section 1.5.5 - Deciding not to follow an Advance Health Directive](#)).

2.9 Substitute decision-making pathway¹³⁷

This decision-making pathway is contained within the National Advance Care Directives Framework, developed in 2011 by the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. The pathway is recommended to be used as a basis for decision-making by substitute decision-makers and can also guide health professionals.



Decision-Making Framework - Summary Points

General

1. If the patient has formally documented their wishes in an Advance Health Directive before loss of decision-making capacity then, legally, these wishes prevail over those of the family.
2. Doctors and medical staff have a duty to respect the patient's right to refuse unwanted treatment and health care.
3. There are clinical, ethical and legal differences between decision-making around providing medical treatment as opposed to withholding or withdrawing life-sustaining medical treatment.
4. Patients' preferences for life-sustaining treatment are not static over time and should be regularly reviewed by the doctor responsible for the patient's care, particularly as the patient's condition deteriorates.

Collaborative approach

5. When a patient lacks capacity to make decisions about end of life care for themselves, the decision-making should be collaborative, including family members and the health care team (subject to confidentiality obligations).

Communicating with families

6. Early open, frank and honest communication with patients and families about goals, prognosis and options can improve patient care by identifying, respecting and protecting patients' choices. It may also prevent disputes over treatment and care.
7. Family members who agree to withdrawing treatment may need support through feelings of guilt, anxiety and bereavement.

Disclosure and informed consent

8. In non-urgent situations, the legislation requires that consent is obtained to withhold life-sustaining medical treatments. The assumption is that there is sufficient time to discuss treatment options. This provision is also linked to the requirement for informed consent.
9. While there is some uncertainty over 'informed consent' with regard to withholding and withdrawing life-support measures, it would be cruel and inhumane to offer or disclose treatment options that cannot be provided or would be considered potentially futile. This would not constitute good medical practice.

Dispute Resolution

10. Families of patients without decision-making capacity who demand continued treatment might have unrealistic expectations about what can be achieved, particularly when the treatment is not considered standard for that condition or when its application would be completely ineffective and would not benefit the patient.
11. If open, honest and frank communication has not forestalled or resolved disagreements with families, options include:
 - providing support (through other health professionals, pastoral care workers, social workers, other counsellors) to the family
 - allowing families time to come to terms with the impending death of their loved one
 - offering a second opinion
 - considering a time-limited treatment trial
 - involving an independent third party to help resolve any issues
 - giving patients and their family the option of transferring to another facility
 - consulting the Public Guardian

12. Clear and thorough record keeping will be required in all cases.

3.0 Clinical considerations

Clinical decisions to withhold or withdraw life-sustaining measures seek to avoid unwanted, excessively burdensome or insufficiently beneficial interventions for patients at the end of life. Discussions about withholding life-sustaining measures should always be approached with sensitivity and with close attention to the clinical context and specific goals and desires of the individual for whom the measures are being considered.

3.1 Good medical practice – clinical considerations

The practice of medicine is complex and multifaceted, but the key objective is to serve the best interests of the patient. The concept of good medical practice was introduced in the legal framework in [section 1.8](#) because the need for doctors to adhere to the standards is a legislative requirement. Doctors are expected to base their practice of medicine on some fundamental principles including - integrity, truthfulness, fidelity, compassion, and confidentiality. A code of conduct for doctors from the Australian Medical Board on meeting the standards of good medical practice¹³⁸ also states that the doctor-patient relationship should be based on qualities such as respect, openness, trust and good communication in order to build effective and trusting partnerships with patients and their families.

Professional judgments are made by doctors about how they practice medicine and apply these qualities. Sometimes these judgements may conflict with a patient's wishes for their end-of-life care. Good medical practice also requires adults' wishes to be respected to the greatest practical extent. This may include respecting an adult's right to die rather than receive medical treatment to which they have a profound religious objection (*for example*, refer to Blood transfusions in [Section 3.2.4](#)).

Good medical practice requires the doctor responsible for the care of the patient to adhere to the accepted medical standards, practices and procedures of the medical profession in Australia. All treatment decisions, including those to withhold or withdraw life-sustaining treatment, must be based on reliable clinical evidence and evidence-based practice. All available information will be collected about the patient's condition, diagnosis and prognosis, including the stability of the patient's condition over a period of time and the underlying pathology.

Where doubt exists about the diagnosis or prognosis, advice should be sought from another senior doctor or consultant with experience of that condition before making decisions about withholding or withdrawing active medical treatment. This should also be the case when the health care team has limited experience of the condition, particularly with comparatively rare disorders, or there are disparate views about treatment to be provided. For example, where a patient is in a post-coma unresponsive state, advice will usually be sought from a clinician with expertise in the long-term consequences and management of brain injury.

Where the doctor in charge of a patient's care has reasonable doubts about a treatment's potential benefit (or concerns the treatment could cause potential harm), treatment should be given for a trial period with a subsequent pre-arranged review. If, following the review, it is decided the treatment has failed or ceased to be of benefit to the patient, its withdrawal may be considered. The appropriate consent pathway must be followed if there are any changes to prognostic information following expert opinion.

Treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to withdraw treatment which has been initiated.

Wider consultation, including a second opinion from an experienced doctor should be sought where there are doubts about a proposed decision. The method of obtaining second opinions should be governed by the standards of good medical practice and nature of the circumstances. For example, palliative care professionals should be involved in discussions with dying patients

and their families, and senior doctors or consultants should determine the efficacy of the use of artificial hydration and nutrition for a dying patient and be involved in decisions to withhold or withdraw it.

Doctors will be protected from criminal liability where they provide palliative care in good faith and with reasonable care and skill. The care must be reasonable having regard to the patient's state at the time and the individual circumstances and must be documented by the doctor in charge of the patient's care. The protection does not extend to euthanasia or assisted suicide which are illegal and liable for criminal prosecution. (Refer to – Ethical Considerations – [Section 4.6 Moral questions](#) for further discussion about these topics.)

3.2 Specific life-sustaining measures

3.2.1 Cardiopulmonary resuscitation (CPR)

CPR is defined as a life-sustaining measure in both *the Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998*. Doctors have at their disposal a range of clinical procedures about how to perform CPR in a variety of contexts. The information in this section is not intended to replace that material, rather it offers considerations for decision-making about CPR for patients at the end of life in the context of advance care planning, in particular resuscitation planning.

CPR is performed to restore breathing (sometimes with support) and spontaneous circulation in a patient in cardiac and/or respiratory arrest. CPR is an invasive medical intervention and includes one or a combination of the following:

- chest compressions
- attempted defibrillation with electric shocks
- injection of powerful drugs
- ventilation of the lungs.

The probability of success for CPR depends upon several factors, including where the arrest occurs, the patient's age, how soon after the arrest CPR is attempted, and the equipment and staff available to deliver it. The rate of survival after CPR in hospital to discharge ranges between 15 and 20 percent.¹³⁹ Lower rates of survival (one to four percent) are reported in patients with pre-existing hypotension or renal failure, and negligible survival rates are reported for conditions, including septic shock, acute stroke, metastatic cancer and severe pneumonia.¹⁴⁰ The American Heart Association reported the following survival rates in 2015:¹⁴¹

2015 Out-of-Hospital Cardiac Arrest	2015 In-Hospital Cardiac Arrest
Incidence: 326,000	Incidence: 209,000
Bystander CPR (overall): 45.9%	Survival Rate Adult: 25.5%
Survivor rate (overall): 10.6%	Survival Rate Children: N/A
	(in 2014 the survival rate for children was 36.8%.)

It has been reported that significant variations have been identified in the incidence and outcomes of out of hospital cardiac arrest across geographical regions in Australia and internationally.¹⁴² The reported survival rates for out-of-hospital resuscitation in Australia vary from three percent to 71 percent, with the time to defibrillation shown to be a key factor in survival.¹⁴³ A recently established 'epistry' to collect data on out of hospital resuscitation throughout most of Australia and New Zealand has been established, but at the time of publication, is yet to report data from its findings.¹⁴⁴ Therefore, recent figures, particularly on Australian out of hospital CPR survival rates are difficult to accurately confirm.

It is widely acknowledged that clinicians are often reluctant to raise and/or discuss difficult issues, such as planning for resuscitation, particularly where the outcome is uncertain. However, failure

to discuss unfavourable prognostic information may leave patients and their families with poor appreciation of their prospects. This impairs the ability of patients and their families to make informed choices about treatment options including CPR when they may wish to do so. It can also heighten the potential for misinterpretation of likely treatment goals.

To avoid the family witnessing their loved one dying in a distressing manner, care should be taken not to expose those close to the patient to unsuccessful CPR attempts, particularly if the prognosis is potentially clinically futile and there will be no benefit to the patient. In cases where there is an identifiable risk of cardiac and/or respiratory arrest because of an underlying incurable condition (such as cancer), or the patient's medical history (such as recent myocardial infarction or stroke), or current clinical condition (such as severe sepsis), resuscitation planning should be commenced.

While it is often difficult to predict with any certainty those situations where an arrest may occur, there are many situations where the likelihood of cardiac and/or respiratory arrest is sufficiently high as to warrant discussions about CPR. Since the implementation of the Acute Resuscitation Plan (ARP) in 2010, initiating resuscitation planning in the context of goals of care can include the following:¹⁴⁵

- recurrent admission to hospital with severe chronic illness
- a diagnosis of metastatic cancer
- steady deterioration of a chronic respiratory, cardiac, liver or neurological illness
- other progressive advanced life-limiting illnesses, such as severe end stage dementia or frailty.
- decreasing activity – functional performance status declining and increasing dependence in most activities of daily living
- general physical decline and increasing need for support
- advanced disease - unstable, deteriorating complex symptom burden
- decreasing response to treatments, decreasing reversibility
- choice of no further active treatment
- progressive weight loss (>10%) in past six months
- repeated unplanned/crisis admissions
- critical or life-changing event e.g. serious fall, bereavement, transfer to nursing home

Refer to [Appendix 8](#) – possible triggers for initiating an Acute Resuscitation Plan (ARP) for further information. See also [3.3.2 – Acute Resuscitation Plan \(ARP\)](#).

Even where CPR is successful in re-starting the patient's heart and maintaining breathing for a sustained period, the benefits of prolonging life must be weighed against the potential burdens to the patient. Prolonging life is not always beneficial; if CPR may be successful in re-starting a person's heart and breathing for a sustained period, the potential benefits of prolonging life must be balanced against the potential harms and burdens of CPR.¹⁴⁶ For example, unsuccessful CPR attempts can also result in a range of coma states, unmanageable pain, long-term dependence or other potentially debilitating and adverse effects for the patient. As distressing as this is for all concerned, the patient's substitute decision-maker/s must be consulted on all decisions during this difficult time.

The British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing have recently republished guidance about decisions relating to cardiopulmonary resuscitation.¹⁴⁷ This guidance provides useful advice when a decision not to provide CPR is clinically indicated:

A decision that CPR will not be attempted, because the risks outweigh the benefits, should be made only after careful consideration of all factors relevant to the patient's current situation, and after

discussion with the patient (unless they refuse such discussion) or with those close to patients who lack capacity. These factors include:

- the likelihood of re-starting the person's heart and/or breathing for a sustained period
- the level of recovery that can be expected realistically after successful CPR
- the person's known or ascertainable wishes, including information about previously expressed views, feelings, beliefs and values of those who lack capacity
- the person's human rights, including the right to life, the right to be free from degrading treatment (which may include the right to a dignified death) and the right to respect for a private and family life
- the likelihood of the person experiencing continuing pain or suffering that they would find intolerable or unacceptable
- the level of awareness the person has of their existence and surroundings.¹⁴⁸

Requests for CPR

Even when informed that the clinical evidence suggests that the harms and burdens are likely to outweigh any possible benefit, sometimes patients or their families may request that CPR be attempted. Although the healthcare team may doubt whether the risks associated with CPR are justified by a very small chance of success, the patient whose life is at stake, or indeed their family looking on, may be willing to accept that chance. Realistic information must be provided sensitively to patients and their families about the nature of CPR, the chance of success in their specific circumstances and the likely risks, including the risk of long-term neurological damage. However, if CPR is still requested, despite the clinical advice that more harm could be caused than benefits provided, this should usually be respected. If the patient subsequently suffers cardiac or respiratory arrest, further clinical decisions must be made in accordance with the new set of circumstances, taking account of both the clinical situation at the time and the patient's wishes. Remembering that if the patient requests CPR before losing capacity, this represents an objection to the withholding and withdrawal of life-sustaining measures under the guardianship laws, and consent from the patient's substitute decision-maker/s will be needed *not* to provide CPR.

These difficult situations are often a potential source of confusion. Some patients and their families may be under the misapprehension that CPR has the same success as it does on the television. Doctors are not obliged to provide futile medical treatment because someone requests or demands it; that is, treatment that is contrary to their clinical judgement. However, this does not obviate an obligation for the health care team to consider and discuss people's wishes to receive treatment, even if it has the potential to offer only a very small chance of success or benefit. Where attempted, if CPR has a reasonable chance of successfully re-starting the heart and breathing for a sustained period, and a person has decided that the quality of life that can reasonably be expected is acceptable to them, their wish for CPR should be respected. In the unusual circumstance in which the doctor responsible for a patient's care feels unable to agree to their expressed wishes for attempted CPR, or where there is lack of agreement within the treating team, a second opinion must be obtained. Transfer of the patient's care to another doctor or team can be considered if there is still a lack of agreement and it is possible to do so.

It should also be remembered, that while health providers are under no legal or ethical obligation to offer or provide medical treatment that is 'futile', the determination that CPR is 'futile' or 'inappropriate' is not wholly objective and is influenced by the values and assumptions of the doctor about the potential outcomes.¹⁴⁹ If unilateral decisions about CPR are taken by doctors, the subjective nature of such assessments should be acknowledged, and should be open to review, where this is appropriate and where there is time to do so. If attempting CPR is thought to be futile then this opinion must be justified and the reasons for it recorded in the patient's medical records and cross referenced on the patient's active Acute Resuscitation Plan (ARP).¹⁵⁰

CPR – Summary Points

Discussions about CPR as a life-sustaining measure must also include any potential risks and side-effects. The doctor in charge of the patient's care has responsibility for all clinical decision-making in this regard. However since CPR is a life-sustaining measure under the guardianship legislation, all reasonable efforts should be taken to involve the patient and their substitute decision-maker/s in the decision-making process through a collaborative approach. The following points highlight matters to consider about decisions around providing or not providing CPR.

1. Decisions about CPR must be made on the basis of an individual assessment of each patient's case.
2. Before making treatment plans regarding CPR, all efforts must be made to contact those closest to the patient, and/or the patient's statutory health attorney. If this is unsuccessful, the Office of the Public Guardian should be contacted, as circumstances permit.
3. Advance care planning, including making decisions about CPR, is an important part of good clinical care for those at risk of cardiac/respiratory arrest. Resuscitation planning should be initiated in those patients considered at risk of cardiac/respiratory arrest.
4. It is not necessary to initiate discussion about CPR with a patient if there is no reason to believe that the patient is likely to suffer a cardiac/respiratory arrest.
5. Where no explicit decision has been made in advance, there should be an initial presumption in favour of CPR.
6. If CPR would not re-start the heart and breathing, it should not be attempted.
7. Where the expected benefit of attempted CPR may be outweighed by the burdens, the patient's informed views are of paramount importance. This applies to both patients with capacity and patients without capacity.
8. If the patient lacks capacity, those close to the patient should be involved in discussions to explore the patient's wishes, feelings, beliefs and values.
9. If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable Advance Health Directive refusing CPR, these wishes must be followed.
10. Where there is lack of agreement about the likelihood of success for administering CPR to a patient, a second opinion should be sought. If agreement still cannot be reached, a second opinion should be obtained from a more experienced or senior clinician, and transferring the patient to another health care team considered.
11. All decision-making about administering CPR must be carefully documented in the patient's records by the health care team. The ARP form was designed for this purpose and provides a, established process for this to be recorded and made available when it is needed.

3.2.2 Artificial hydration and/or artificial nutrition

Artificial nutrition and hydration refers specifically to techniques for providing food or water because the patient is unable to swallow. It includes the use of a nasogastric tube, percutaneous endoscopic gastrostomy (PEG feeding) and total parenteral nutrition. The provision of nutrition and hydration by artificial means requires the use of medical and/or nursing skills to overcome an inability to swallow, in the same way that artificial provision of insulin is given to diabetic patients to overcome the body's own inability to produce that substance. The measures are specifically singled out in the legislation.

Withholding artificial nutrition and hydration is a controversial area.^{151 152 153} In part, this is because the benefits and burdens of either nutrition or hydration may not be well known and involve difficult assessments of the patient, including requiring a sound scientific base before prescribing them. For example, patients may increasingly lose interest in eating or drinking in the later stages of a progressive or chronic illness. Often this occurs at a time when other body systems begin to shut down and may be part of the natural dying process. Problems in making assessments can arise because some patients under-report their symptoms as they may no longer be lucid at this time. Complications also arise where there are different perceptions and expectations between doctors, members of the health care team and those close to the patient, about the presence or severity of symptoms, and the type of medical interventions the patient would want (or not want). For example, there may be emotional difficulties in deciding not to provide what those closest to the patient see as basic nurture and care.¹⁵⁴

Artificial nutrition at the end of life is an issue that is riddled with emotions, probably more so than any other medical treatment. Eating food, sharing food, sitting at meals together, are significant social events in all cultures across the world. Feeding the young and the ill is a powerful instinctive act, which may be hard to suppress. If we do not eat, we die; this is a truth universally known, and felt. That the reverse is also true, the dying often do not eat, is less widely known and much harder to accept. Noticing the anorexia of terminally ill patients, many caregivers have an urge to press food and drink on them, and if these patients cannot feed themselves many caregivers, professional or not, will want to make sure they will receive nourishment no matter how. How to negotiate these powerful urges, and at the same time serve the best interest of the patient?

Concerns about decision-making around withholding or withdrawing artificial hydration and nutrition go beyond the clinical to the societal level. Some commentators see that it is potentially dangerous to allow some forms of life-sustaining measures (artificial hydration and nutrition) to be withheld or withdrawn because it may eventually result in society's tolerance of withholding and withdrawal of life-sustaining measures from vulnerable adults, even though the withholding or withdrawal may be inappropriate.¹⁵⁵

The controlling idea is that policies of not providing [medically administered nutrition and hydration] will lead to adverse consequences because society will lose its ability to limit decisions about [medically administered nutrition and hydration] to legitimate cases, especially under pressures of cost containment in health care. Whereas 'death with dignity' first emerged as a compassionate response to the threat of overtreatment, patients now face the threat of under-treatment because of the pressures to contain the escalating costs of health care ... Some fear that the 'right to die' will be transformed into the 'obligation to die,' perhaps against the patient's wishes and interests.

Some regard the provision of hydration and nutrition as basic care which should always be provided unless the patient's imminent death is inevitable. Others make a distinction between the insertion of a feeding tube – which is classed as treatment – and the provision of nutrition and hydration through the tube, which is considered basic care. From this perspective, there are subtle differences between a decision not to insert a feeding tube, or not to reinsert it if it becomes dislodged, compared with a decision to stop providing nutrition and hydration through an existing tube. There is, however, no such distinction in the law - artificial nutrition and hydration are disqualified as life-sustaining measures in acute emergencies, and, as such, cannot be withheld or withdrawn without consent. The law considers that the withholding and/ or withdrawal of these measures does not occur in acute situations, therefore, there is time to

discuss this with the patient if they have capacity, or their substitute decision-maker if they do not, to obtain consent not to commence or continue.

Although artificial nutrition and hydration are referred to in these guidelines together, there are good clinical reasons why the provision of each should be assessed separately. For example, with some terminally ill patients, subcutaneous intravenous fluids may avoid dehydration, decrease pressure sore risk and aid comfort, but the provision of nutrition artificially would be too invasive to be in the patient's best interests. With other patients it is appropriate for both nutrition and hydration to be withheld or withdrawn. Withholding a treatment may seem more acceptable to health care professionals, patients and their families, as starting a treatment implies there is an inherent utility to that treatment; this may lead to withdrawing a treatment being more emotionally difficult, particularly artificial hydration and/or nutrition.¹⁵⁶

Doctors are advised to seek a second clinical opinion before withholding or withdrawing artificial nutrition or hydration from patients whose death is not imminent. This opinion should be sought from a senior doctor/consultant with experience of the patient's condition and who is not directly involved in the patient's care. This is to ensure that in this most sensitive area, the patient's interests have been thoroughly considered and reassurance given to the patient's family. The research shows that misconceptions associated with artificial nutrition and hydration cause emotional burden.¹⁵⁷ Therefore, discussions should start while patients are capable of participating in decision making. Health care professionals have to pay attention to build both knowledge and confidence on artificial nutrition or hydration issues in patients and caregivers, to acknowledge the importance of family members' opinions and to actively address concerns and fears to dispel myths about artificial nutrition or hydration discontinuation.¹⁵⁸

It must be remembered that adult patients with capacity are entitled to refuse artificial nutrition and/or hydration, and their refusals must be respected.¹⁵⁹ Although patients are not obliged to justify their decision to refuse artificial hydration and/or nutrition, health professionals should try to ensure they have fully understood their situation and are not under any misapprehension about the nature of the treatment or the implications of their refusal. It is not considered suicide to refuse artificial nutrition and hydration.⁵ Everyone has the right to refuse or discontinue a medical treatment. A person at the end of life is dying, not by choice, but because of a particular condition or disease. It is not considered suicide to refuse or stop a medical treatment that will not restore the patient to a level of health they would find acceptable.

Provided it is able to achieve its physiological aim, artificial nutrition and/or hydration should never be withheld or withdrawn from a patient with capacity who has expressed a wish to remain alive. The provision of artificial hydration and/or nutrition in these circumstances will benefit the patient, at least in the short term, by alleviating their distress.

The law acknowledges the exceptional sensitivity of decision-making in this area by always requiring consent to withhold and or withdraw artificial hydration and nutrition.

Assisted ventilation is a method used to mechanically assist or replace spontaneous breathing when a patient is unable to do so on their own. The methods for delivering assisted ventilation can be invasive or non-invasive. An example of an invasive method for artificial respiration (as it is sometimes called) occurs when an endotracheal or tracheostomy tube is inserted into the patient to deliver air directly to their lungs. Invasive ventilation methods most often occur in acute care settings for a short period of time. Sometimes patients with chronic lung conditions may require long-term assisted ventilation that they can achieve at home under the care of respiratory specialists.

The main form of mechanical ventilation is positive pressure ventilation that increases the pressure in the patient's airway by forcing additional air into their lungs. Whilst assisted ventilation

⁵ A decision in *Hunter and New England Area Health Service v A* 120091 NSWSC 761 upheld the supremacy of individual's rights in a case involving a quadriplegic patient who requested removal of artificial hydration and nutrition.

is identified as a life-sustaining measure, it can also create adverse side-effects, including pneumothorax, airway injury, laryngeal trauma, alveolar damage and ventilator-associated pneumonia.

Assisted ventilation is usually intended to provide assistance for breathing for limited periods of time. It is not a cure for a disease - even a lung disease. Assisted ventilation is one of the most common life-sustaining measures given to dying patients. Common medical indications for use include:

- acute lung trauma (including acute respiratory distress syndrome - ARDS)
- apnoea with respiratory arrest, including cases from intoxication
- chronic obstructive pulmonary disease (COPD)
- acute respiratory acidosis with partial pressure of carbon dioxide, which may be due to paralysis of the diaphragm from such things as spinal cord injury, or the effect of anaesthetic and muscle relaxant drugs
- increased work of breathing as evidenced by significant tachypnoea, retractions, and other physical signs of respiratory distress
- hypoxemia with arterial partial pressure of oxygen with supplemental fraction of inspired oxygen
- hypotension including sepsis, shock, and congestive heart failure.

In clinical terms, the primary goal of artificial ventilation is to improve gas exchange and reduce the work of breathing in patients with acute respiratory failure, without causing iatrogenic lung injury.¹⁶⁰ It is also recognised in the literature that decision-making about whether to withhold or withdraw artificial ventilation is among the most difficult and complex in medicine. Some of these challenges relate to artificial ventilation being defined along the continuum of life-sustaining measures, including providing oxygen (in any form) to assist or replace breathing, for example, it could be that providing oxygen is a comfort measure.

Although it could be argued that limitation or removal of mechanical ventilation causes a more imminent demise than does limitation or removal of artificial nutrition, hydration, medications, or dialysis, the limitation of cardiopulmonary resuscitation and other critical interventions also can have as imminent a ramification. Thus, although relatively little of end-of-life care debates have centered specifically on mechanical ventilation, the distinctions between mechanical ventilation and other forms of life support technology are probably artificial and irrelevant.¹⁶¹

Ethical misconceptions about foregoing ventilator support have also been identified in some of the recent literature.¹⁶²

- withdrawal of ventilatory support is a form of patient abandonment
- foregoing ventilatory support violates the principal of beneficence
- there is a difference between withholding and withdrawing ventilatory support
- it is unethical to administer sedatives and analgesics to dying patients if doing so may hasten death.

Irrespective of definitional issues, decision-making about whether to commence or to continue assisted ventilation carries with it the same legal and ethical principles as apply to other life-sustaining measures. If the patient lacks capacity, consent will need to be obtained from the patient's substitute decision-maker/s, clear communication will be required with those closest to the patient, and careful documentation of all decision-making processes will be essential. In acute emergencies, consent to provide oxygen to a patient who lacks capacity would not be required, unless the patient has (at a time when they had capacity) expressly refused to accept artificial ventilation. Again, as with other life-sustaining measures, if the treating doctor is directly aware that a patient has expressed an objection to having artificial ventilation (in any form) withheld or withdrawn, consent will be required from the patient's substitute decision-maker.

It should also be noted that decisions around assisted ventilation are potential sources of conflict between the treating health care team and the patient and those who support them. Research suggests that health care professionals and decision-makers can reach consensus about serious issues such as ventilatory support through ongoing and honest communication and negotiation. This was illustrated by an observational study in a medical ICU that found that, through the course of successive family meetings, clinicians and families were able to reach consensus about the appropriate plan of care in 96 per cent of cases.¹⁶³

3.2.4 Blood transfusions

While blood transfusions are specifically precluded under the legislation as life-sustaining measures for the purposes of consent, they are still an important life-prolonging treatment, and therefore need to be addressed in the broader context of end-of-life care. Issues about blood transfusions generally arise when:

- a patient refuses a blood transfusion as part of an advance care planning discussion with their doctor/s; or
- a substitute decision-maker/s refuses to consent to a blood transfusion for a patient without capacity; or
- a blood transfusion is specifically refused in a valid AHD.

The difference between providing and withholding a blood transfusion within the context of life-sustaining measure should be kept in mind: there are differences in the decision-making pathway and the requirements in the law. Guidance will most often be required in circumstances where there is dispute, disagreement, or uncertainty about blood transfusions and the use of blood products for people who are Jehovah's Witnesses. In particular, issues may arise when the health care team is uncertain of its position about a treatment decision, or when there is uncertainty as to the extent of the person's commitment to the faith, the extent of their decision-making ability, and the rejection of blood transfusions.

An adult who has capacity has the right to refuse blood transfusions, and this decision must be followed.

This is the position at common law and also under the Queensland Criminal Code.¹⁶⁴ Where medical treatment (such as a blood transfusion) is provided against the decision of an adult with capacity, it amounts to an assault. The assault under the Criminal Code may give rise to either criminal charges or to a civil action for battery.

However, where the treating doctor reasonably considers an adult patient has an impaired capacity to make a decision about their healthcare, and a transfusion of blood or blood products is required urgently to meet an imminent risk to the life or health of the patient, a transfusion may be administered without consent as long as the doctor does not know of an objection by the patient in an Advance Health Directive. Sometimes, there is not a straight-forward decision-making pathway. However, for a patient without capacity, where objections are known (and, arguably, a patient who is a member of the Jehovah's Witness faith would fall in this category), consent will be required from the patient's substitute decision-maker before administering the blood transfusion.

It is highly likely that patients who are of the Jehovah's Witness faith will carry information to that effect. Many followers carry a 'No Blood Card' (reviewed annually). Some may even wear a bracelet identifying that they belong to that particular faith. Caution should be exercised in this area because simply carrying a card or wearing a bracelet of membership to the Jehovah's Witness faith may not necessarily be sufficient evidence for a refusal of a blood transfusion, save for urgent and acute situations.

It is the law in Queensland that a blood transfusion is not permitted without the consent of either the patient (if they have capacity), or the substitute decision-maker/s (if the patient does not have capacity).

Within any faith there is a range of adherence to the religion's stated precepts by its members. No person is wholly defined by their membership of a church, and membership of the Jehovah's Witnesses should be considered as only one influence in forming a person's views. A person's adherence to the faith, especially in circumstances where there is no available card, requires investigation and verification. In cases where there is dispute or disagreement as to the person's commitment to the faith and their opposition to blood transfusions, the Office of the Public Guardian should be contacted if the patient lacks capacity. This is because it is likely that other life-sustaining measures may be required in addition to a blood transfusion.

Within practical limits, the wishes of a patient from the Jehovah's Witness faith who has refused a blood transfusion must be fully explored by speaking with them directly without other members of the family or members of the faith present. Some Jehovah's Witness patients may actually wish to consent to receiving blood transfusions but are reluctant to agree for fear of being ostracised by their religious community. In order to ensure that patients are not acting under duress, doctors would be well advised to assure the patient that the nature of any treatment administered (including blood transfusions) is confidential and will not be unlawfully disclosed to any third parties. There is also a possibility the Jehovah's Witness patient may change their mind when faced with the likelihood of serious disability or death. In addition, the Jehovah's Witnesses' religious understanding does not absolutely prohibit some procedures. The doctor in charge must make a considered judgement if an adult Jehovah's Witness patient lacks capacity and there is no time to consult a substitute decision-maker/s for any of the following:

- Small blood fractions such as immunoglobulins, haemophiliac preparations, albumin, cryoprecipitate, SPPS.
- The following surgical techniques on the condition that there is a continuous extra-corporeal circuit: haemodilation, heart-lung dialysis, intra and post-operative blood salvage and reinfusion, and renal dialysis.

A number of high-profile national and international cases serve as a reminder for doctors to not provide blood transfusions without the explicit consent of patients. For example, in 1979, the Supreme Court of Ontario, Canada in the now well-recognised case of *Malette* found that a doctor who administered a blood transfusion in an emergency to a patient carrying a card indicating her wishes not to have a blood transfusion, had committed an assault and was liable to damages. This was despite the blood transfusion having been administered in emergency circumstances, being done conscientiously and appropriately in terms of her medical condition, and consequently saving her life. The trial judge and the Supreme Court both found that an assault had taken place and awarded damages against the doctor. It should also be noted that in some other cases, Jehovah's Witness patients have failed in claims of battery.

Every effort should be made to locate the patient's decision-maker if they lose capacity and it is known (or suspected) the person may be from the Jehovah's Witness faith. Generally, it is the case that advance treatment refusals for blood transfusions made by competent adults must be followed. Still, in decision-making around end of life, it is recognised there are many times when one answer to multiple problems may not be straight forward. Therefore, it is recommended that where a doctor believes that providing a blood transfusion to an incapacitated patient known to have expressed an objection to the measure (for example, as a Jehovah's Witness) would be consistent with good medical practice, a second opinion from a more experienced clinician should be sought. Where time permits, consideration should also be given to contacting the Office of the Public Guardian, if this is deemed appropriate in the circumstances.

Queensland Health has a consent form ([available on QHEPS](#)) for blood transfusions that must be completed before giving a blood transfusion to an adult patient.

To assist with the decision-making process, the following questions are prompts for decision-making where a patient lacks capacity:

1. Does the patient carry a 'No Blood Card'?
2. Does the patient have a valid AHD refusing blood transfusions?
3. Has the person appointed an Enduring Power of Attorney/s with or without instructions regarding blood transfusions?
4. Was or is the patient accompanied by a family member or other close person that is a member of the Jehovah's Witness faith?
5. Has the person left instructions with members of the family regarding blood transfusions?
6. Has the person left instructions with their general practitioner regarding blood transfusions?
7. Has the person been a practising member of the Jehovah's Witness faith, or have an association with a church, congregation or minister, and could any of these sources verify their adherence to the practice of no blood transfusions?
8. Has the health care team explored the possibility of alternate products such as blood expanders or alternate treatments to blood transfusion, when these products or treatments may be acceptable to Jehovah's Witnesses?

Refer to Health Support Queensland ([Pathology Queensland](#)) website about further information in relation to blood and blood products for [Jehovah's Witnesses](#).

For further information about blood and blood products generally refer to the Patient Safety and Quality Improvement Service website, in particular [Standard 7](#) of the [National Safety and Quality Health Service Standards](#).

3.3 Resuscitation planning

Resuscitation planning in these guidelines refers to advance discussions and decisions regarding actions to be taken for a patient in the event of organ failure, more specifically a cardiac and/or respiratory arrest. In all instances this will involve consideration of CPR. However, other life-sustaining measures may also be appropriate in acute settings, depending upon the circumstances. While resuscitation planning is a subset of advance care planning, the clinical considerations of withdrawing and withholding life-sustaining measures fits more squarely within medical decision-making. The desired outcome of timely resuscitation planning is the completion of an Acute Resuscitation Plan (ARP), which is a medical order that provides clinical authority to act on its directions. (More about the ARP is discussed in the sub-sections that follow.)

Planning resuscitation for a patient depends upon the extent to which death is regarded as an unavoidable and impending consequence of the patient's underlying illness. The doctor responsible for the care of the patient has an important role in helping the patient and those closest to them make appropriate plans for their future treatment and care in a sensitive but realistic manner, making clear if resuscitation methods such as CPR could be successful. Helping patients to make a clear decision about their wishes about resuscitation as early as appropriate, should be regarded as a marker of good practice in any health care setting. If the patient and/or their family have already engaged in timely advance care planning discussions, the decisions around whether to attempt or withhold resuscitation should be reasonably familiar and not surprising. Ideally, advance care planning discussions about other aspects of care at the end of life (such as living and care arrangements, hospitalisations and the like), should complement resuscitation planning decisions – the patient and those closest to them are in the most appropriate position to enable this to occur.

Comfort care and palliative support must always be initiated if the decision is to withhold or withdraw active medical treatment.

Resuscitation planning involves discussing with the patient and his or her family the likelihood of resuscitation attempts being successful in restoring breathing and circulatory function of the patient. While there are many variables, such as the time and location of a cardiac arrest (if this occurs), the doctor in charge should present, in the current circumstances, the overall prognosis

in the most realistic and compassionate way possible. Where a patient's condition deteriorates, some difficult decisions will likely be faced by the patient or the patient's substitute decision-maker/s if the patient lacks capacity. For example, when a patient is in the final stages of an incurable illness and death is expected within a very short time, attempting CPR is unlikely to be clinically successful. In fact, it may unnecessarily prolong the patient's life to the extent they may suffer an inhumane and undignified death.

This is an emotionally-charged time for the patient themselves, the patient's family and friends; and at the same time, the healthcare team will be faced with exceptionally difficult and challenging clinical decisions. For example, some patients may also need other life-sustaining measures to stabilise their condition, such as artificial ventilation. They may also require a range of other interventions, such as renal dialysis or haemofiltration and circulatory support with inotropic drugs and/or an intra-aortic balloon pump. The patient may also incur other post-CPR conditions, including injuries associated with rib or sternal fractures, hepatic or splenic rupture or severe brain damage through lack of oxygen. All of the preceding factors should be taken into consideration by the healthcare team as part of the decision-making process around resuscitation planning, particularly for very frail patients.

In these situations, palliative care professionals and/or health professionals experienced in the palliative approach should be involved in discussions as early as possible with the patient and/or the patient's family, particularly where death is reasonably predictable. There should be a full clinical assessment of the chances of a successful outcome, documented on the patient's Acute Resuscitation Plan (ARP) and/or in the progress notes. It is important to identify those patients at foreseeable risk of dying in the short term, and for whom questions about the use of CPR exist, so that decisions about CPR can occur in a timely manner to the degree possible in advance of an emergency situation. Ensuring that discussion takes place about CPR, the patient's preferences recorded and a clinical decision made in advance where possible, is preferable to making decisions in a crisis when there may be insufficient time to gather and consider all the relevant information about the patient's wishes and clinical condition. Completing an Acute Resuscitation Plan (ARP) can guide the discussions and the recording of medical decisions in this regard.

3.3.1 Presumption in favour of resuscitation when there is no documented decision

If no explicit decision has been made in advance about resuscitation and the express wishes of the patient are unknown and cannot be ascertained, and if uncertainty exists about diagnosis or prognosis, there should be a presumption that doctors and other members of the healthcare team will make all reasonable efforts to attempt to revive the patient in the event of cardiac or respiratory arrest. In such emergencies, there will rarely be time to make a thorough assessment of the patient's condition and the likely outcome of resuscitation efforts, and so attempting resuscitation will usually be appropriate.

Medical and nursing colleagues should support anyone attempting resuscitation in such circumstances. There may be some situations in which resuscitation efforts are commenced on this basis, but during attempted resuscitation, further information comes to light that makes continuing resuscitation efforts inappropriate. That information may consist of an ARP or a valid AHD refusing, for example CPR in the current circumstances, or further clinical information showing the treatment will not be successful. In these circumstances, it would be appropriate to withhold further resuscitation attempts.

For some patients, attempting resuscitation will be clearly inappropriate (for example, a patient in the final stages of a terminal illness where death is imminent and unavoidable and resuscitating the patient would not be successful), but for whom no formal decision about resuscitation has been made. In such circumstances, senior doctors and/or consultants who make a considered decision not to commence resuscitating a patient should be supported by their colleagues, and the decision and its rationale/justification appropriately documented.

3.3.2 Acute Resuscitation Plan (ARP)

The introduction of a formal substitute decision-making scheme in the *Guardianship and Administration Act 2000* has confirmed that 'Not for Resuscitation' (NFR) Orders have no legal status and cannot be relied upon in the absence of other forms of consent to withhold or withdraw medical treatment. Therefore, NFR Orders or 'Do Not Resuscitate Orders' legally cannot be used as valid consent to any proposal to withhold or withdraw life-sustaining treatment.

NFR Orders are replaced by a standard Acute Resuscitation Plan (ARP) form, which was developed in consultation with a range of government agencies, including the Queensland Coroners, public health professionals and health administrators. The ARP form was formally endorsed and implemented in all Queensland Health facilities in 2009-2010. A reproduction copy of the ARP form is at [Appendix 10](#).

The ARP form was specifically designed to record the decision-making pathway around life-sustaining measures and provides a tested process for consistent documentation of clinical recommendations to withhold or withdraw medical treatment in acute situations. In conjunction with these guidelines, the ARP form is also intended to prompt discussion with patients and/or their substitute decision-maker/s about resuscitation planning in the event of an acute event, such as cardiac or respiratory arrest. An ARP can be valid for the current admission, until a specified future date or for the current and subsequent admissions.

A Cover Sheet was also developed to manage copies of 'active' ARPs for patients transferred between health facilities and during transit. The ARP Cover Sheet advises receiving health care facilities of the existence and purpose of the patient's active ARP. Individual facilities may use this form at their discretion. For further information, see section on [patient transfers](#) below.

As with NFR Orders, the ARP is not a legal document, nor does it substitute for legal consent; it is a medical record, and provides clinical authority to act on the directions when urgent decisions are required. Also, the ARP form is not strictly a consent form like the AHD (or surgical consent form), but documents the patient's consent to withhold and/or withdraw life-sustaining measures and therefore, can be acted upon. Because CPR is considered an acute emergency, consent is not required, provided the treating doctor is not aware the patient has not objected to the withholding of CPR. The ARP was specifically designed to be used in acute settings, therefore it is a distinctive purple-coloured short form located at the front of the patient's medical record. Where there are electronic records, alerts are in place for a patient with an active ARP. The processes around completing ARPs formalises an important part of advance care planning in acute settings, and, therefore, facilitates improved decision-making and outcomes for patients at the end of life. Since the ARP is a hospital form and not a consent form, there is no legal basis in Queensland for patients (or their families) to sign the ARP. Further, consent in Queensland can be verbal; the ARP simply documents the consenting discussions.

3.3.3 Who is suitable for an ARP?

Initiation of an ARP is intended for those patients who are considered in all reasonable circumstances to be at risk of cardiac and/or respiratory arrest in the foreseeable future, or for whom death is predicted to be within 12 months. While some aspects of advance care planning may be appropriate to discuss with otherwise healthy and well patients, discussing resuscitation planning for patients who are not acutely ill, particularly when not initiated by the patient, could be misinterpreted. However, for some patients, often those with serious, chronic and ultimately fatal conditions, cardiac and/or respiratory arrest is an anticipated consequence of their illness. While this may be foreseen, the timing of an acute event is less predictable, and so resuscitation planning appropriately respond is desirable.

In anticipation of the patient's deteriorating condition, discussions about end-of-life decision-making are best initiated as soon as practicable. This will identify any unmet needs and preferences and give a clear decision pathway for other members of the healthcare team in the case of an acute event. Ideally, discussing resuscitation planning should occur as part of the advance care planning process in which the patient is able to express views about end-of-life

wishes at a time when their health is reasonably stable, they have time to contemplate such matters, and decisions are not made on their behalf when no one knows what they would have wanted.

Building upon guidance from the Gold Standards Framework and other seminal research in this area, [Appendix 8](#) contains detail about possible triggers to initiate an Acute Resuscitation Plan (ARP) form. Within this context, the [Advance Care Planning Clinical Guidelines 2017](#) provides further detail on the stages of a person's disease trajectory, potential triggers for initiating end-of-life discussions around advance care planning, resuscitation planning and potential actions associated with those triggers.

3.3.4 Completing an ARP

Before completing an ARP, healthcare professionals who are most likely to encounter ARP forms should be familiar with the Quick Guide. The Quick Guide is a tear-off section attached to the side of the ARP form that assists doctors to complete the ARP form. The Quick Guide contains a set of instructions that can be used to complete the form, as well as information about for whom the form applies, and when it may be appropriate to complete it. The Quick Guide also contains important information about legal considerations, including for emergency situations, and contact information if further information and support is required.

Section 1 – Clinical Assessment

Clinical assessment and appropriate treatment options should be guided by good medical practice, which includes discussions with the patient and/or their substitute decision-maker(s).

- This ARP form is for use in all Queensland Health facilities (e.g. hospitals, aged care and other residential facilities).
- The Quick Guide attached to this form contains important information and should be read prior to completing the form.
- If there is insufficient room on this form to record information, please cross-reference with the progress notes.

1. Clinical assessment

Record details/assessment of relevant medical conditions relating to the patient's physical and mental health. This section may include clinical reasons why resuscitation planning is necessary.

This section of the ARP records details or an assessment of the patient's relevant medical conditions, relating to their physical and mental health. It is also recommended to record the clinical reasons why resuscitation planning is necessary. Recording a clinical assessment on the ARP form *does not* replace a full clinical assessment of the patient. If there is insufficient room on the form to record all relevant details, information can be cross-referenced in the patient's medical record.

Any discussions held with the patient and/or their substitute decision-maker(s) about the patient's medical status should also be recorded in this section. It is recommended to seek a second opinion if there are any doubts or uncertainties about the patient's medical condition or prognosis. For example, the patient's views about their medical condition may be different to that of the doctor.

Section 2 - Capacity assessment

2. Capacity assessment

- ☐ I believe that the patient **has capacity*** to consent to and/or refuse medical treatment.
- ☐ I believe that the patient **does not have capacity** to consent to and/or refuse medical treatment.

If there is a change in capacity, this form must be reviewed.

Details of assessment:

*A patient with capacity can understand information about their medical treatment and treatment options, weigh up the benefits, risks and burdens of each choice and freely and voluntarily make and communicate a decision. Please refer to the *Clinician Guide Capacity Assessment* for further information.

This section is where details about a patient's capacity and whether or not they have the capacity to consent to, or refuse, medical treatment are recorded. Having capacity means the patient can:

1. understand information about their medical treatment and treatment options;
2. weigh up the benefits, risks and burdens of each choice; and
3. freely and voluntarily make and communicate a decision.

If the patient has capacity, it is not mandatory to document the 'Details of assessment'. However, there may be circumstances where it is appropriate, such as where there is potential for fluctuating capacity. If there has been any dispute over a patient's capacity, or if a second opinion has been sought, it may be appropriate to note this in this section of the ARP. It may also be useful to note the method of capacity assessment that was used.

A second opinion and/or a mental health assessment may be required if there are any doubts or uncertainties about the patient's capacity to make decisions about health matters, particularly over the longer term. This may also be relevant if a patient has fluctuating capacity, or an episodic mental illness which may affect the patient's capacity to make health care decisions. Further information can be found in section Information about assessing capacity for patients at the end of life is contained in these guidelines under section [1.4 – Capacity](#).

Section 3 - Resuscitation management plan

3. Resuscitation management plan

If an acute deterioration or critical event occurs, it is clinically indicated to:

Provide e.g. ventilation, IV fluids, supportive therapies

Not provide e.g. defibrillation, intubation, antibiotics

There is further documentation in the progress notes on the following dates:

If a cardiac or respiratory arrest occurs, it is clinically appropriate to:

CPR	<input type="checkbox"/> Provide	<input type="checkbox"/> Do not provide
	A decision not to provide CPR does not limit other treatment or care	

Acting on the Resuscitation management plan: if this section differs from Section 4 (Patient choices), follow an appropriate dispute resolution process (see Section 4 in Quick Guide). If the dispute remains unresolved, or this section is incomplete or unclear when a resuscitation decision is required, attending clinicians should exercise their clinical judgement based on the circumstances, and document this.

The resuscitation management plan should give clear direction to staff who are present if the patient arrests (or in the event of an acute deterioration) and need to rely on the form about what they should do.

The provision or non-provision of CPR is a significant consideration in resuscitation planning. However, there are many other factors which should be considered, such as the patient's autonomy, their best interests, and the purpose of any interventions planned. Remember, while the patient has capacity for decision-making, they have a legal and ethical right to refuse all medical treatment, even if this results in their death or would make it happen sooner. Conversely, there may be cases where a patient and/or their substitute decision-maker(s) are requesting treatments and/or interventions that are not clinically indicated, inappropriate, or the provision of which would be futile. Refer to Section 4 - Patient choices for guidance on how to respond when a patient's choices differ from the health care team's assessment, recommendations and/or resuscitation management plan.

The patient and the treating doctor, with other members of the healthcare team, may decide that it is clinically inappropriate to provide CPR. It is important to recognise that a direction to not provide CPR does not mean 'do not provide any treatment'. Completion of this section does not exclude the provision of other medical interventions and treatments which are not specifically mentioned. For example, it is always appropriate to provide medication and other therapies to manage pain, suffering and discomfort, even if they are not mentioned on the ARP form.

Even if it is not clinically appropriate to provide CPR, a patient may still benefit from a range of treatments and therapies that contribute to quality end-of-life care. The 'Provide' and 'Not provide' free text boxes should be completed to indicate a level of appropriate intervention, or other treatments which are appropriate and have been consented to. The plan could also include whether or not it is appropriate for attending staff to call for the Medical Emergency Team.

The Resuscitation management plan represents the doctor's clinical decision about what would be clinically appropriate if the patient's heart stops and they stop breathing. Therefore, it should give clear direction to attending teams in the event of an acute deterioration.

DOCTORS:

- What do I think is good medical practice for THIS patient in THIS situation?
- What can realistically be offered NOW?
- Do I think anything will change MY decision about CPR into the future?
- What CAN I provide this patient to improve their life and health?
- What would I do, or instruct others to do, if the patient arrests NOW?
- If am not available, what would I want an attending team to do if this patient suffers an arrest during this admission or at some point in the near future?
- Am I prepared to stand behind, and can I defend this clinical decision?
- Should I get advice from someone more experienced?

If the Resuscitation management plan is not signed, incomplete or unclear at the time of an acute deterioration, attending clinicians must exercise their clinical judgement in the circumstances, document what they did and why, and be prepared to stand by this decision. Where time permits, second opinions in these circumstances are highly recommended.

Where consent has been obtained to the Resuscitation management plan, it provides clinical and legal authority to act at the time the patient suffers an acute deterioration. If it is clinically appropriate to withhold resuscitation, that is, not provide CPR when the patient arrests, then a conversation must be held with the patient (if they have capacity) or the patient's substitute decision-maker with the objective of obtaining consent to this approach. Consenting details are documented in Sections 4 and 5.

If the patient or their decision-maker is demanding clinically inappropriate medical treatment, all efforts should be made to explain why providing CPR (or other life-sustaining measures) will not be in the patient's best interests, and what treatment and care is clinically appropriate for the patient. As appropriate, involve other members of the healthcare team in these decisions, and seek second opinions from more experienced doctors and consultants. If reasonable efforts to resolve the situation are unsuccessful, escalate to Executive and/or local hospital management, as local circumstances and time permits. It must be remembered that substitute decision-maker/s have responsibilities under the law; if substitute decision-maker/s are not acting in the best interests of the person they are responsible for, the Public Guardian can be called upon to intervene. For example, substitute decision-makers may not be complying with the *Health Care Principle under the Guardianship and Administration Act 2000*. For further information, see [Appendix 4 – General Principles and Health Care Principle](#).

If the dispute remains unresolved despite reasonable attempts, and the patient suffers an acute deterioration, attending clinicians should exercise their clinical judgement based on the circumstances, and document the decision-making pathway. Except in some acute emergency situations, consent is required to withhold or withdraw life-sustaining measures. Therefore, legally, clinically and ethically it is not appropriate to create "artificial" emergencies to avoid obtaining consent where there is a likelihood of a dispute, or where the conversations are "too difficult" because there are ongoing demands for "futile" medical treatment. Think dispute resolution!

Section 4 - Patient choices

4. Patient choices

The patient has the following views and wishes about their end-of-life care: (e.g. CPR, pain management options, living and visiting arrangements, spiritual and/or cultural support). Discuss the views and wishes of patients who have impaired capacity with their substitute decision-maker(s). Record the dates and times of discussions.

Has the patient participated in advance care planning?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Provide details:		

This section records the patient's views and wishes about their end-of-life care. If there is insufficient room on the form, cross reference in the patient's medical record.

A patient with capacity is entitled to refuse medical treatment, even if their decision is not agreed to by any other person, is inconsistent with good medical practice and will result in their death or cause it to happen sooner. A patient may have already recorded these choices and decisions in an Advance Health Directive. Where patients feel strongly about treatment and care at the end of life, they should be encouraged to carry out advance care planning, and potentially complete an Advance Health Directive. Ensure all this documentation is cross-referenced in the medical record, and the most current information is on the ARP form.

The patient's attending healthcare team is responsible for determining whether or not a patient's Advance Health Directive is valid. The most senior doctor available will need to resolve any inconsistency between a valid Advance Health Directive and the patient's stated choices with the patient or their substitute decision-maker(s) if the patient does not have capacity. Where the patient has or regains capacity and expresses decisions contrary to what is recorded in their health directive, they should be encouraged to review their Advance Health Directive.

Healthcare professionals may encounter patients (and/or substitute decision-makers) who request treatments which are not medically indicated and would be in all clinical and ethical respects, considered futile. Where a patient's choices differ to the recommendations of the healthcare team (that is, what has been indicated in the resuscitation management plan), this could represent a recognised objection under the law, even in an acute emergency. In these situations, the laws in Queensland require thorough documentation of the decision-making pathway, even if there is agreement. (See Patient objections section below for more detail).

If there are inconsistencies between the patient's choices or those of the patient's substitute decision-maker to what is being proposed in the Resuscitation management plan, this may be the first indication that a dispute resolution process should be initiated.

The patient choices section should also be used to initiate or escalate any discussions or counselling about resuscitation planning if the choices of either the patient (if they have capacity) or their substitute decision-maker(s) (if the patient has impaired capacity) differ from the clinical decision about the appropriateness of resuscitation. In these situations, involvement of all members of the healthcare team is recommended.

If need be, a new ARP can be initiated as the healthcare team works through and resolves

It is not appropriate for an ARP form to be completed **ONLY** when the patient choices section and the clinical decision are consistent, or to wait for full agreement between all parties before initiating the ARP.

Patient Objections

The law recognises that a person can object to life-sustaining measures being provided, withheld or withdrawn. Queensland Health's policy position is that direct knowledge of an objection is required from the patient, rather than hearsay (e.g. from a family member). The patient's objection should have been expressed directly to the treating doctor as close as possible to the acute deterioration or event. For example, it may not be appropriate for members of the healthcare team to try to establish the authenticity of 'hearsay' in acute emergency situations while attempts are being made to save the life and health of the patient.

For the withholding or withdrawal of medical treatment, an objection may be expressed by the patient as a verbal request to "do everything" or "keep me alive" or "don't let me die", or by their conduct, or in formal terms through an Advance Health Directive.

Effect of objection by patient to withholding or withdrawing life-sustaining measures

	Emergency	Non-emergency
Capacity	<ul style="list-style-type: none"> - Objection = demand for treatment - Doctors are under no legal or ethical obligation to offer or provide treatment that is not clinically indicated (no benefits, cause harm) - Discuss with patient, if time permits - Provide treatment at discretion OR withhold/withdraw treatment in best interests of patient - Document the decision-making pathway. 	<ul style="list-style-type: none"> - Time to manage objection/ demand for treatment - Patient cannot demand clinically inappropriate treatment - Discuss with patient in the context of their life goals - Commence dispute resolution process, including: second opinion, family conference, referral to hospital executive - Document the decision-making pathway.
Impaired capacity	<ul style="list-style-type: none"> - Doctors cannot override patient objections Need consent from substitute decision-maker (legal position) - If decision-maker/s demands clinically inappropriate treatment and dispute cannot be resolved in time available, withhold/withdraw medical treatment if consistent with good medical practice (policy position) - All reasonable efforts should be made to obtain consent – this may include an urgent decision from the Public Guardian - It may be inappropriate/futile to continue attempting to save the patient's life while efforts are being made to obtain consent – use clinical judgement based on good medical practice - Document the decision-making pathway. 	<ul style="list-style-type: none"> - Time to manage objection/ demand for treatment - Objection can be overridden by doctor on grounds the patient: <ul style="list-style-type: none"> o Has no or minimal understanding of what is involved; o And will suffer temporary or no distress - Need consent from substitute decision-maker to withhold/withdraw treatment - If no consent, or decision-maker demands clinically inappropriate treatment, commence dispute resolution process - Document the decision-making pathway.

When patient choices differ from the doctor's assessment and/or Resuscitation management plan, a dispute resolution process should be initiated, as circumstances permit:

- Doctors are not obliged to offer nor provide medical treatment to a dying patient that offers no benefit, would cause harm and would in all reasonable respects, be considered futile.
- If patients and/or their families request choices for treatment that do not meet the standards of good medical practice, doctors must make all efforts (including involvement of counsellors, if this is appropriate) to inform the patient and/or the family of the risks involved.
- Depending upon the urgency of decisions required at the time, it may also be appropriate to allow more time and arrange further family discussions/conferences for the patient and/or their family to come to terms with the gravity of decisions around withholding or withdrawal of life-sustaining measures.
- If, despite all efforts to resolve the conflict, the situation fails and requests for inappropriate and/or unwanted treatment continue, the doctor must:
 - o seek a second opinion from and/or involvement of an experienced clinician, as circumstances permit
 - o refer the matter to Executive, or hospital management, as soon as practicable, as per local arrangements

- where the patient lacks capacity, refer the matter to the Public Guardian if the doctor believes the substitute decision-maker/s are not adhering to the Health Care Principle (see [Section 1 – Legislative Framework](#) for more information).
- In these circumstances, it is vital that clear and detailed documentation occurs at all stages of all discussions held (also see [Section 2.6 – Disputes](#) for more information).

Remember, **document document document**; ‘good documentation - good defence, poor documentation - poor defence, no documentation - little defence.’ Any previous advance care planning discussions or documents should also be recorded. If there is insufficient room on the form, cross-reference with the patient’s medical record. In some cases a patient may have documented their end-of-life choices in other formats, which can also be referenced on this part of the form.

When the patient’s choices disagree with the medical opinion: Tips following discussions with the Queensland Coroners Court

What should the attending team do in situations where the Resuscitation management plan indicates “NOT PROVIDE CPR”, and the ARP (and/or medical record) also contains evidence of efforts made to resolve the dispute?

1. If there is time, escalate the matter to more senior doctors or to hospital administration, as guided by local practice.
2. If there is no time, the attending team must exercise clinical judgement based on the “acute emergency” circumstances. This may involve choosing to follow the instruction in the Resuscitation management plan in the knowledge that the dispute remains unresolved.
3. If the patient’s death is reportable, the Office of the State Coroner has indicated that it will be looking for the appropriateness of the clinical decision-making and best efforts made to resolve the dispute in the circumstances – all recorded (or cross referenced) on the ARP. In other words, the relevant Coroners would be looking for evidence of appropriately completed ARPs, where they apply and where there has been time to complete one.
4. There is strictly no suggestion from the Office of the State Coroner that an inability to obtain consent requires the attending team to compromise the standards of good medical practice by providing “futile” life-sustaining measures causing harm to the patient.
5. Good medical practice and clinical judgement should prevail in all circumstances, which includes obtaining consent and documenting all stages of decision-making, with the doctor in charge being prepared to stand behind their decision/s.
6. Good medical practice also requires appropriate and thorough documentation of decision-making involving life-sustaining measures. If completed appropriately, ARPs provide a systematic way to record decision-making and can therefore fulfil evidentiary requirements of discussions about consent.

Section 5 - Consenting details

5. Consenting details

Complete this section, irrespective of the patient's capacity.

Patients with capacity can provide their own consent. For patients with impaired capacity, consent must be obtained from a substitute decision-maker(s), in the order below.

The patient has:

- | | | |
|--|------------------------------|-----------------------------|
| 1 Advance Health Directive (AHD) | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2 Tribunal-appointed Guardian | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3 Attorney(s) for health matters under Enduring Power of Attorney or AHD | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4 Statutory Health Attorney [†] | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

5 If no to all, the Adult Guardian must be contacted for consent. Ph: 1300 QLD OAG (753 624)

Name/details of substitute decision-maker(s): (e.g. relationship to patient, phone number, location of original AHD)

Record the dates and times of discussions held with, and consent obtained from, the patient and/or substitute decision-maker(s). Cross reference with the progress notes.

Details of consenting discussions:

[†] A **statutory health attorney** is, in the following order: a spouse (including de facto and same sex partners) in a continuing relationship, an adult who has care of the person (not a paid carer), an adult who is a close friend or relation (not a paid carer). (s. 63 Powers of Attorney Act 1998)

This section of the ARP records details about how consent to the overall treatment plan around withholding and withdrawing life-sustaining measures has been obtained, or is still in the process of being obtained. If considered relevant or necessary, cross-reference the dated progress notes in the patient's medical record about the process of obtaining consent.

Under the guardianship scheme in Queensland, all patients who lack capacity have a substitute decision-maker. Sometimes there can be more than one substitute decision-maker. If there is no appointed guardian, attorney or statutory health attorney available, the Public Guardian becomes the statutory health attorney and can be contacted to represent the patient's best interests. However, it is best to locate the most suitable decision-maker for the patient as soon as practicable, and not delay until decisions are required in a crisis and the only consenting option remaining is the Office of the Public Guardian.

If the decision is to withhold or withdraw medical treatment is required in an acute emergency situation, all reasonable efforts should be made to contact the nominated substitute decision-maker(s), with the objective of obtaining consent to the proposed approach. Good medical practice and clinical judgement will determine the best approach to the consenting process. Consent is not a "contract" in the legal sense. There is no "offer and acceptance," but rather a conversation to ensure information is provided and broad understanding is obtained to the overall treatment plan. This is to avoid criminal and civil action (e.g. assault) for providing medical treatment against a person's wishes, and also to obtain the appropriate consent to withhold or withdraw life-sustaining measures, as required by law.

When having the conversation, discuss with the patient or the patient's substitute decision-maker/s such matters as their condition, prognosis, goals for treatment and care, and overall treatment plan.

COMMUNICATION IS KEY: The overall treatment plan should be discussed in the context of what can and cannot be done (within reasonable limits of what medicine can achieve and the human body is capable of sustaining) for the patient in a sensitive and compassionate, yet honest way.

The conversation about resuscitation planning may include discussion, in broad terms, of available treatment options, palliative care and other community support services. Silence or ambivalence from patients or substitute decision-makers is not consent. Ensure the overall treatment plan is understood by the patient or the patient's substitute decision-maker/s. For further information about communication and care at the end of life, see [Appendix 11 – Communication resources for advance care planning](#).

It is important to note that, should a patient without capacity have an enduring legal document such as a valid AHD or EPOA, these documents have priority over all other forms of consent and must inform the decision-making as they are legally binding. Anything recorded in an ARP for a patient who holds enduring legal documents should reflect the choices documented in these formal documents. However, AHDs do have some limitations. For example, the directions in an AHDs must relate to the clinical situation at the time a decision is required. Also, if the directions in an AHD are uncertain or inconsistent with the standards of good medical practice, doctors may override them, even though they are a legal document. It is vital that the reasons for overriding AHDs are thoroughly documented, and the doctor is prepared to stand behind that decision, if required to do so. For further information, see [Section 1.5.5 – deciding not to follow an Advance Health Directive](#).

Within the Consenting details section, there is also space to record the dates and times of discussions held with, and consent obtained from, the patient and/or the substitute decision-maker/s. Cross-reference with the patient's record if there is insufficient room on the ARP form. Within clinical and practical limits, consent should be obtained as contemporaneous as possible to the acute event occurring. This may mean re-visiting the issue of consent with either the patient, or their substitute decision-maker/s as the patient's condition deteriorates. It should be noted that revisiting consent for palliative care patients may be inappropriate; consult palliative care specialists for guidance and/or involvement, as appropriate.

In Queensland, consent to the provision of healthcare, which includes withholding or withdrawing life-sustaining measures can be verbal or expressed in ways other than in writing. This means that there is no need to obtain written or signed consent from the patient or substitute decision-makers. Recording consent on the ARP is simply evidence of the consenting discussion having occurred. The legal requirement to document this for a patient who lack capacity occurs under section 63A(3) of the *Guardianship and Administration Act 2000*, which requires all the various things enabling the measure/s to be withheld or withdrawn to be documented in the patient's record; effectively meaning the patient or their decision-maker/s do NOT need to sign the ARP. The recording of details of the consenting discussion by a doctor (or other healthcare professionals, if appropriate) is sufficient to provide evidence of consent having been obtained.

It is Queensland Health's policy position that there is no legal, ethical or practical requirement for patients and/or the substitute decision-maker to sign the ARP form.

Section 6 – Clinician authorisation

6. Clinician authorisation	
<p>This ARP form remains valid:</p> <p><input type="checkbox"/> For this admission</p> <p><input type="checkbox"/> Until date: <input type="text"/> / <input type="text"/> / <input type="text"/></p> <p><input type="checkbox"/> For this and subsequent admissions</p> <p>Consultant / medical officer's name:</p> <p><input type="text"/></p> <p>Signature: <input type="text"/> Date: <input type="text"/> / <input type="text"/> / <input type="text"/></p> <p>Authorising medical officer's name*, if applicable:</p> <p>Dr <input type="text"/></p> <p><small>* If required, the authorising medical officer will be a more experienced senior medical officer/consultant and must be involved in all decisions to withhold/withdraw medical treatment.</small></p>	<p>Recommendations for review, if applicable: (e.g. will the ARP apply during planned surgery?)</p> <p><input type="text"/></p> <p><input type="text"/></p> <p><input type="text"/></p> <p>Other clinicians involved in the development of this ARP form and/or provided with a copy: (e.g. Emergency Department team, Palliative Care Service, GPs, allied health and nursing professionals)</p> <p><input type="text"/></p> <p><input type="text"/></p> <p><input type="text"/></p>

If changes are required, this form must be voided and a new ARP form completed

Validity

The validity period of an ARP form is intended to incorporate an element of flexibility by allowing for a variety of clinical circumstances. The options provided for the form's validity section allow for circumstances where the patient's Resuscitation management plan needs to be regularly reviewed. As such, some patients will have:

1. one ARP for their current admission; or
2. several voided ARP forms, with one active over a current admission; or
3. one ARP that is valid only until a certain date (say, after surgery); or
4. one ARP that originated in another facility, and has been re-written and endorsed for the current admission; or
5. one ARP that remains valid across multiple admissions; or
6. a voided ARP form (which no longer applies, but may be used to guide decision-making).

If the ARP form is valid until a future review date or for this and other subsequent admissions, it means the ARP is 'active'- particularly relevant if the patient is transferred to another facility.

Regardless of the validity period, it is appropriate to regularly review a patient's ARP form. However, it is recognised that for some patients (e.g. palliative patients or patients with chronic illnesses and significant co-morbidities), revisiting resuscitation planning discussions on each admission may be unduly distressing or inappropriate. For this reason, there is an option for an ARP to be valid 'for this and subsequent admissions'. However, even if a patient has an ARP that is active 'for this and subsequent admissions', the ARP form can be voided should it no longer apply.

Medical officer's authorisation

Where possible, the most senior doctor available should sign and/or authorise the patient's ARP form. This is particularly relevant where patient choices differ with the decision about CPR and future medical treatment, as they will have the seniority and experience to make decisions with the patient (and/or their substitute decision-maker/s) about their care. Another important reason for senior doctors to initiate (and/or oversee) the completion of ARP forms, is that for many patients at the end of life, complex diagnosis and prognostic expertise is required, particularly when there is a high potential for imminent acute deterioration. The ARP is not a lengthy form and was specifically designed to apply most likely in emergency situations and record decisions to withhold or withdraw life-sustaining medical treatment for our most vulnerable patients. A properly completed ARP:

- is not an onerous, overly time-consuming administrative exercise
- provides clinical authority for an attending team to act on its directions, in the absence of the doctor who completed the form or other senior doctors present
- records all the elements required by law to withhold or withdraw life-sustaining measures
- has the potential to avert unwanted, unnecessary and invasive medical treatment being provided
- potentially avoids the situation where a patient suffers a painful and undignified death.

While junior doctors should be encouraged to participate in resuscitation planning with patients, they should not authorise the ARP form. It is also highly recommended that junior doctors seek advice from the most senior doctor/consultant available before signing an ARP form. It is also recognised that there are very diverse clinical situations across Queensland, and it may be appropriate, in say very remote areas, for other health professionals to sign on behalf of a senior doctor that they have consulted by another means, for example, via telehealth or over the phone.

Recommendations for review

The 'recommendations for review' section allows for review of the form, and indicates whether changes are required. For example will the ARP apply during surgery? Other causes to review the ARP may also include changes to the patient's condition or their capacity, or changes to their wishes for end-of-life care (See next section for further detail about re-writing ARP forms – 3.3.5 – ARP administration).

Involvement of other clinicians

Other clinicians may also be involved in clinical assessments of the patient, such as general practitioners, allied health staff and nursing professionals. Dying patients may also be under the care of specialist palliative care professionals. It may be appropriate to contact the patient's GP when completing an ARP, as they may have a long-term relationship with the patient and be well-placed to offer pertinent information and considered advice. While it would be appropriate to forward a copy of the patient's ARP to their GP, this should be arranged as local circumstances permit, in consideration of privacy and confidentiality obligations.

3.3.5 ARP administration

Filing ARP Forms

The importance of this document, and the prominence that it should hold in a patient's medical record, has been recognised throughout the ARP form's development. As such, it has always been recommended as best practice, that **the current ARP form be filed at the front of the patient's record, in consideration of local practice** (e.g. electronic records). Some Hospital and Health Services (HHS) file voided copies of the ARP under a "legal" section of the patient's record, while others file under an "Advance care planning" divider. This can be guided by local practice, procedures and circumstances.

When a new volume of a medical record is created for a patient and they have a current ARP in place, the active ARP must be transferred to the front of the current volume of their chart. For patients who have multiple active charts, a copy of the ARP can be made for each, so long as it is noted which volume of the patient medical record the original ARP is filed in.

Re-writing an ARP Form

From an administration perspective, re-writing ARP forms does present some minimal challenges that can be overcome by establishing approved local practices and procedures. The first premise is that ARPs should be re-written when new information is required to be entered on the form. Some information that may lead to re-writing an ARP form can be of a major nature, such as changes to the patient's clinical condition, the patient regaining capacity for decision-making or changing their mind about their preferences for resuscitation; and some changes could be considered minor, such as change of a phone number or address, name of substitute decision-maker and inclusion of a tick for an AHD.

While it is recognised that in urgent situations there is not enough time to complete paperwork as attempts are being made to save the life and health of a patient, at the same time, it was never intended for the ARP form to be a quick tick and flick exercise, particularly where there is time to complete the form. The ARP form was intended to be relied upon in acute emergency situations by clinicians who may not have been involved in the assessment of the patient and importantly to guide end-of-life decision-making for some of our most vulnerable patients. Queensland Coroners were involved in the development of the ARP form and have stated they will be looking for the forms during Coronial investigations. While there is no definition of what constitutes major or minor changes, a few matters should be considered by doctors or other health professionals when making amendments to an ARP or writing a new ARP:

- the ARP will represent a piece of evidence before the Coroners Court or other court of law, so therefore needs to be as clear and unambiguous as possible

- if the ARP form becomes uncertain because it is unable to be deciphered or interpreted by an attending team, incorrect actions may occur at the time a decision is required
- if there are too many “amendments”, for example by crossing out, or adding extra detail, the decision-making trail could become confusing and uncertain
- the ARP, which includes changes and voided forms, should “tell the full story” of resuscitation planning for the patient.

Therefore, while there is no “one size fits all” instruction about when to re-write a new ARP, HHSs must use their own discretion taking the above points into consideration and involving other relevant areas within their HHS, such as policy, clinical forms and records, patient safety and death and mortality reviews.

HBCIS and the ARP form

There is no specific mandated field in HBCIS or EDIS to provide an electronic alert to staff that there is an ARP in place for a patient. Alerts are site-specific, and users should check with their HBCIS administrator to determine whether an alert is in place at the facility. While electronic alert systems would be ideal across all HHSs, there are consistently identified issues with these, not the least of which is uniformity. It was believed at the time the ARP was being implemented that these issues were not a first priority.

However, some staff are reporting that they use the HBCIS alert system to notify others that an ARP is in place for a patient. Ideally, an electronic ARP alert would indicate the existence of an ARP, its validity period, and as much information as possible about which treatments and interventions are appropriate for that patient. At the time of publication, a project is underway to develop an electronic ARP for iEMR. The rollout for some HHSs is scheduled for 2017.

If a patient is transferred with an ARP from another facility, the ARP should be reviewed and if necessary rewritten on admission. Review of the ARP should involve reviewing any of the patient’s other advance care planning documents. Where new treatments become available, or a patient’s circumstances change, the patient should be encouraged to update their advance care planning documents, if they have them.

Voiding an ARP Form

Sometimes it may be necessary to void a patient’s ARP form. For example, the form may have been reviewed and require major changes, or the patient may have changed their mind and no longer holds the views recorded on the ARP form. In these situations, the form needs to be clearly marked as a previous, out-of-date version.

To void the form, a doctor should **clearly print ‘VOID’ across the form between two diagonal lines** (see image below). This notation should be signed and dated. Voided ARP forms should be retained on the patient’s medical record. Medical record maintenance is not consistent Statewide, so it is at the HHS discretion to decide the most appropriate place to retain voided forms. Many HHS facilities agree that the ‘Legal’ section of the medical record is an appropriate place to retain voided ARP forms. It is important that voided ARP forms are not discarded as they can inform clinical decision-making and ‘tell the story’ of the patient’s journey through the resuscitation planning process.

The image shows a sample of a Queensland Government 'ACUTE RESUSCITATION PLAN' form. The form is marked 'DRAFT - NOT FOR USE' in large, bold, diagonal letters. It contains sections for patient information, clinical assessment, capacity assessment, and resuscitation management. A signature and date '23/8/10' are visible in the bottom right section.

Patient transfers

The Acute Resuscitation Plan Cover Sheet assists in the information sharing process when a patient is transferred between health care teams and/or facilities. A copy of the patient's ARP form should be attached to the Cover Sheet when the patient is transferred to another health care team or facility. A copy of the ARP coversheet is at [Appendix 10 – Acute Resuscitation Plan \(ARP\)](#).

The Cover Sheet aims to alert staff involved in the transit of a patient, and transfer of their care, that a resuscitation plan is in place. A copy of the patient's 'active' ARP form (valid until a specified future date or valid 'for this and subsequent admissions') should be provided to the receiving health care team or facility. Voided or lapsed ARP forms can also be provided for information purposes. The original ARP must be retained on the patient's medical record in the facility in which it was completed.

The ARP Cover Sheet can also be used to send a copy of the patient's ARP form to external health care professionals, such as their GP, a nursing home, residential aged care facility or palliative care service. Facilities may use this form at their discretion.

If the patient is transferred to another facility (within or outside the HHS) with an 'active' ARP form in place, the doctor responsible for the patient's care at the receiving facility must initiate a new ARP form. When completing a new ARP form, the doctor should verify whether the clinical and other information on the copy of the ARP form is correct. If there has been insufficient time to complete a new ARP form at the receiving facility, the healthcare team may act on its information and clinical instructions based on clinical judgement at the time a decision is required.

If the patient is transferred to a private health facility, the copy of the ARP form is provided for information purposes only. Facilities other than those associated with Queensland Health are responsible for following their own procedures and processes for documenting or acting on resuscitation planning decisions. This includes the Queensland Ambulance Service when the patient is in transit.

3.3.6 Role of healthcare professionals

This section provides Queensland Health staff with information and guidance to understand their role in the decision-making process in resuscitation planning.

In consideration of all the circumstances, unilateral decisions to provide, withhold or withdraw life-sustaining measures should not be made by any single member of a patient's healthcare team. Any decisions made should be through a collaboration between the patient (and/or their substitute decision-maker/s), and members of a multidisciplinary healthcare team. This means that individual clinicians should not undertake resuscitation planning in isolation from either the patient or other members of the healthcare team.

Individual members of the treating team (such as nursing and allied health staff) may have closer or prolonged involvement with the patient and through this contact may have developed a close relationship and be aware of the patient's values and wishes. Other team members may also be more involved in how the patient is psychologically or spiritually coping with illness.

Each member of the healthcare team may bring valuable perspectives and information to the process of planning care and their collaborative involvement should be actively pursued. All treatment decisions for acutely ill patients at the end of life who do have capacity should be made in the context of the provision of good quality care. In discussing resuscitation planning with patients, all health professionals are obliged to adhere to Queensland Health's standards for privacy and confidentiality.

In this very challenging area, it may be that some patients may not wish to discuss treatment options, nor involve some members of their family in discussions about resuscitation planning.

With input from and close collaboration between the multidisciplinary healthcare team, most of the difficult issues such as this can be worked through and resolved with each member of the team bringing their own unique expertise and perspectives.

Doctors

Because of the legal, ethical and clinical nature of the decision-making around providing or withholding and withdrawing life-sustaining measures, doctors are ultimately responsible for the ARP form. The ARP form replaced NFR or DNAR Orders for which doctors have been traditionally accountable over the several decades. Hence, there is little difference in the intent of both 'orders'; both provide instructions about withholding and withdrawing CPR at the time decisions are required where doctors may not be available, such as when a patient suffers a cardiac arrest at 2:00am. Both orders provide clinical authority to act in emergency situations. Where the ARP differs from an NFR Order is in the further detail required, particularly by doctors. The ARP is not simply about what life-sustaining measures will be withheld (for example, no CPR), it also requires information about what other treatments and therapies will continue to be provided. Except in some acute emergency situations, consent to withhold or withdraw life-sustaining measures is required by law; the ARP assists with documenting the consenting pathway during the decision-making process which is required by law. Doctors should be involved at all stages of the resuscitation planning process and this should be documented on the ARP and cross-referenced in the patient's medical record.

In addition, the ARP form requires high-level diagnostic assessment and prognostic expertise, and while sometimes cases may appear straight forward, every patient is different. Therefore doctors should be involved in all decision-making about whether or not to provide CPR, particularly where there is time to do so. Doctors are also responsible to identify patients being 'at risk' of suffering an acute event in the foreseeable future and managing the patient's care through deterioration and worsening of their disease or condition. However, while doctors have a key responsibility for resuscitation planning, completion of the ARP form was also designed for the input of other healthcare professionals. For example, other healthcare professionals can obtain details of the patient's decision-maker/s or locate their AHD, they can also initiate discussions in the context of providing better multidisciplinary end-of-life care for the patient, and support for the patient's family.

Importantly, a completed and current ARP form provides guidance for other members of the healthcare team, and doctors should ensure the form is legible and can be followed at a time when the signing doctor may not be present. By signing an ARP form, doctors are providing clinical authority for other healthcare professionals to act on their advice, when they are not available.

Doctors will also be part of a Medical Emergency Team (MET) should it be appropriate to call for one in the event of a patient's arrest or acute deterioration. Doctors will be responsible for engaging with attending staff, other members of the MET and the patient's ARP form in undertaking the appropriate course of action for that patient.

Decisions to withhold or withdraw life-sustaining measures should reflect good medical practice for the patient at that time and location, based on thorough clinical assessment. However, for patients assessed to have capacity to make decisions about health matters, it is important to recognise they may refuse medical treatment, including life-sustaining measures, even if this results in their death or would cause it to happen sooner. The fundamental rights of patients to autonomous decision-making also means that no one else, not even family members, needs to agree with their decision.

In other words, the decision of a patient who has capacity to refuse medical treatment can be inconsistent with what would be considered good medical practice. This is an area where the tension between patient autonomy and good medical practice requires careful and sensitive discussions, decision-making and thorough documentation. It is also recognised that there is not

always the luxury of time to have such emotive conversations, particularly in more urgent situations. (See [section 4.0 – Ethical considerations](#) for further information about patient autonomy.)

It can be difficult and confronting to initiate resuscitation planning discussions with a patient and/or their substitute decision-maker/s. It is important that these discussions take place at the earliest time practicable to avoid the circumstance of crisis-driven decisions being required at the dying patient's bedside. Doctors are often in the best place to identify patients in the earlier stages of deterioration. Early discussions can also help to ensure that the patient is involved in treatment decisions, and that their wishes are respected at the end of their life. Providing the patient and/or their substitute decision-maker/s Advance Care Planning information may be a useful discussion prompt at this stage. Refer to the [Advance Care Planning Clinical Policy Guidelines](#) for further information about advance care planning.

Nursing professionals

Nursing staff play an integral role in the process of resuscitation planning. Because of their close proximity and ongoing care of the patient, they are in a strong position to prompt doctors to complete an ARP for a patient. Nurses should also be encouraged to participate in planning discussions, as their ongoing relationship with the patient (and those close to them) can provide valuable perspective and guidance in the end-of-life decision-making process.

Nursing staff will also be part of a Medical Emergency Team (MET) should it be appropriate to call for one in the event of a patient's arrest or acute deterioration. It is very likely that it will be a nursing professional who initiates a MET call, having reviewed the patient's ARP and determined that it is appropriate to do so.

Should attending nursing staff initiate a MET call, they will engage with other attending staff, other members of the MET (including other nursing professionals) and the patient's ARP form in carrying out the appropriate course of action for that patient.

Nursing staff may also be responsible for ensuring other documentation that may be associated with an ARP is current and appropriately filed. Such documentation may include a certified copy of the patient's AHD.

Should the patient be transferred to another facility or discharged, nursing professionals may also be required to oversee or organise this process. An [ARP Coversheet](#) is available to accompany copies of a patient's ARP form, which may be sent to the patient's GP or (for example) residential aged care facility.

Allied health professionals

Allied Health professionals, such as social workers and psychologists, will often develop a close and ongoing relationship with a patient (in both inpatient and outpatient settings). They may provide ongoing care to the patient, and should be encouraged to participate in resuscitation planning discussions as appropriate.

Allied health professionals can be in a strong position to understand a patient's base-level functionality which affords insight into that person's best interests. They may also be in a position to understand the family dynamics and how that might impact on other end-of-life decisions, such as care arrangements and the interaction of other lifestyle factors.

Community liaison officers may assist with Aboriginal and Torres Strait Islander patients. Contacts with community organisations for multicultural and spiritual guidance may also involve allied health professionals.

Administration officers, patient safety and health management information staff

While it is not appropriate to engage administrative and health information management staff in end-of-life planning discussions, these officers play an important role in the administrative management of the patient's medical record and information.

Ward reception staff, for example, may be tasked with filing a patient's ARP form – of which its location at the front of the chart is imperative. Nursing and other attending staff seeking guidance on whether or not to initiate a MET call will rely on the patient's ARP form being located where it should be, as the form is designed to be immediately accessible in an emergency.

Administration officers may also be tasked with ensuring other documentation associated with the ARP is correctly filed in the patient's record. For example, ensuring a certified copy of a patient's AHD or any changes to a patient's decision-maker are accurately filed in the patient's chart.

Other administrative and health information management officers (such as coders and medical record department staff) may be involved in the management of a patient's chart. These staff members will need to be aware of the appropriate way of managing both current and voided ARP forms, often between multiple volumes of medical records. Patient safety staff can be involved in reviews of ARPs for a variety of reasons, including death reviews. Patient safety staff may also be asked whether or not it is appropriate to re-write an existing ARP form, for example on the grounds that there are too many amendments to the original form, making the form illegible and/or unclear to be followed.

3.3.7 Resuscitation planning, the ARP and surgery

Ordinarily, resuscitation efforts do not require consent from a patient or their substitute decision-maker, because they are deemed to be emergency interventions. Current Queensland Health policy is that there should be a presumption in favour of resuscitation where there is no time to properly assess the appropriateness of resuscitation and no prior decision or consent has been obtained. Clinical judgement underpins action taken in these situations. However, if there is time to obtain a decision from a patient or their substitute decision-maker to the provision of potentially life-saving measures, or to withholding or withdrawal of what would otherwise be life-sustaining measures, then the law requires a decision to be sought (the source of this is the common law for patients with capacity, and *Powers of Attorney Act 1998* and *Guardianship and Administration Act 2000* for patients with impaired capacity). This forms the basis of good medical practice (which requires adherence to clinical and ethical standards) and the legal expectation of "informed" consent.

Planned surgery would be an example of time being available to obtain consent, compared with unplanned emergency surgery. Prior to elective surgery taking place, surgical and anaesthetic consent is obtained from the patient or their substitute decision-maker, and in Queensland Health at least, consent forms include a statement to the effect that the doctor has explained to the patient that "if immediate life threatening events happen during the procedure, they will be treated accordingly." This implies that, in the operating theatre, healthcare professionals will act in accordance with usual practice and attempt resuscitation, if required. The consent form, as signed by the patient or their substitute decision-maker, then forms part of the evidence that informed consent has been obtained to the surgery, the anaesthetic approach (which, in itself, involves "resuscitation" measures), and any more emergent resuscitation efforts required in surgery or in post-operative care.

From late 2009, ARPs replaced NFR orders in patients' charts in Queensland's public hospital system. One of the initiative's key drivers, based on at least two controversial Coronial Inquests around the time,¹⁶⁵ was to improve compliance with the legal framework around end-of-life decision-making, and in particular, to ensure that:

- resuscitation planning commences earlier to avoid decisions being made in a crisis

- greater attention is paid to communicating effectively with patients and their families, and
- clearer documentation of the decision-making pathway is recorded in patients' medical record, as required by law.

The completion of an ARP is indicated for a patient at risk of cardiac or respiratory arrest in the foreseeable future. Particular consideration should be given to completion of the form for adult patients who are terminally ill or who are expected to die within 12-24 months, where an arrest would be directly connected to the disease trajectory.

The ARP is a medical order and clinical tool which forms part of the documentation process of resuscitation planning for a patient, and is to be used in conjunction with discussions with other members of the healthcare team about treatment and care options as well as conversations and consent discussions with patients and their family/decision-makers. In some instances, surgery will be indicated for certain patients with ARPs stating that no CPR is to be provided (keeping in mind that the ARP allows for clear guidance, in free text, as to measures that should be provided, and those that should not, in the event of an arrest). However, there exist a number of scenarios of palliative procedures where a patient may have an ARP indicating no CPR, for example deflation of distended proximal bowel from rectal cancer or repairing a fractured (neck of femur) NOF as a palliative measure, to enable treatment in the ward and transfers without pain until death occurs. Such issues may cause tension between the consent obtained for a surgical procedure, together with standard anaesthetic practice, which assumes that resuscitation will be attempted; and the clinical indications and patient wishes expressed in an ARP (e.g. where a terminally ill cancer patient and clinician feel there is no benefit from active CPR efforts).

Issue

Given the intimate relationship between the practice of anaesthesia and resuscitation itself, it can present challenges for an anaesthetist to know whether to provide even routine anaesthetic care if all procedures that are generally considered as "resuscitation" measures are not to be provided or there is some confusion. Some of the literature supports this view, in that some anaesthetists may feel that anaesthetic practice supports suspension of 'not for resuscitation' orders, for three reasons:^{166 167}

1. Any patient who agrees to an surgical procedure also agrees to a series of interventions, including the administration of anaesthesia, that is hoped will lead to a desirable benefit. The use of general anaesthetic involves the deliberate depression of vital systems followed by their resuscitation. Separating the administration of anaesthesia from resuscitation is therefore difficult and somewhat artificial.
2. There is a difference between a cardiorespiratory arrest that occurs spontaneously and one that results from a therapeutic intervention (with CPR rarely being effective in the case of the former, with the latter much more likely to be reversible).
3. Every anaesthetic agent promotes some degree of cardiovascular instability, and administration of these agents often involves a delicate balance between anaesthetic goals and cardiovascular collapse. If deprived of the flexibility to move between different techniques, the anaesthetist may have to favour less anaesthesia and greater hemodynamic stability.

The literature also reveals it has been suggested that surgeons are reluctant to comply with 'not for resuscitation' orders because their interventions are the most visible and their therapeutic expectations the most specific, and that deaths occurring in the midst of a medical procedure are generally viewed as bad outcomes.¹⁶⁸

Preferred position

Queensland Health's preferred position about ARPs and surgery is summarised as follows:

- It is not clinically appropriate to have a blanket policy that ARPs apply or do not apply in the surgical context. The better position for the treating team to take is one based on a case-by-case approach, which would require clinicians to:

- CONSIDER the ARP's status in the surgical context, prior to surgery occurring
- DISCUSS the anaesthetic/ surgical issues with:
 - the treating doctor who completed the ARP
 - the patient and/or their substitute decision-maker/s (including how the patient's condition might influence anaesthesia, risks particular to the patient, what the anaesthetist is able to do or adjust clinically based on the patient's wishes and expected outcomes)
- DECIDE with the patient or their substitute decision-maker how the ARP will apply in the operating theatre and in the post-operative recovery period (see below for suggestions from the United States)
- DOCUMENT the discussions and decision in the patient's medical record (and/or on the ARP and surgical consent form, if appropriate). It may also be appropriate to consider the completion of a new ARP at that time and to void the current one.
- Proposed surgery should not automatically void an ARP. Considering the status of the ARP prior to surgery will help to determine what is in the best interests of the patient in the circumstances. It may not always be appropriate to convince the patient or their family that suspension of the previously accepted approach is the only option.

There are a number of bodies of opinion which support the above approach. In the United States, surgeons and anaesthetists have reached the view that automatic suspension of DNR orders cannot be justified for patients who require a surgical procedure. Recent guidelines published by the American College of Surgeons (ACS)¹⁶⁹ and the American Society of Anesthesiologists (ASA)¹⁷⁰ in relation to the care of patients with 'do not resuscitate' orders. The ACS expects surgeons to take a leadership role in these situations and to adopt a policy of "required reconsideration" of previous advance directives, including discussion and documenting of the approach to be taken in relation to the proposed operation. The ASA focuses on communication with patients and between clinicians, as well as documentation, and review of DNR orders and advance directives. It states that "policies automatically suspending DNR orders or other directives that limit treatment prior to procedures involving anaesthetic care may not sufficiently address a patient's rights to self-determination in a responsible and ethical manner." Part of the guidelines also deals with dispute resolution.

Of interest are the three suggested approaches by the ASA following review:

1. Full attempt at resuscitation.
2. Limited attempt at resuscitation defined with regard to specific procedures, e.g. patient may continue to refuse chest compression and defibrillation but agree to other measures (the anaesthetist should inform the patient which resuscitation measures are essential to the success of the procedure)
3. Limited attempt at resuscitation defined with regard to the patient's goals and values, i.e. allowing the surgical/anaesthetic team to use clinical judgment in determining which resuscitation measures are appropriate in the context of the situation and the patient's goals/values.

While there is some debate in the literature around the merits and practical applicability of these options, almost all agree that a collaborative approach is required. The ASA also makes it clear that plans for post-operative care should clearly indicate if or when the original DNR or directive will be reinstated, and suggests some resolution processes where anaesthetists do not agree with the patient's decision (e.g. conscientious objection, raising of concerns regarding good medical practice).

Specific guidance on this issue in Australia from professional bodies includes that from the Australian and New Zealand Intensive Care Society (ANZICS), which recently published guidelines on end-of-life decision-making, incorporating resuscitation management plans.¹⁷¹ The ANZICS guidelines promote a collaborative approach to all aspects of care at the end of life, including 'individualising' a patient's resuscitation plans. The Australian and New Zealand College

of Anaesthetists (ANZCA) Code of Professional Conduct and Professional Standards (e.g. PS38 and PS26),¹⁷² support the importance of discussing the impact of a 'not for resuscitation order' in the context of proposed surgery; there is specific reference to the entitlement of capable patients to know the implications of any proposed treatments and to refuse treatments, even where they may be life-saving and/or best medical practice. Similarly, the Royal Australasian College of Surgeons (RACS) Code of Conduct is based on longstanding ethical and professional principles and reflects community expectations that patients are entitled to feel that their views are listened to and to expect openness, honesty and empathy from their treating surgeon.¹⁷³

A blanket revocation of ARPs is not justified for patients presenting for elective surgery. It is recommended that a review of the ARP consider the current circumstances and involve the patient, their substitute decision-maker, the treating surgical team, and other members of the multidisciplinary team, as appropriate. An active ARP does not exclude the provision of other medical interventions and may be compatible with palliative surgical procedures to provide pain relief. In situations where surgery is likely to be planned, the ARP should be reviewed as to its appropriateness should a cardiorespiratory instability arrest occur under anaesthesia. It may be considered in individual cases that cardiorespiratory instability during anaesthesia is readily reversible compared to cardiac arrest from disease progression. Resuscitation may be appropriate but whether the 'NO CPR' checkbox on the ARP remains or is temporarily suspended during anaesthesia, should be discussed with the patient or their substitute decision-maker prior to surgery and clearly documented.

Who is responsible for the ARP/surgery discussion?

There is some debate about whether the treating doctor, the surgeon or the anaesthetist should be discussing the status of a patient's ARP with the patient or their substitute decision-maker/s. This should largely depend on local practice, as each facility can make its own procedures in this regard. However, it would be a problem if each clinician believed that one of the others was assuming responsibility, and no discussions occurred. At the very least, the preferred approach would be a discussion involving the treating doctor (e.g. oncologist) and the surgeon with the patient/family/substitute decision-maker.

What if the patient's wishes differ from those of the treating doctor or surgical team?

On the ARP form, ideally Section 3 – Resuscitation management plan and Section 4 – Patient choices, should agree. There will, of course, be times when there is disconnect, especially if a patient objects to the withholding or withdrawal of life-sustaining measures against the clinical judgement of the doctor, adding a further layer of complexity. A doctor may think it appropriate to provide CPR in certain circumstances but the patient will not consent to this. Further information about the effect of objections can be found in [Section 1.6 – objections to providing or not providing](#). The Quick Guide attached to the ARP provides some dispute resolution approaches in this situation, and the expectation is that the ARP has been completed with time to take steps to resolve any potential for conflict (rather than waiting for emergency situations). If not resolved before surgery is considered, this disconnect will need to be resolved as part of the discussions about resuscitation in surgery.

What if the patient has an Advance Health Directive (AHD) refusing CPR?

A patient may not only have an ARP which states that the patient is not to be provided with CPR; they may also have a valid AHD which refuses CPR and/or other life-sustaining measures. This should have been noted in the ARP and the hospital should have a certified copy of the AHD in the hospital records.

The AHD can only apply in certain clinical circumstances if the direction it contains is to withhold life-sustaining measures (e.g. terminal illness and the patient is expected to die within 12 months) and it may be overridden by a doctor if the direction is uncertain or against good medical practice. As with the ARP, if the hospital is aware that the patient has an AHD, then planned elective surgery is an opportunity to revisit the terms of the AHD. If the surgery is required urgently, and it

is known that the patient's AHD refuses CPR, a clinical judgement as to the benefits and burdens of resuscitation attempts will need to be made at the time the patient's condition deteriorates. It is important to remember that the AHD is the patient's document with legal effect, and not a clinical tool like the ARP. If the patient has capacity and wishes to revoke part of the AHD, this must accord with legal requirements, which should be done in writing. The situation may become more complex if the patient has lost capacity, and a substitute decision-maker is trying to assess what the patient may have wanted in the circumstances, and weigh this against medical advice and what is in the patient's best interests.

Informed consent policy and consent forms

Following implementation of the ARP, and after discussion with the Patient Safety Unit, the Informed Consent policy and all relevant consent forms were amended to provide for patients (or their substitute decision-maker/s) acknowledging that they will be "treated accordingly" if an immediate life-threatening event happens during surgery:

"I acknowledge that the doctor has explained : ... if immediate life-threatening events happen during the procedure, they will be treated based on my discussion with the doctor or my Acute Resuscitation Plan."

For the majority of patients who will be undergoing surgery (who would clearly wish to be resuscitated and to have a successful outcome from their surgery), the reference to the ARP will not be relevant and should not alarm. The intent of this change was to trigger discussion of the issue with any patient with an existing ARP, prior to signed consent being obtained, to ensure that the appropriate resuscitation approach is taken during/post-surgery. This should mean that risks are explained and the patient and/or their family, in consultation with the treating healthcare team, makes an informed decision about resuscitation and the applicability of the ARP in the surgical context. A new ARP should be prepared, or notes made in the patient's medical record, to reflect the outcome of the discussions.

If a patient or their family continues to insist that they would not want resuscitation attempts during surgery, inconsistent with the surgical team's view of good medical practice and its duty of care. The recommended means of addressing this is as follows:

- the surgeon may ultimately accept that to resuscitate would be inconsistent with good medical practice for this particular patient, and they respect the decision of the patient, if they have capacity, or their substitute decision-maker if the patient does not have capacity (and they document the decision, with associated legal protection for their actions)
- the surgeon or the patient's treating doctor encourages the patient to complete an AHD if they feel strongly about not being resuscitated (and the surgeon abides by the patient's clear directions and the law in this area, with associated legal protection for their actions)
- the surgeon waits to see what happens in surgery and makes a clinical judgement in an emergency if the patient arrests (although this carries risk given the prior knowledge of the patient's wishes)
- the surgeon could tell the patient that it is a tenet of their practice to resuscitate, and that patient might have to get surgery elsewhere (conscientious objection)
- the surgeon seeks a second opinion or refers the matter to management for dispute resolution
- if the patient loses capacity, the surgeon contacts the Public Guardian in relation to the decision made by the patient's substitute decision-maker (if the surgeon is concerned that the substitute decision-maker is not acting in the patient's best interest, in breach of the Health Care Principle).

For the reasons above, it would not be appropriate to simply state, from a policy perspective, that the ARP does or does not apply to procedures requiring some form of anaesthesia. As suggested above, planned surgery should trigger review of the patient's ARP and its applicability in the surgical context. The natural consequence of this being that the ARP's

status should be reviewed for each surgical procedure, and subsequently documented in the patient's medical record, with consideration given to creating a new ARP, if this is appropriate.

Surgical Procedures and the ARP (Johari Window)

	EMERGENCY (Not planned)	NON EMERGENCY (Planned)
ARP	<ul style="list-style-type: none"> - The ARP is NOT automatically suspended - The ARP could be evidence of an objection to urgent health care being provided (i.e. patient may not want surgery or resuscitation attempts being made) - If ARP indicates PROVIDE CPR: <ul style="list-style-type: none"> o resuscitation attempts during surgery appropriate - If ARP indicates DO NOT PROVIDE CPR: <ul style="list-style-type: none"> o assess circumstances at the time o exercise clinical judgement o IF TIME, resolve with surgical team whether resuscitation attempts appropriate o document decision-making pathway, e.g. reasons why directions in ARP not followed during surgery o be prepared to STAND BY the decision - If ARP requires dispute resolution (unresolved disparity between Resuscitation management plan and patient wishes) USE CLINICAL JUDGEMENT based on circumstances. 	<ul style="list-style-type: none"> - Assumed time available - Discuss OVERALL TREATMENT PLAN with patient/substitute decision-maker (SDM), including: <ul style="list-style-type: none"> o risks of anaesthesia o if resuscitation should be attempted during surgery o whether the ARP should be suspended for the surgical procedure o if strong views, encourage completion of an AHD - Obtain consent for surgery from patient/SDM - Case conference between treating doctor and surgical team discusses: <ul style="list-style-type: none"> o risks to patient during and after surgery o patient/SDM views about resuscitation attempts during surgery - If ARP indicates DO NOT PROVIDE CPR and anaesthetist default position is to resuscitate, this will need to be resolved.
NO ARP	<ul style="list-style-type: none"> - Assess circumstances at the time - Exercise CLINICAL JUDGEMENT - IF TIME, resolve with surgical team whether resuscitation attempts appropriate - IF TIME, obtain a second opinion from a more senior colleague - Document decision-making pathway, e.g. reasons why resuscitation provided - Be prepared to STAND BY the decision. 	<ul style="list-style-type: none"> - Assumed time available to assess patient's condition and determine prognosis - Treating doctor assesses whether appropriate for patient to have ARP - Discuss OVERALL TREATMENT PLAN with patient/SDM, including: <ul style="list-style-type: none"> o risks of anaesthesia o if resuscitation should be attempted during surgery o if patient has strong views, encourage completion of an AHD or EPOA - Case conference between treating doctor and surgical team discusses: <ul style="list-style-type: none"> o risks to patient during and after surgery o patient/SDM views about resuscitation attempts during surgery - Obtain consent for surgery from patient/SDM.

3.3.8 Test your knowledge: ARP Quiz

Please select only one answer for each question

1. The ARP form removes the need for difficult discussions with patients or their substitute decision-maker/s about the patient's prognosis and treatment options.

True
False
2. The completed ARP form requires documentation of a capacity assessment of the patient.

True
False
3. Resuscitation planning should be undertaken with:

A. All patients with chronic conditions.
B. Patients who are reasonably at risk of suffering an acute event in the foreseeable future.
C. Everyone, regardless of age or health.
D. Only the family of patients who are very ill.
4. A patient's ARP form must be filed at the front of their medical record.

True
False
5. The original of the ARP form must go with the patient if they move to another health care facility.

True
False
6. A patient needs to sign their ARP form before it could be acted on, because otherwise it is not able to demonstrate that their consent to provide or withhold treatment has been obtained.

True
False
7. An ARP form should be completed for every patient on admission.

True
False
8. Dr Brown has a patient for whom resuscitation planning is appropriate, so he initiates an advance care planning conversation with the patient. Dr Brown is of the opinion that it would be good medical practice not to provide CPR to the patient and communicates this to them. However, the patient has requested that Dr Brown must "do everything possible". What should Dr Johnson do in these circumstances?

A. Agree with the patient and indicate on their ARP form that CPR is to be provided.
B. Disagree with the patient and indicate on their ARP form that CPR is not to be provided.
C. Document the discrepancy on the ARP form and involve all members of the health care team to facilitate a resolution.
D. Talk to the patient's substitute decision-maker instead.

9. Helen is a nurse at a hospital. A patient presents with complications associated with end-stage chronic kidney disease. The patient tells Helen that they have “had enough”, and no longer wish to be on dialysis. There is no evidence in their medical record of any previous advance care planning or discussions about resuscitation planning (i.e. an ARP form). What should Helen do?
- A. Tell the patient that they must continue with dialysis because that is what the doctor decided.
 - B. Get the doctor-in-charge to discuss with the patient what treatment they wish to receive. The doctor then needs to complete an ARP form for them.
 - C. Continue discussing with the patient why they don't want to receive dialysis, and then record the conversation on the ARP form.
 - D. Don't tell anyone about the conversation because if the patient doesn't want dialysis, they won't be given other treatments either.
10. A patient with dementia is in the care of Dr Orange. The patient does not have capacity, but has a substitute decision-maker (her daughter). The patient's daughter says that the patient told her she didn't want active treatment if she could no longer look after herself. Dr Orange is suspicious because the patient appears to be happy, in no pain, and in Dr Orange's opinion, has at least another 3 years to live. What should Dr Orange do?
- A. Take the substitute decision-maker's word and document 'not for CPR' on an ARP form.
 - B. Document that the patient is 'for CPR' on the ARP form because the clinical decision is more important than agreement.
 - C. Decide not to write an ARP form for the patient and rely on clinical judgement if the patient arrests.
 - D. Refer the matter to the Office of the Public Guardian because the substitute decision-maker is not acting in accordance with the *General Principles* and the *Health Care Principle*.

Answers to ARP Quiz

1. False
2. True
3. B. Patients who are reasonably at risk of suffering an acute event in the foreseeable future.
4. True
5. False
6. False
7. False
8. C. Document the discrepancy on the ARP form and involve all members of the health care team to facilitate a resolution.
9. B. Get the doctor-in-charge to discuss with the patient what treatment they wish to receive. The doctor then needs to complete an ARP form for them.
10. D. Refer the matter to the Office of the Public Guardian because the substitute decision-maker is not acting in accordance with the General Principles and the Health Care Principle.

Clinical Considerations – Summary Points

General

1. Doctors are expected to base their practice of medicine on some fundamental principles, including: integrity, truthfulness, fidelity, compassion, confidentiality, patient-centeredness, communication and clinical judgement. The key object of the practice of medicine is to serve the best interests of the patient.
2. All members of the healthcare team are obliged to consider the patient as a unique individual.
3. Where doubt exists over a diagnosis or prognosis, advice should be sought from a senior clinician with experience of that condition before making decisions about withholding or withdrawing life-sustaining treatment.
4. Treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to withdraw treatment which has been initiated.

Good medical practice (clinical considerations)

5. A code of conduct for doctors from the Australian Medical Board on meeting the standards of good medical practice also states that the doctor-patient relationship should be based on qualities such as respect, openness, trust and good communication in order to build effective and trusting partnerships with patients and their families.

Cardiopulmonary resuscitation

8. Where no explicit decision has been made in advance, there should be an initial presumption in favour of CPR.
9. Decisions about CPR must be made on the basis of an individual assessment of each patient's case.
10. The benefits of prolonging life with CPR must be weighed against the potential benefits or harms that could potentially be caused to the patient.
11. Before making treatment plans about CPR, all efforts must be made to contact those closest to the patient, and/or the patient's substitute decision-maker. If this is unsuccessful, the Office of the Public Guardian should be contacted, as circumstances permit.
12. Ensuring that a decision about whether or not to provide CPR is made in advance is preferable to making decisions in a crisis.

Artificial hydration and/or artificial nutrition

13. Consent is always needed to withhold and withdraw artificial hydration and nutrition.
14. Patients with capacity are not obliged to justify their decision to refuse artificial hydration and/or nutrition, but health professionals should try to ensure that they understand the implications of their refusal.
15. It is not considered suicide to refuse artificial nutrition and hydration.

Assisted ventilation

16. If a patient lacks capacity, consent will be needed from the substitute decision-maker/s before making treatment decisions regarding withholding or withdrawing artificial ventilation.
17. In acute emergencies, consent to provide oxygen to a patient who lacks capacity would not be required, unless the patient has (at a time when they had capacity) expressly refused to accept artificial ventilation.

Blood transfusions

18. Where medical treatment such as a blood transfusion is given against the decision of an adult with capacity, it potentially constitutes assault.
19. Queensland Health has a consent form ([available on QHEPS](#)) for blood transfusions that must be completed before giving a blood transfusion to an adult patient. This will apply to a patient if they have capacity or their substitute-decision-maker if they do not.

4.0 Ethical Considerations

4.1 Introduction

End-of-life treatment and care has always been prominent within the subject of clinical ethics. As discussed previously, around 30 per cent of hospital inpatients are in the last year of life. Yet this is only part of the picture; of the almost 30,000 people who died in Queensland, over half died in hospital. The vast array of literature about end-of-life care and new techniques to manage dying patients should equip the health professional, but instead, there are sometimes mixed messages, often leaving doctors, other healthcare professionals and the public confused.¹⁷⁴ Some of this confusion may be explained by the ways in which the meaning and value of death have changed in contemporary society, also the rapid expansion of available medical technology coupled with the emergence of increasingly active patient advocacy for those without capacity, has caused end-of-life decision-making to become one of the most vexed areas in medicine. Regardless of whether a dying patient has capacity for decision-making, there will be profound complexity about the decision to withhold or withdraw life-sustaining measures, even if the patient has formally expressed their wishes.

Queensland Health acknowledges the tension across the three major themes in the ethics of withholding and withdrawing life-sustaining measures - the sanctity or preservation of life (government knows best), patient autonomy (patient knows best) and good medical practice (doctor knows best). Incorporating ethics considerations into decision-making for patients at the end of life enables reflection upon what is good for a patient, what is in their best interests and how we might balance this with the best interests of other patients. While the principles of ethics are the same in adult end-of-life care as in other fields of medicine, how the principles are applied for the dying can have differences. For example, patients may come to harm when the term 'end of life' is used vaguely for those who are dying. It is important clinically and ethically to be clear about what this means to a patient and their families.¹⁷⁵

This part of the guidelines concerns ethical perspectives of end-of-life decision-making. Legal and clinical considerations are contained in earlier sections and all three elements are equally important in decision-making at the end of life; ignoring or playing down any one of these critical components has the potential to increase the complexity, and therefore risk in end-of-life decision-making. The considerations contained in this section of these guidelines are just that. There is no mandated approach that governs an ideal ethical approach. Often this is a complex interplay of experience, personal convictions, those involved and the situation itself. Therefore, the ethical considerations offered are designed to provoke critical thinking about the issues rather than offer simple algorithms for some of the most complex decision-making in health care.

From the literature, there are four often-quoted bioethical principles that provide an accepted framework for medical decision-making and communication with patients:¹⁷⁶

1. **Autonomy:** respect the right of a person to make their own decisions about their own health and future. Respect for autonomy is a component of respect for human dignity.
2. **Beneficence:** the duty to do the best for the person or to act in their best interests – i.e. undertake actions that are intended to benefit the patient (to do good)
3. **Non-maleficence:** the duty to do no harm to patients or others
4. **Justice:** incorporates the notions of equity and fair distribution. The ethical principle emphasises that health professionals have responsibility to the wider community as well as to individual patients.

These principles support ethical clinical practices including:

- Providing necessary pain relief based on the patient's individual clinical need.

- Withholding or withdrawing life-sustaining measures that are no longer effective or that do not benefit the patient; including any treatment the patient has refused.
- Complying with a patient's end of life wishes, including those expressed in an AHD.

4.2 Ethical Principles and Concepts

A brief discussion of the four accepted bioethical principles - autonomy, beneficence, non-maleficence, and justice is provided to enable an ethical context for considerations about decision-making for patients at the end of life.

4.2.1 Respect for autonomy

Autonomy is a concept that has far broader application than bioethics – it is the value that liberal democracies place on individuals controlling their own lives.¹⁷⁷ Autonomy is paramount for patients who possess decision-making capacity, but it is also a major consideration for patients who do not have capacity to make decisions about their health care. Respect for autonomy also extends to family members and legal substitute decision-makers who make decisions on behalf of the person who lacks capacity. According to traditional bioethical analysis, the centrality of the individual in contemporary Western society requires that adults be permitted to make their own decisions about what medical treatment they want and do not want. To do otherwise would be an inexcusable invasion of individuals' interests in bodily integrity and in charting their own life plan in accordance with their own values, preferences, and interests.

To be autonomous requires a person to have the capacity to deliberate a course of action, and to put that plan into action. Respect for autonomy in the end of life area also requires acceptance of a person's decision with which the health professional may not necessarily agree with. This concept is associated with the right of people to make decisions about refusing medical treatment, even if that would cause their death or make it happen sooner. In providing optimum care and treatment for a person facing end-of-life decisions, health professionals should do their best to advocate for a patient's rights, including their right to make decisions with which not everyone agrees.

The principle of personal autonomy has become a key concern of modern society, and in the health context is associated with enabling patients to make their own decisions about which health care treatment they will or will not consent to.

'[A] patient's unequivocal right to refuse medical treatment is well established and is ethically justified by the principle of autonomy, according to which people have a right to self-governance, to act freely in accordance with a self-chosen plan. Control over our body has been taken to be central to the interpretation of autonomy. In the context of end-of-life care, the right to refuse treatment places a recognised limit on interventions by doctors, who must respect refusals even against their best clinical judgement and even if a patient's life is at risk as a result.'¹⁷⁸

Just as respect for patient autonomy cannot be interpreted as an entitlement for patients and their families to receive every requested medical intervention, a doctor is not obliged to secure patient consent to the withholding or withdrawal of futile or inappropriate treatment which is not clinically indicated. Thus, the concept of informed consent has greatly influenced the ethical debate about respect for autonomy. This idea has led many to propose that a better approach to assuring patient autonomy is to adopt 'shared decision-making' – which includes considering factors such as adequate time to make decisions, an environment that is not perceived as threatening or hostile, and the presence of adequate social support.¹⁷⁹

Health professionals should always be mindful of their obligations and the ways in which the patient's legal and ethical rights should influence their decision-making. Decision-making about life-sustaining measures sometimes sees an ethical collision between patients' rights, community

expectations and the clinical obligations of the health care team. Every effort must be made to demonstrate that there is a balance between the duties and the obligations imposed by those rights and responsibilities, and reasonable and proportionate decisions based on ethical principles can be reached in every case.

4.2.2 Beneficence

The goal of medicine is to promote the welfare of patients, and health professionals possess skills and knowledge that enable them to assist others. Beneficence is defined as active well-doing, altruism, or conduct aimed at the good and well-being of others. Beneficence is action that is done for the benefit of others.¹⁸⁰ Beneficent actions can be taken to help prevent or remove harms or to simply improve the situation of others. Doctors and other health professionals are expected to first do no harm, but they also have an obligation to help their patients. Ethicists often distinguish between obligatory and ideal beneficence. Ideal beneficence comprises extreme acts of generosity or attempts to benefit others on all possible occasions. The strong tradition within Western medicine suggests that health professions should do all that is within their power to benefit patients.

However, the principle of beneficence requires that health care professionals provide both appropriate treatment and an assurance that treatment will not result in more harms than benefits. Advances in medical technology that manifests in invasive burdensome interventions where this treatment is not clinically indicated could be seen to violate the principle of beneficence if the patient ends up in a far worse condition than before the medical treatment was instituted. Care should be exercised when using the principle of beneficence to justify recommending clinical treatment for a patient as a patient's autonomy could be overridden by paternalistic approach to decision-making (i.e., 'doctor knows best').¹⁸¹ Therefore, a collaborative approach to decision-making around the benefits of recommended treatment should feature in all decision-making around end-of-life care.

In health care, the tension between the ethical principles of beneficence and non-maleficence are particularly apparent in decisions regarding commencing risky treatments or withdrawal of measures that are no longer thought to be beneficial.¹⁸²

4.2.3 Non-maleficence

Non-maleficence is the principle of refraining from causing unnecessary harm, summed up by the famous saying: '*primum non nocere*' – first do no harm. Although some medical treatment may cause pain or harm, non-maleficence refers to the moral justification behind why some harm is acceptable in the context of providing optimal care for the person. If the act is for a greater good for the patient and will improve their overall health and well-being, it is justifiable. For example, doctors should not offer or provide medical treatments that are not clinically indicated, would not benefit the patient and would cause them harm. In other words, health professionals must not do anything that would deliberately harm patients without the action being balanced by proportional benefit. Because many medications, procedures, and interventions cause harm in addition to benefit, the principle of non-maleficence provides little concrete guidance in the care of patients. Where this principle is most helpful is when it is balanced against beneficence. In this context, non-maleficence the risks of treatment (harm) must be considered in relation to the potential benefits. Ultimately, the patient or their decision-maker if the patient lacks capacity, must be sufficiently informed to decide whether the potential benefits outweigh the potential harms.

The potential benefits of any medical treatment and care must outweigh the risks in order for the action to be ethical.

4.2.4 Justice

Justice is the principle that governs social fairness and access. The word 'justice' suggests concepts such as fairness, rightness and equity. In the context of health care, the principle of justice involves determining whether someone should receive or is entitled to receive a health care resource. As with the other bioethical principles, the concept of justice covers a broader spectrum than health care:

Justice is the first virtue of social institutions, as truth is of systems of thought. A theory however elegant and economical must be rejected or revised if it is untrue; likewise laws and institutions no matter how efficient and well-arranged must be reformed or abolished if they are unjust. Each person possesses an inviolability founded on justice that even the welfare of society as a whole cannot override. For this reason justice denies that the loss of freedom for some is made right by a greater good shared by others. It does not allow that the sacrifices imposed on a few are outweighed by the larger sum of advantages enjoyed by many... an injustice is tolerable only when it is necessary to avoid an even greater injustice. Being first virtues of human activities, truth and justice are uncompromising.¹⁸³

Arguably, because of unrealistic expectations about the benefits of technology and medical advancement, death can all too often be seen as a failure of the health system, rather than a natural and inevitable part of life. A life cannot be prolonged indefinitely, and to assist patients and their families to accept the inevitability of death is one of the most difficult challenges for health care professionals. That new medical treatments and technologies are available has increased requests for such treatments, especially at the end of life.¹⁸⁴ However, as some observe, within the context of health care, it is clear that basic ideas of justice are not applied equally. Equity of access to the health system is not the same for all, irrespective of whether a person lives in Queensland or elsewhere in the world. Disparities in relation to access exist within certain groups, such as Indigenous Australians, the elderly, and people living with disabilities. Thus, the principle of justice is also related to the notion of resource allocation and health care, discussed later in this section.

4.3 Patients' right to know and choose

As discussed, the principle of patient autonomy is critical in end-of-life decision-making. It is a general principle of law and medical practice that people have a right to consent to or refuse medical treatment. The courts have recognised that adults have the right to say in advance that they want to refuse treatment should they lose capacity in the future – even if this results in their death. 'In contemporary ethics, the principle of autonomy asserts that humans have a right to non-interference when making decisions about themselves.'¹⁸⁵

In some cases, a patient may have expressed a refusal of all treatment. These wishes must be taken into consideration at the time a decision is required. For a patient without capacity, their wishes to refuse all or some forms of treatment may be ascertained in four ways:

1. Formally, through their valid Advance Health Directive.
2. Informally, through a family member or close friend.
3. Through previous discussions with a doctor responsible for the patient's treatment.
4. Through previous discussions with the patient's General Practitioner.

Within this framework, all patients facing end-of-life choices have a right to be informed about their condition and their treatment options in an open, honest and compassionate manner. This includes the patient's family or substitute decision-maker where the patient lacks capacity for decision-making. Ideally, discussion with families about treatment options for a patient will have occurred before the patient loses the capacity to determine their end-of-life views and wishes. Uncertainty about prognosis or likely response to treatment should be communicated to the patient's family (preferably in non-technical language) as early as possible. Where possible, prognostic information should be given by a health professional who is respected as an expert,

palliative care health professional, or doctor with experience in discussions with dying patients and their families.

However during these discussions, the doctor responsible for the patient's care is under no obligation to disclose or offer treatments that for clinical reasons can never be provided - that is, treatments that, for reasons of good medical practice will be potentially futile and of no benefit to a dying patient. Discussing options for medical treatments with a patient's family is an exceptionally difficult and emotion-charged time, particularly when choices are limited. Disclosing medical treatments that cannot be clinically offered to a dying patient would be considered counter-productive, confusing and distressing, not only for the patient but also for the patient's family.

4.4 Respecting and following patient choices

Respecting a patient's choices begins with the very first discussions held between a patient and members of the health care team. Ideally, the doctor in charge of the patient's care should play a coordinating role for the patient's end-of-life care, which is an important factor in meeting the standards of good medical practice. Though in practice, it is also recognised that this may not always be possible.

The patients' beliefs and values will influence their end-of-life choices and, therefore, must always be respected. Every patient experiences spiritual and/or religious feelings in a unique way. Some may directly raise these issues, whereas others may not discuss them, but may be troubled by them. They may even make medical choices based on them that may be considered unreasonable. In these situations, doctors and other members of the health care team, as appropriate, should take all reasonable steps to discuss such matters with the patient to address their spiritual or religious concerns in the context of providing better care.

While a patient's choices must always be respected, they may not always be capable of being followed. Respect for life must acknowledge that there comes a point in all lives where no more can reasonably or helpfully be done to benefit patients other than keeping them comfortable and free from pain. In these cases, palliative care and support will take priority over active treatments.

There is a difference between 'respecting' and 'following' patient choices. Respect is a broad concept that provides for careful consideration followed by acceptance of a person's wishes or decisions irrespective of whether they are consistent with those of the health care team. All patients in all situations are entitled to be treated as unique individuals and afforded fair and non-discriminatory assessment of their condition. While a patient has capacity, the doctor responsible for their care must discuss the implications of any requests or refusals of particular treatments with them. Respecting patient choices has greater potential for flexibility, whereas following patient choices must be tempered by the views of the medical profession about what is clinically possible.

4.5 Patient's right to refuse treatment

Refusal of medical treatment is one of the most difficult decision-making areas in health care, not only because the law is so complex, but also because of the multiple variables that have led to a person refusing treatment. There are two ways the law looks at treatment refusal - under common law through the regulatory regime and AHDs.

The common law position on refusal of medical treatment is based upon the principle of respect for personal autonomy.¹⁸⁶ A person with capacity has the right to refuse any medical treatment, including palliative care, while they have capacity. A clinician could face charges for assault if they were to provide treatment against the decision of a person with capacity. It could also result in a complaint to the Office of the Health Ombudsman.

While a patient has capacity, they may choose to refuse all forms of conventional medical treatment. These wishes must be followed while the patient has capacity. For example, a patient may refuse all active treatments and choose to return to the family home to die, comforted by family and supported by palliative care professionals. With the patient's consent, their decision to refuse all or certain forms of treatment should be discussed with their family/carers while the patient still has capacity.

If a patient no longer has capacity, their substitute decision maker/s must take into account the wishes of the patient as expressed in the refusal of treatment. If the substitute decision maker/s determine that to continue or commence treatment is in the best interests of the patient, they may consent on the patient's behalf. A doctor would not be held liable for assault in such circumstances. However it would be the doctor's responsibility, knowing of the patient's refusal, to ensure that the substitute decision maker/s was informed of that refusal.

If the doctor believes the patient's decision to refuse treatment is inconsistent with good medical practice, they should seek a second opinion from a more senior doctor or even refer the patient to a consultant as the situation warrants. Ideally, the doctor responsible for the patient's care should have already discussed the implications of refusing treatment with the patient and, with the patient's consent, those closest to them. In these situations, patients should be encouraged to formalise their wishes for treatment refusal, for example through an AHD. Careful and thorough documentation of discussions is required in these situations.

Similarly, if the treating doctor believes the patient may be suffering from clinical depression or some other mental condition that has unduly influenced their decision-making and caused them to refuse treatment, they must seek the opinion of a health professional with expertise in this area, for example, a psychiatrist. It may be appropriate to negotiate with the patient an agreed plan of continuing treatment and further discussion in the near future, while acknowledging that sustained wishes for treatment refusal are ultimately paramount. Where a patient has formalised their treatment refusal through an AHD and they lose capacity, doctors may withhold or withdraw treatment without obtaining further consent, in accordance with the patient's wishes and the standards of good medical practice. (Refer to [Section – 1.5.1 Advance Health Directives](#) for further information).

It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. The courts have recognised that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future – even if this results in their death or would cause it to happen sooner.

The decisions of patients who refuse medical treatment will ideally be based on sufficient accurate information including an awareness of the condition, the proposed treatment, any significant risks or side-effects, the probability of a successful recovery, the consequences of not having the treatment, and any alternative forms of treatment. Such information should always be offered but legally, patients are not required to have accepted the offer of information in order for their refusal to be valid. In addition, as mentioned, a treatment refusal by a competent patient need not be agreed to by the health care team or members of the patient's family.

4.6 Moral questions

While the two terms are often used interchangeably, there is a distinction to be made between morals and ethics. For the purpose of these guidelines, the following definitions are offered:

- Morals, such as a person's moral principles and convictions, are qualities that determine a person's character. Understanding the difference between, and notions of, right and wrong come from personal convictions - a person's morals. Moral principles are normative in nature; that is, they are the basis from which an imperative to act originate.

- Ethics relate to personal, institutional and broader social regulations and systems. To act ethically is to regulate one's (and/or others') behaviours so they are in accordance with a moral or set of morals. Ethics is a systematic approach to morality, based on reason and moral justification.

There are two significant and distinct approaches to moral philosophy - objective and subjective. Objective approaches to moral philosophy seek to determine universal principles applicable to all, whereas subjective approaches tend to hold that ethical behaviour is not universal in nature and is determined by context and consequence. For the purpose of these guidelines, while each patient's clinical treatment will be determined on a case-by-case basis, the four Governing Principles embody moral principles that are to be applied to all patients.

Principle 1:	All decision-making must reflect respect for life and the patient's right to know and choose.
Principle 2:	All decision-making must meet the standards of good medical practice.
Principle 3:	All efforts must be made to obtain the appropriate consent through a collaborative approach.
Principle 4:	There must be transparency in and accountability for all decision-making.

The types of moral questions raised in this section are directed at those individuals who are responsible for making (and justifying) their decision-making processes for life-sustaining measures. Therefore health care professionals can refer to this section to test their own values about what they consider to be right and wrong.

Other interested parties may find this guidance useful if they are faced with these decisions at some future time in their lives. Answers to these moral questions are subjective, and as such there are many shades of grey as answers cannot realistically be determined on a yes or no basis. However, they can provide a process for ethical deliberation for decision-making in this difficult area and will either affirm personal values or challenge them.

4.6.1 What is benefit?

Our health system and its health professionals have a general duty to provide treatment which benefits all patients; the bioethical principle of beneficence being one of the four cornerstones of modern health care. Benefit, in this context, means an advantage or net gain for the patient. Benefit can be physiological or it can also be other factors important to the patient, such as quality of life. A therapeutic benefit occurs when a medical treatment or procedure confers some sort of symptomatic relief for the patient or improves the patient's condition or prognosis in a real and meaningful way. This treatment is justified as it provides a real benefit.

Health professionals also have responsibilities toward society in addition to the responsibilities they have to individual patients. Health care professionals are employed by society to provide medical care that is safe, appropriate and affordable. The practical expression of beneficence therefore requires judiciousness and genuine concern for the wellbeing of the total society. This must necessarily include the wise use of scarce resources and some recognition of the financial and clinical limits to clinical medicine. Thus, beneficence may be overridden by other considerations.¹⁸⁷

The decision to prolong life by providing life-sustaining measures is usually, but not always, a benefit. When we consider benefit in health terms, concepts like progress, recovery, remission, symptom reduction and pain relief are raised in the context of the discussion. However all these concepts have degrees of benefit. For example, the benefit may be that a patient is able to maintain status quo in their condition without further deterioration. In other cases, benefit may keep the patient alive, but fail to halt the progression of a serious illness.

In making the treatment decisions, a patient with decision-making capacity will weigh relative benefits and burdens among treatment options.¹⁸⁸

The burden of prolonging life in the most extreme cases where there is multiple morbidity and no reasonable prospect of recovery should weigh on the side of palliative care rather than finding cures through active treatment. Arguably, in these cases, there is little or no benefit in subjecting the patient to an endless regime of tests and therapies that are potentially futile and have no chance of restoring their health. Applying life-sustaining measures to prolong life in these circumstances may be causing more harm to the patient than benefit, particularly if pain is involved. This is where the health care team must carefully weigh up and consider all factors in a patient's quality of life.¹⁸⁹

Patients differ in their perceptions of benefits and burdens and in how they balance them. For most, but not all, patients, consequences of treatment that are experienced as benefits include:

- the relief of pain and/or symptoms that cause suffering
- improved functionality
- the opportunity to live longer, if the quality of prolonged life is acceptable to the patient
- the opportunity to do things that have meaning or give pleasure to the patient
- the possibility of fulfilling specific goals.

(Source: Berlinger N, Jennings B and Wolf SM. 2013. P. 54.)

Another key community expectation of the health system is treatment benefits will outweigh the harms. In decision-making about withholding and withdrawing life-sustaining measures, a similar test applies. It is a tenuous moral and ethical balancing act to determine what benefits a patient might receive against harm done to them. Open and honest communication at all points along the decision-making pathway with a patient's family can assist in the decision-making process.

When discussing the concept of how the patient benefits from certain forms of treatment, unilateral decisions about withholding or withdrawing a life-sustaining measure must never be made on behalf of a patient with capacity. Patients with capacity are in the best position to judge what represents an acceptable level of burden or risk for them, and their wishes must be respected even if this results in perceived harm to them. As previously discussed, this important principle underpins the concept of patient autonomy.

In circumstances where a patient does not have capacity, they are not involved in assessing whether benefit is achieved. This decision then falls to the patient's family or other substitute decision-maker to act on wishes expressed by the patient when they had capacity, and perhaps recorded in an AHD. For example, if a patient is known to have the view that there is no intrinsic value in prolonging life at any cost, life-sustaining measures would, arguably, provide no benefit to that individual and would not be in their best interests.

The ability to apply reason in these instances hinges on the patient's level of awareness. For example, important factors in assessing a patient's awareness is demonstrated by them:¹⁹⁰

- interacting with others
- awareness of their own existence and having the ability to take pleasure in the fact of that existence
- having the ability to achieve some purposeful or self-directed action or to achieve some important personal goal.

Should treatment or health care be able to recover or maintain any of these abilities, this likely indicates some benefit to the patient. Benefits are increased if improvements are in the context of the patient's known wishes and values about quality of their own life.

4.6.2 How can risk of harm be minimised?

The concept of non-maleficence is embodied by the phrase, 'first, do no harm'. Many consider that should be the main or primary consideration in health care (hence *first*): that is, it is more important not to harm your patient, than to do them good.

Just how the idea of harm can be determined is another key moral question. There is always the presumption that medical treatment provides benefit to a patient. However, in terms of end-of-life care, patients may be harmed by both the withdrawal of treatment too quickly and by prolonging the treatment beyond the point where it is able to benefit the patient.

It is also the case that patients with capacity, or patients whose views are known, are also harmed by treatment being provided or withheld or withdrawn against their wishes.¹⁹¹ For example, where patients are known to have refused treatment, particularly through an AHD, these instructions must be followed. While there are some legal protections in limited circumstances, doctors who choose not to follow valid AHDs are increasing their risk of liability, both criminally and civilly. (Refer to section 1.5.5 – [Deciding not to follow an Advance Health Directive](#) for further information on this issue.)

Equally where patients are known to have expressed views about their own quality of life, even conversationally at a time when they had capacity, these wishes must also be taken into account in the decision-making process. To treat a patient against their stated wishes is, in itself, of harm to the patient and may be even be viewed by the courts as a form of assault.¹⁹²

Harm may also be caused by reluctance and prevaricating about withholding or withdrawing life-sustaining measures. Failing to make difficult decisions and thereby subjecting a patient who lacks capacity to unnecessarily prolonged, painful and undignified invasive treatment could also qualify as harm.

There may be a disparity in perspectives between harm and benefit in many medical treatments, for example, CPR, artificial nutrition and blood transfusion. Despite its exclusion as a life-sustaining measure in Queensland's legislation, if an adult Jehovah's Witness expressly forbids having a blood transfusion at the cost of prolonging their life, this wish must be followed. Likewise, doctors are not obliged to accede to treatment demands by patients (or their families) that are not clinically indicated and, in the opinion of the treating doctor, would harm the patient or provide no benefit for them.

Quite often more time is needed to assess the best interests of the patient, particularly where there are doubts or disputes. In these instances, consideration should be given to a trial of treatment which allows time for the patient to stabilise and provides more information about the likelihood and extent of any improvement. Families may also benefit from this period as they come to terms with the condition and likely prognosis of their loved one. Failing to give patients and their families this opportunity for improvement where there is even the slightest chance it may be successful could also be harm.

Reducing the risk of causing harm in end of life care should involve careful consideration of the patient's medical condition and likely prognosis. This information should be communicated to patients and their families as soon as possible to avoid crisis-driven decision-making.

4.6.3 What is the meaning and value of death?

Death is the only great certainty. The subject of powerful social and religious symbolism, it continues to be contemplated by philosophers, probed by biologists, and its reality dealt with by families and clinicians on a daily basis.

Our cultural and individual orientations toward death are intimately interwoven. It is well documented that in Western culture, the attitude towards death is often denial (or perhaps more accurately, suppression). Death is defined in one piece of Queensland legislation as the irreversible cessation of circulation of blood in the body of the person, or the irreversible cessation of all function of the brain of the person.¹⁹³ But a discussion about the ethical meaning

of death in society goes much further than a clinical determination that death is simply the cessation of life.

The meaning and value of death impacts upon decision-making in almost every sphere of society. Pondering this moral question captures (but is not limited to) such issues as:

- attitudes regarding care for the elderly, frail and chronically ill
- resource allocation in our health care budgets
- how we celebrate a life once it ends
- changing attitudes to death
- debated on whether there is there such a thing as a 'duty to die'; and
- what is a good death.

The meaning and value of death confronts health professionals on a daily basis in hospital wards across the state. Nowhere is this more demonstrable than through decision-making about commencing or continuing or withholding or withdrawing life-sustaining measures.

More concerning for some researchers¹⁹⁴ is the absence of an agreement on the definition of dying. The lack of a clear definition means that, for the purposes of research, we can never be certain about who to include in the population or cultural groups and who to exclude. Research into end of life issues becomes, by its very nature, subjective because of this lack of conceptual clarity.

In short, I view the absence of conceptual and operational congruity regarding definitions of 'dying' and/or 'terminally ill' as the most important issue facing end-of-life research. I cannot see the field breaking new ground or 'reaching the next level' without resolving this issue.¹⁹⁵

Leaving the definition of 'dying' aside, it can be confidently stated that people are living longer than they did more than one hundred years ago. This is for many reasons, most significantly the successful combination of medical innovation and modern societies' preoccupation with keeping its population safe and healthy. For example, from around the 1880s, the average life expectancy of a newborn boy was 47.2 years and that of a newborn girl 50.8 years. By 2014, average life expectancy had risen to 80.3 years for newborn boys and 84.3 years for newborn girls.¹⁹⁶

Unfortunately, in many cases, this increase in lifespan and decrease in mortality rates have not been matched by an extension of good health. The years we have gained are often spent with disability, disease, dementia and aggressive medical interventions. This is what some commentators have termed "the medicalisation of death."¹⁹⁷

Before life sustaining measures such as artificial hydration, nasogastric feeding and ventilators, no patient continued for long in deep coma. With the aid of modern medicine, some patients with severe loss of brain function can be kept from a rapid death. Many, however, become irreversibly unresponsive. With intervention of modern medical technology, these patients can be seen breathing, their heart beating through monitors, and may even be observed to have different facial expressions, but are in a persistent coma state from which they almost certainly will not recover.

Such artificially supported bodies present ethical dilemmas, for which the application of traditional means of determining death is neither clear nor fully satisfactory. This illustrates why decision-making about withholding and withdrawing life-sustaining measures has become so medically complex and ethically challenging. It is not just the clinical side of death that is challenging for the health care team. Awareness of death confronts us with questions that go to the very nature of existence. Often those at the end of life question the meaning and nature of life and whether there is continued existence beyond life itself. This type of existential questioning can manifest in an infinite variety of ways and represents coping mechanisms for human confrontation with death.¹⁹⁸ Such questions about the meaning and value of death are not, however, confined to the dying; they have been debated by famous philosophers for thousands of years. Over the last two centuries, however, death has become something that medicine has sought to conquer and, in

the process, turned from something familiar personal and social to something lonely, lacking meaning and surrounded by the trappings of modern medicine.¹⁹⁹

More recently, empirical research has attempted to coordinate an ethical response to the medicalisation of dying from health system perspectives. For example, in the United States, the President's Commission for the Study of Medicine and Biomedical and Behavioral Research prepared a lengthy paper to define death in 1981.²⁰⁰ Definitions about how death is determined and defined caused other papers to follow, including to address ethical issues around organ and tissue donation.²⁰¹

The idea that our society prefers to cheat or postpone death indicates, at the extreme end, an attitude that there should be no limits to medical care because of the sanctity of life. Attitudes to the sanctity of life are directly related to the meaning and value of death. Sanctity of life is embedded in most of our social structures, most prominently in our legal and health care systems. However, the general interpretation by the courts in Australia is that while the principle of sanctity of life is very strong, it is not absolute.²⁰²

Palliative care professionals, in particular, have increasing responsibilities in caring for growing numbers who are dying and comforting the bereaved family and friends. However, it should not be left to the sole responsibility of palliative care teams to address end of life decision-making. Irrespective of personal attitudes to the meaning and value of death, it should be that all the health care team leading up to the time of palliation will respect all patient's wishes and respond to the ultimate problem of death in a thoughtful and caring manner by acknowledging rituals that reflect and advance values of human worth, dignity and enduring connection.

A Good Death

The notion of a good death has been discussed for many decades, but empirical research on what constitutes a good death began only twenty or so years ago.^{203 204} Common elements of a good death have been identified as capturing any combination of the following:²⁰⁵

Core Theme	Subtheme
Preferences for dying process	How, where and control over who is present Preparation for death (e.g. attending to 'unfinished business', funeral arrangements) Support of cultural practices before and after death
Pain-free status	Not suffering Pain and symptom management ²⁰⁶
Emotional well-being	Emotional support and psychological comfort ²⁰⁷ Chance to discuss the meaning of death
Spirituality	Access to religious/spiritual comfort if desired Time to meet with spiritual advisers
Dignity	Respect as an individual person To be able to leave when it is time to go, and not to have life prolonged unnecessarily ²⁰⁸
Life completion	Saying goodbye Strengthening relationships with loved ones ²⁰⁹ Acceptance of death Achieving a sense of completion in life ²¹⁰
Treatment preferences	Access to information and expertise of whatever kind is necessary Retaining control over decisions and clear person-centered decision-making ²¹¹ Control over treatment and timing of death Being prepared for what to expect ²¹² Being treated as a 'whole person' ²¹³ Seamless continuity of care across health care settings and home ²¹⁴
Quality of life	Preferences are respected and met where possible Acceptance, pleasure and gratitude Quality of life until death
Relationship with health care	Trust/support/comfort from physician/nurse Physician comfortable with death/dying

Core Theme	Subtheme
professionals	Discuss spiritual beliefs/fears with physician Effective patient-physician communication and physician-family communication ²¹⁵
Other	Physical touch Being with pets Grief and bereavement support before and after the death ²¹⁶
Preferences for dying process	How, where and control over who is present Preparation for death (e.g. attending to 'unfinished business', funeral arrangements) Support of cultural practices before and after death

Figure 3 - Core Themes and Subthemes of a Good Death and/or Successful Dying

A good death allows people to determine who is present, to have time to say goodbye, to control the timing of death, and not to have continued medical interventions when quality of life is low and there is little or no hope of improvement. Failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying.²¹⁷

4.6.4 Can health professionals object to treating a patient on the basis of conscience?

Under a range of legislation, even if a patient with capacity requests it, health professionals are not obliged to provide treatment which contravenes good medical practice. Also, in very limited circumstances, doctors are excused from providing care to a patient that goes against their conscience or clinical judgement.

In the case where health professionals have a conflict of interest or object on the grounds of conscience, this must be declared as early as possible to ensure the patient receives appropriate hand-over to another doctor and/or health care team.

If this arises, the dissenting health professional's views should be communicated to the health care team so if the situation arises where conscientious objection is needed on the part of a doctor, a back-up clinician, or team identified to accept responsibility for the patient's care can be put in place. In some cases, it may be necessary to get a second opinion, preferably from a clinician with specific expertise, to provide a more independent view about withholding or withdrawing a particular treatment. This particular step could consume valuable time, particularly in the case of an acute emergency. While health professionals objecting on the basis of conscience is acceptable, it should be declared at the earliest possible time so that there is no risk of harm to the patient.

4.6.5 Can resource allocation be used to justify withholding or withdrawing medical treatment?

Cost is an ethical issue in health care and the ethical goal of treating all patients equitably requires all health professionals not only to make the best use of available resources, they also have to grapple with the moral as well as fiscal dimensions of resource allocation and health cost.²¹⁸ However, making the best possible use of resources inevitably means that some patients, whose lives might potentially be prolonged, may not receive all possible life-sustaining treatment.²¹⁹

Decisions around life-sustaining measures must represent an appropriate balance between the clinical and resource needs of different patients, while having regard to the availability of appropriate medical treatments, particularly in acute settings.

Increasing levels of technology not only present ethical dilemmas about assessing when treatment ceases to benefit the patient, but also raise the issue of cost when the decision is made

to withhold or withdraw a particular treatment. Where funds are limited, individual facilities, doctors and patients all compete for sometimes scarce resources. Different models of care such as increasing home and community care for those who are dying is likely to reduce demand on hospital and residential aged care services.²²⁰ Irrespective of how cost-reducing models of care are introduced, the relationship between financial considerations and decision-making about life-sustaining medical treatment and end-of-life care is too complex to lend itself to comprehensive ethics guidelines appropriate for all care settings. Reflection on issues integral to ethical practice can aid in the development of policy that is ethically sound from a procedural standpoint.²²¹

Taking account of all relevant factors including obtaining consent, the decision about whether to withhold or withdraw life-sustaining measures will ultimately be made by the doctor responsible for the patient's care, with advice from the rest of the health care team. This is part of the difficult role health professionals face daily - balancing decisions about resources and allocating them to patients in need.^{222 223}

Some of this decision-making also takes into account the likelihood of prolonging life leading to a significant recovery for one patient against the likelihood of merely delaying death for a short period of time or prolonging the dying process for another. Although it is highly unlikely the courts would expect all possible treatment to be given to prolong a life irrespective of costs or the impact on other patients, the onus is on the most senior doctor/consultant in the treating team to clearly articulate the decision-making that led to the final outcome. Meticulous record-keeping is crucial in these circumstances.

The demands on limited resources and the concomitant but competing best interests of other patients are factors that will feature in all decision-making about life-sustaining measures. The duty of care owed to all patients who lack capacity is to act in their best interests. The allocation of resources to ensure this is afforded to every patient represents decision-making at its most difficult. Other challenges could arise if, for example, patients or their families request potentially life-prolonging treatment to be continued for as long as technically possible, even though there is no realistic hope of recovery. Complying with such requests could well be at the expense of other patients who may be assessed as having a reasonable chance of recovery if treatment is provided.

Although the courts have given little guidance, using resource allocation as an excuse for withholding or withdrawing life-sustaining measures would most likely be challenged legally, and, arguably, charges could potentially be faced under a range of different legislation. A number of legal cases have examined the provision of medical treatment on the grounds of such things as futility (most notably the *Bland* case).²²⁴ However, the legal implications of using resource allocation in defence of a decision to withdraw a life sustaining measure is yet to be tested.

Particular care needs to be taken to ensure that all decisions have been carefully considered, based on an individual's care needs, and not made on the basis of unjustifiable discrimination (both of the patient as an individual and of the patient compared to others).

Decision-making regarding life-sustaining measures must be based on the patient's best interests, underpinned by good medical practice. While it is acknowledged that balancing competing interests is profoundly complex, the extent of the duty of care for the entire health care team would be judged on a case-by-case basis if the decisions were to be tested by the court. Concluding resources are too costly to keep the patient alive simply because the treatment is 'futile' treads a dangerous legal path and is fraught with ambiguity and both clinical and ethical complexity.²²⁵

Decisions regarding life-sustaining measures must always be well-supported by clinical evidence, second or expert opinions, and by reference to other relevant national guidelines. Should there be any doubts about a particular course of action expressed by any member of the health care team, or expressed by a member of the patient's family, these concerns should be discussed with senior clinical and managerial colleagues and referred to the Office of the Public Guardian

should the patient lack capacity. All records should be kept in the patient's file and later referred to the hospital area ethics committee, or as other local circumstances allow.

Resources for gravely ill or irreversibly and severely brain-damaged patients who will never recover cannot be allocated to treat other patients, and this exceptionally difficult ethical dilemma will necessarily comprise some decision-making about life-sustaining measures. For example, does a patient who suffered severe trauma at a young age and now lives in a disability long-term facility meet this criteria despite maintaining an acceptable base-line functioning? The British Medical Association²²⁶ have also addressed some of these issues in their guidance, but do not provide definitive advice, ultimately leaving the final decisions to the doctor in charge, supported by the treating health care team.²²⁷

'It is very concerning that the reality is, that cost factors probably have a disproportionate influence on decision making for this very vulnerable patient group and it is also concerning that the lack of a clear societal consensus on this most vexed area may unfairly leave doctors open to criticism.'

The legal system in Australia provides guidance only insofar as: should health care professionals *not* do the best for a patient with resources that are genuinely available, breaches of care standards would occur, likely resulting in negligence claims. As such, health professionals should never use lack of current or indeed future resources to deny treatment for any patient. To do so establishes a conflict since, in essence, the choice to treat the patient (or not) is being compared with the treatment for another (future) patient whose condition and prognosis is unknown. Each patient should be assessed on a case by case basis, taking all the clinical factors into consideration. In the case where two patients share the need for the same limited resource, which is adequate for both, 'the patient with the greater clinical need should have the first access. This is the essence of triage.'²²⁸

It is important to acknowledge that doctors are well placed to make informed decisions about patient care that can include economically smart choices, as long as patient care does not suffer. Regrettably, a common misconception held by family regarding withdrawal of medical treatment is that medical staff do so to 'free the bed' for someone else. Doctors are advocates for their patients, and are bound to act in their best interests, both by law and by adhering to the standards of good medical practice. Their primary duty is always to the patient they are treating, and the care of that patient must not be compromised for the care of another potential patient.

Education and counselling about the indications for withholding or withdrawal of medical treatment are probably the best way to help the family come to terms with the prospect of withdrawal of medical treatment and for continued trust in the health care team.

4.6.6 Euthanasia and assisted suicide, a difference?

In Queensland, euthanasia is unlawful to the extent that it constitutes killing under the *Queensland Criminal Code 1899*.²²⁹ Euthanasia and assisted suicide both involve deliberate acts or omissions that are undertaken with the intention of ending a person's life and are inconsistent with the duty of care of a medical practitioner or other medical professionals.

Both euthanasia and assisted suicide are criminal offences and are not endorsed by this document, nor by Queensland Health.

Relevant sections of Queensland's *Criminal Code 1899*, include sections 284, 296 and 311:

- (284) Consent by a person to the causing of the person's own death does not affect the criminal responsibility of any person by whom such death is caused.
- (296) A person who does any act or makes any omission which hastens the death of another person who, when the act is done or the omission is made, is labouring under some disorder or disease arising from another cause, is deemed to have killed that other person.

(311) Any person who —

(a) procures another to kill himself or herself; or

(b) counsels another to kill himself or herself and thereby induces the other person to do so; or

(c) aids another in killing himself or herself;

is guilty of a crime, and is liable to imprisonment for life.

The word ‘euthanasia’ is derived from two Greek words (*eu* – well or good, and *thanatos* – death), in other words “good death.” It is also often called “mercy killing” in the popular media. The process of euthanasia is a deliberate, intentional act of one person to end the life of another person in order to relieve that person’s suffering. For example, a doctor injects a patient with a lethal drug to relieve that person from unbearable physical pain. The term euthanasia is often used in different ways. Two of the most common are:²³⁰

- **Voluntary euthanasia:** where a person with capacity requests another person kill them, or help them to commit suicide; and
- **Involuntary euthanasia:** where a person with capacity is euthanised against their will (i.e. he or she has not expressed the wish to die, or has asked that he or she not die).

Passive and active euthanasia are also distinguished within the literature. Passive euthanasia entails the withholding of common treatments, such as antibiotics, necessary for the continuance of life. For example, withholding ventilator support for breathing may be considered an act of passive euthanasia because the person would die on his or her own without the ventilator. Discontinuing dialysis could be another example. Passive euthanasia is often thought of as a “allowing a person to die” because while the action by the doctor removes the supportive treatment, the life-threatening illness or medical situation actually ends the patient’s life.

Active euthanasia entails the use of lethal substances or forces, such as administering a lethal injection, to kill and is the most controversial means. Passive euthanasia has more recently emerged under similar term; “voluntary palliated starvation” or VPS, which occurs when a person with capacity refuses to eat or drink and receives palliative care to relieve any suffering she or he experiences from dying due to a lack of food and water. Some authors argue that, at least in some circumstances, such a death would be lawful for the individual and doctors involved, and consistent with principles of medical ethics.²³¹

Proponents of euthanasia believe it is the compassionate choice, and supported by the same constitutional safeguards that guarantee such rights as marriage, procreation and the refusal or termination of life-saving medical treatment. Proponents feel the language of the often-cited Hippocratic Oath negates the reality of terminal disease, and believe that terminally ill people should have the right to end their pain and suffering with a quick, dignified death. Further, supporters of euthanasia believe that allowing people to ‘die with dignity’ is kinder than forcing them to continue their lives with suffering and represents the final right – to choose when, where and how to die.

Opponents of euthanasia use the ‘slippery slope’ argument and see little difference between it and murder, and challenge that any test to differentiate between voluntary and non-voluntary cases will ultimately fail. Also citing the Hippocratic Oath, they argue that doctors have a responsibility and a sworn duty to keep their patients alive. Opponents also point to alternative treatments and palliative care that addresses pain and other distressing symptoms. Many opponents believe that legalising euthanasia will unfairly target the poor and disabled, groups with little access to advanced, possibly life-saving medical care. Opponents also believe that once legalised, the practice would be difficult to regulate and thus potentially lead to unintended consequences, such as the vulnerable feeling they have a “duty to die”, which could capture those suffering frailty or depression, and concerningly those who may be coerced by family members for financial gain.²³²

At the core of the debate between proponents and opponents of euthanasia is how to reconcile competing values - the desire of individuals to choose death with dignity when suffering, and the

need to uphold an inalienable right to life of every person, as recognised by article 6(1) of the UN's International Covenant on Civil and Political Rights.²³³

While health professionals generally understand the distinctions between euthanasia, physician-assisted suicide, and the withdrawal of life support, public debate tends to conflate these terms, potentially leading to misinterpretation and often intense media scrutiny.

The calls for legal reform in this area have also echoed throughout the various Australian parliaments since 1993, with 51 Bills introduced under various names seeking to remove the prohibition on territories legislating in this area in one shape or another.²³⁴ Also, support for legalising euthanasia has been growing steadily over the last decade in Australia and elsewhere in the world. For example, in March 2015, an ABC Vote Compass survey received 34,000 responses from New South Wales residents to the statement "Terminally ill patients should be able to legally end their own lives with medical assistance". A total of 72 per cent of people strongly agreed or agreed with the proposition, compared with 16 per cent of respondents who did not. Eleven per cent of people said they were neutral.²³⁵ A follow up survey conducted from May 8 – May 19, 2016 drew 201,404 respondents; 75 per cent agreed with the statement, 16 per cent disagreed, and nine per cent were neutral.²³⁶

Yet, as with any complex and controversial debate there are more than two sides; cautions against legalising euthanasia come from all disciplines, including from medicine and other health professions, ethics, law, politics and faith-based organisations. For example, a study by psychologists in New Zealand found that while physicians would provide information to patients enquiring about euthanasia, they were far less inclined to be actively involved.²³⁷ More recently, the British Medical Association which represents more than 170,000 doctors across the UK, rejected a motion to adopt a neutral stance on assisted dying. The result being that more than half the delegates who attended the 21 June 2016 Annual Representative Meeting in Belfast voted to oppose assisted suicide – a stance that organisation has retained throughout its history.²³⁸

In Australia, the Australian Medical Association (AMA) conducted a similar survey of its members during 2015-16. 4,000 of 30,000 Australian doctors responded, and narrowly voted to retain the AMA's existing policy that doctors should not take any action primarily intended to cause the death of a patient. Doctors could, however, "relieve symptoms which may have a secondary consequence of hastening death" This resulted in the AMA's updated position statement published on 24 November 2016.²³⁹ The relatively close margin of about 55-45 per cent for and against or undecided on the existing policy underlines that doctors are as divided as the public. From the position statement: "The AMA recognises there are divergent views within the medical profession and broader community in relation to euthanasia and physician-assisted suicide." Crucially, an even clearer majority of AMA members said if voluntary euthanasia were made legal at the state and territory level, doctors should be involved in helping terminally ill people die rather than dig in on principle and boycott the process.²⁴⁰

Assisted suicide

Suicide is the intentional act of killing oneself. Assisted suicide occurs where a person intentionally kills himself or herself with the assistance of another (who provides the knowledge or means to do it). For example, where a friend or relative obtains a lethal drug and provides it to the person to use to commit suicide. With physician-assisted suicide, a doctor provides a patient with a prescription for drugs that a patient could use to end his or her life.

The main distinction between physician-assisted suicide and active euthanasia is that the doctor is not the person physically administering the drugs. Physician-assisted suicide is only contemplated by—and would only be considered as an option for—patients who are conscious and capable of making their own decisions.

In contrast to active euthanasia, where a doctor or some other person would deliberately end a person's life, assisted suicide is an active choice by a person to end his or her own life. For some people, physician-assisted suicide seems a viable option that would allow the opportunity to forego suffering and loss of control. Although a distinction is often drawn between physician-assisted suicide and active voluntary euthanasia, in general the moral issues that arise are common to both.

The gradual extension of legal rights in the end-of-life arena has led to current debate over physician-assisted suicide. On one side of the debate, proponents of physician-assisted suicide seek to show that there is no moral difference between withholding lifesaving treatment and providing a patient the means to end life. On the other side of the debate, opponents of physician-assisted suicide argue that the artificial hastening of death is unlike allowing the unhindered progression of a terminal illness. However, the courts generally hold that an individual's right to self-determination, including choices about death, outweighs a normative societal interest in the sanctity of life.

'Advocates of physician-assisted suicide argue that it has the advantage of reassuring terminally ill patients that they can continue living in the knowledge that they can end their own lives if and when they choose; and that because they die by their own hands, their action is likely to represent a voluntary and informed choice.'²⁴¹

Depending upon where one stands on the moral justification argument, assisted suicide is seen as different from withholding or withdrawing life-sustaining treatment in accordance with good medical practice by a qualified medical practitioner. When medical treatment is withheld or withdrawn, and it causes the death of a patient, the law generally regards the cause of death as the patient's underlying condition rather than the actions of others. Patient autonomy and the right to choose one's destiny is a core right in our society. This principle is upheld in all decisions underpinned by good medical practice. If it is accepted that it is a fundamental right of all persons to choose the manner and timing of treatment at the end of life, it must be ensured that this choice is a *genuine* expression of the patient's autonomy.

'Autonomy is not served if the person chooses to die out of incompetence, irrationality, mistake, fraud or coercion. Accordingly, before we honour a patient's request for life-shortening action, whether a treatment withdrawal or an assisted suicide, we would want to confirm that the request is a valid exercise of self-determination.'²⁴²

The same commentator in a co-authored article more than ten years later has observed that:

While once widely rejected as a health care option, physician aid in dying is receiving increased recognition as a response to the suffering of patients at the end of life. With aid in dying, a physician writes a prescription for life-ending medication for an eligible patient. Following the recommendation of the American Public Health Association, the term *aid in dying* rather than "assisted suicide" is used to describe the practice.²⁴³

In January 2013, a round table on the theme of legal reform and assisted death was hosted by Australia21, a non-profit organisation dedicated to exploring multidisciplinary approaches to complex policy issues. Outcomes from the round table were published and the themes and perspectives in support of reform were identified as follows:²⁴⁴

1. Competent adults should be able to make decisions about their own life and death. Increasingly, older or terminally ill people want the security of knowing that they can obtain assistance to end their life if they judge that it has become too burdensome and insufferable or meaningless.
2. Some people are dying in physical, psychological and/or existential pain in a way that should not be tolerated in a humane and compassionate society.
3. The law is unsatisfactory and, in important respects, incoherent.
 - There is uncertainty about what it means to "assist" someone to die, whether a person will be prosecuted if they do so and, if they are prosecuted and found guilty, whether they will be imprisoned.
 - Legal liability for doctors can depend on their intention when treating their patient – did they intend to relieve symptoms or end the patient's life? Although voluntary euthanasia is illegal in all states and territories in Australia, doctors not infrequently prescribe heavy sedation to patients with intractable pain to relieve their symptoms, even if doing so risks hastening the patient's death. If their intention is to relieve symptoms, doctors are legally protected by the

“doctrine of double effect” even if they foresee the possibility that the sedation will shorten a patient’s life.

- While there is recognition under the law that a patient can end their life by requesting suspension of unwanted life-sustaining treatment (such as a respirator), a request for active steps to end their life cannot be legally respected.
4. Lives are currently being ended despite existing prohibitions on voluntary euthanasia and assisted suicide.
 - Some individuals take their own lives by suicide (eg. by violent means or, more often recently, by importing illegal drugs from overseas).
 - Some individuals (including family members and doctors who act outside the protection of the doctrine of double effect) take active steps to end a person’s life.
 5. Providing requested assistance to die should be part of how those doctors, who are willing to do so, can care compassionately for suffering patients.

As can be demonstrated, the legal and medical debate over the ethics of physician-assisted suicide continues as the controversy is played out across many themes, media and jurisdictions. These guidelines will not enter into, nor discuss the vast range of considerations for assisted suicide. If the academic, medical and legal community have difficulty agreeing on categorical distinctions between treatment withdrawal and assisted suicide, then these guidelines can do no better than raise the broad issues, and at the same time, reiterate Queensland’s laws in relation to this matter, that is to say, the practice is illegal according to *Queensland’s Criminal Code*.

Doctrine of ‘double effect’; killing and letting die

As stated, it is observed that there is a morally important distinction between passive and active euthanasia. Those who hold this view believe that, whereas it may sometimes be morally acceptable to allow a patient to die, it is not morally acceptable to intentionally kill a patient.²⁴⁵ Therefore while it is clear there is a fundamental moral distinction between actively killing a healthy non-consenting person, and avoiding life-sustaining CPR for a patient with end stage metastatic cancer whose heart has stopped, it can be just as unclear where decisions about withdrawing life-sustaining measures and commencing them are blurred for lack of certainty. It is sometimes argued that the difference between active euthanasia, passive euthanasia and assisted suicide lies in the intention of the practitioner rather than the actual act performed. If the intention is to kill, this is thought to be morally abhorrent, while if the intention is to relieve suffering and allow a ‘natural dying process’, this is thought to be morally acceptable. Since the 13th century, the use of intent as a means to distinguish between acts that are morally permissible and those that are not is central to the philosophical doctrine of double effect.

The central distinction in the doctrine of double effect is the difference between the intentional causation of evil and the foreseeing of evil to be a consequence from the act.

When discussing euthanasia and assisted suicide, the doctrine of double effect would draw a distinction between acting in such a way that death was intended, and acting in a way that caused the death as the foreseen but unintended effect of the pursuit of another goal (such as the patient dying of respiratory suppression from the sedating effects of an opiate).²⁴⁶ Under the doctrine of double effect, palliative care is legal provided the health professional’s intention is to reduce or relieve a patient’s pain and suffering, and not to hasten their death. This is the case even if the health professional knows death may be hastened by providing palliative care.²⁴⁷

Beyond this, health professionals have a legal duty to provide a person in their care with the ‘necessaries of life’.²⁴⁸ If health professionals breach this duty, they may be criminally liable for any consequences to the patient’s life, health or wellbeing. However, this duty will not apply where the patient has capacity and refuses medical treatment such as verbally at the time or in an AHD, or where the treatment is considered by the doctor to be inappropriate in the circumstances (e.g. not clinically indicated). In these cases the health professional is under no duty to provide the treatment, even though the patient will die without the treatment.²⁴⁹ Legal commentators also advise that a health professional does not unlawfully kill a patient if life-sustaining medical treatment is withheld or withdrawn if appropriate legal consents are obtained

and the decision meets the standards of good medical practice. In those situations the person is considered to have died naturally from their medical condition or disease.²⁵⁰

Ethical Considerations – Summary Points

1. There are four well known and often quoted bioethical principles that provide an accepted framework for medical decision-making and communication with patients:
 - I. **Autonomy:** respect the right of a person to make their own decisions about their own health and future. Respect for autonomy is a component of respect for human dignity.
 - II. **Beneficence:** the duty to do the best for the person or to act in their best interests – i.e. undertake actions that are intended to benefit the patient (to do good)
 - III. **Non-maleficence:** the duty to do no harm to patients or others
 - IV. **Justice:** incorporates the notions of equity and fair distribution. The ethical principle emphasises that health professionals have responsibility to the wider community as well as to individual patients.
2. **Both euthanasia and assisted suicide are criminal offences and are not endorsed by this document, nor by Queensland Health.**
3. It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. The courts have recognised that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future – even if this results in their death or would cause it to happen sooner.
4. There are well established ethical and legal principles that doctors are under no moral or legal obligation to offer or attempt medical treatment that could cause harm or would provide no benefit to a patient, in other words the proposed treatment is not clinically indicated.
5. Arguably, because of unrealistic expectations about the benefits of technology and medical advancement, death can all too often be seen as a failure of the health system, rather than a natural and inevitable part of life. A life cannot be prolonged indefinitely, and to assist patients and their families to accept the inevitability of death is one of the most difficult challenges for health care professionals.
6. Supporters of euthanasia believe that allowing people to ‘die with dignity’ is kinder than forcing them to continue their lives with suffering and represents the final right – to choose when, where and how to die. Opponents of euthanasia use the ‘slippery slope’ argument and see little difference between it and murder, and challenge that any test to differentiate between voluntary and non-voluntary cases will ultimately fail.
7. Under the doctrine of double effect, palliative care is legal provided the health professional’s intention is to reduce or relieve a patient’s pain and suffering, and not to hasten their death.

5.0 Special considerations

5.1 People with special needs

End of life decision making, particularly resuscitation planning, is among the most difficult in medicine. When directly related to those in our community that require special consideration, it is even more complex. The six following groups are identified as requiring further guidance in discussing end of life issues:

1. The elderly
2. Children and adolescents (covered in detail in separate documents)
3. Mental health patients
4. People with disabilities
5. Aboriginal and Torres Strait Islander people
6. People from other cultures
7. People from the LGBTIQ community

Each patient should be treated as a unique individual and health professionals should not make assumptions about a patient's fears, needs or wishes based on them identifying with one or more of a particular group. Thus, the information presented in this section is provided for brief context around end of life decision-making and is not intended to be a detailed or thorough study of each group. It highlights important issues for clinicians to consider when making decisions about life-sustaining measures for people in these special groups.

5.1.1 The elderly

As already discussed, Queensland's population is ageing. Death has become an increasingly institutionalised and medicalised experience and hospitalisations have increased significantly for older age groups. In the decade to 2011-12 in Australia, the hospitalisation rate for those aged over 85 increased by 35 per cent for women and 48 per cent for men.²⁵¹ In the near future, the proportion of older people in the population increase faster than population growth. Those aged over 85 will increase from two to four per cent of the population as the baby boomer generation transitions into older age. As a result the number of people who die each year in Australia will almost double in the next quarter of a century.²⁵²

In providing end-of-life care to the elderly, health professionals must be mindful of a number of biases that may affect the thinking of any of those involved in making the decisions. These include:

- a common, but unspoken ethical concern, that health resources should be rationed for the elderly so that they could be used elsewhere where they might 'do more good'²⁵³
- the fact that some younger members of society undervalue many aspects of the lives of elderly people
- the belief that elderly people use a disproportionate share of the medical resources available.

It is Queensland Health's policy that decisions to withhold or withdraw life-sustaining measures must be made on a case by case basis, and age or race or lifestyle must never be used to qualify these decisions.

The elderly, like other demographic groups in our society, are deserving of value, care and respect. The health care team must always consider that the interests of the elderly may not necessarily be the same as the interests of their families, health professionals or health institutions.

While this is not always certain, it is usually likely that an elderly patient, particularly one with dementia, will already have a substitute decision-maker. In the vast majority of cases substitute decision-makers strive to do their best for their elderly loved one, however a number of commentators have raised growing ethical issues relating to elder abuse and exploitation by seemingly well-intentioned substitute decision-makers. Many of these involve financial opportunism at a time when an elderly person is most vulnerable rather than decisions and actions that cause them physical harm. Such issues can rarely be solved through single-dimension approaches, but if the health care team has evidence of or suspects that the substitute decision-maker for an elderly person who lacks capacity is not in accordance with the Health Care Principle (refer to [Appendix 4](#)), they may refer the matter to the Office of the Public Guardian. In these instances, the doctor responsible for the patient's care must use his or her best judgement to ensure good medical practice and evidence-based decision-making underscore all decisions about life-sustaining measures for an elderly patient.

Elderly patients should be encouraged (but never forced) to take part in advance care planning to ensure their wishes for end of life care can be respected. If they have an AHD, care should also be taken to ensure it is reviewed regularly and updated as necessary. They may have completed an AHD at a time when their condition was different to when they lose capacity. Providing encouragement for elderly patients to regularly review directions in their AHD while they are capable, represents the most responsible approach, given AHDs are not time limited.

5.1.2 Children and adolescents

Children and adolescents (under 18 years of age) are not covered under Queensland's guardianship laws,²⁵⁴ and at this time are excluded in guidance documents associated with withholding and withdrawing life-sustaining measures. The basis for decision-making about life-sustaining measures for children is derived from common law, rather than the specific provisions in the guardianship laws. The common law test to be applied for children is whether they have sufficient maturity and understanding to make decisions for themselves. If not, parental or guardian consent is required. In some circumstances, it may be appropriate to seek a court order from the Family Court or a Supreme Court. Separate policies and guidelines about withholding and withdrawing life-sustaining measures from children and adolescents (including neonates) are expected to be available in 2017.

5.1.3 People with disabilities

End-of-life care for people with disabilities poses unique challenges. It requires that clinicians, families and ethicists be aware of biases that influence decision-making, particularly in acute settings where the aim is primarily cure and return to optimal functional level. Because a person has a disability, it should not be assumed they are unable to contribute to decision-making about end of life choices.

Three categories of disability are referred to in the literature concerning end of life care:²⁵⁵

1. A person who has lived with a disability from birth or early life, due to trauma or disease, and is now faced with a serious illness that requires life-sustaining treatment.
2. The otherwise healthy person who acquires a disability through an acute event of disease or trauma and whose condition requires that life-sustaining treatment decisions be made.
3. The person who has lived with a progressive chronic illness, such as lung or heart disease or amyotrophic lateral sclerosis, and may have gradually adjusted to disabilities imposed by the condition and now is faced with life-sustaining treatment decisions.

It is widely documented that both older people and those with decision-making disabilities can encounter discrimination when they seek medical care. Just as ageism and stereotypes about older people may inappropriately limit medical care for the elderly, limits may be placed on medical care merely because of the presence of a disability. It is Queensland Health's policy that decisions to withhold or withdraw life-sustaining measures from every patient must be made on a case-by-case basis, and age or race or lifestyle must never be used to qualify these decisions.

When people with decision-making disabilities reach the end of life, decision-making must incorporate an underlying respect for their autonomy in the broadest sense and also ensure no harm is done. The diagnosis of a life-threatening condition in a person who lives with a decision-making disability, or the progression of an existing condition, may bring the person into new care settings where knowledge of his or her disability and how they live with it are limited or non-existent. Situations that will require ethics consideration include those when determining the decision-making capacity of an adult patient with disabilities when they are unable to communicate or be understood. In these instances collaborative decision-making involving the person and their decision-maker may provide the process needed to afford these patients the same rights as other patients and to avoid harms resulting from delays in making decisions and providing care.²⁵⁶

It is important for clinicians to be objective as well as compassionate, and to strive to know the patient as well as possible. In this way important information from the patient, their families, friends and carers, which will include their legal substitute-decision maker (who may also be their formally appointed guardian), can be gathered to create a picture of who the person is and what their choices may be for end of life care.

Respect for the values and lives of people with disabilities enhances clinicians' ability to assist disabled patients, their families and other members of the health care team to realise the patient's possibilities for continued life and peaceful death.²⁵⁷

Factors that impede clinicians' abilities to provide a range of clinical options for people with decision-making disabilities and their substitute decision-makers range from extreme positions of pity for the imagined plight of the disabled person to reservations about changing course to palliation because of fear of criticism from a multitude of legal and political sources. These factors can immobilise the clinicians' sense of agency to support and facilitate decision-making and to care effectively for persons with disabilities at the end of life. Clinicians should follow the usual steps for making end of life treatment decisions (refer to [section 2.0 – Decision-making framework](#)) and carefully document the process.

In the clinical context, a number of international ethicists have pointed out that using futility as the basis for clinical decision-making for disabled persons is fraught with ambiguity.²⁵⁸ Clinical assessments based on potential futility are inherently value laden – they are not objective medical decisions – and at times the values of the patient and the health-care team may be in opposition, especially if the emphasis is on perceived quality of life.²⁵⁹

5.1.4 Mental health patients

In Australia, there is a common-law right for competent patients to refuse medical treatment, including life-sustaining treatment. In Queensland, this right has received statutory recognition if a person completes an AHD specifying they do not wish to be subjected to invasive life-sustaining, or life-prolonging medical treatment.

Queensland's guardianship legislation begins with the presumption of capacity, therefore every person is entitled to be considered to have capacity to make decisions about health matters affecting them unless an assessment is made that they do not have capacity. Refer to [section 1.4 Capacity](#) for further information.

It is recommended that patients with active mental illness including depression should have their decision-making capacity carefully evaluated. Capacity to make treatment decisions often fluctuates over the course of mental illness. For example, a patient's capacity to understand treatment options can be impeded by psychiatric symptoms or cognitive dysfunction. Similarly, individuals with schizophrenia may have acute psychotic symptoms or long-standing thought disorders that can impair their ability to make informed decisions.²⁶⁰

It should be noted that, while in the grip of major depression, patients may make different decisions from what they would make otherwise. Major depression should be treated before a

patient is asked to undertake advance care planning. If doubt exists about a patient's capacity, or where it is believed major depression is present, psychiatric consultation should be arranged. In the absence of an AHD (completed before the onset of depression), severely depressed patients' decisions to refuse life-sustaining medical treatments should be treated with the utmost caution until attempts are made to treat the depression.

Researchers point out that the diagnosis of major depression in the gravely ill is very difficult.²⁶¹ Low spirits are to be expected in serious illness, and many of the other features of major depression (such as weight loss and sleep disturbance) are also common in physical illnesses. Further, according to Ryan (1996), the difficulty of diagnosis is reflected in studies that reveal that non-psychiatrically trained doctors miss up to half of cases of major depression in the medically ill. However, it is the case that major depression is eminently treatable. If it can influence the seriously ill to refuse treatment, then some of those who do refuse treatment might be depressed and might change their minds if the depression were treated.²⁶²

For mildly depressed patients, researchers suggest that 'it appears reasonable' to respect their wishes for end of life decision-making.²⁶³ In all cases where depression (minor or major) is suspected, it would be prudent for doctors to err on the side of preserving life and treat patients suffering major or moderate depression before respecting a refusal of life-sustaining medical treatments.²⁶⁴

The difficulties presented by a depressed patient with fluctuating capacity who refuses life-sustaining treatments must be taken on a case by case basis, with guidance of health professionals experienced in the area of depressive illness.

The decision to withhold life-sustaining medical treatment that is considered potentially futile will be based upon many factors besides patient preference or presence of mental illness. However, when a treatment is considered not potentially futile, patient refusal is usually central to a decision to stop. Doctors responsible for patients in these situations have a duty to ensure that the refusal is not motivated by a major depression. Patients with cancer and depression experience more physical symptoms, have poorer quality of life, and are more likely to have suicidal thoughts or a desire for hastened death than are cancer patients who are not depressed.²⁶⁵

Given the difficulties of accurate diagnosis, should there be any doubts about the patient's mental status as it relates to depressive states, it is best to seek an opinion from a more experienced clinician, preferably a psychiatrist to review the patient. If an Advance Health Directive is made while a patient is in a depressive state, it is unlikely to be a valid indication of that patient's future preferences.²⁶⁶ The American Psychological Association has a number of resources about end of life care and depressive states.²⁶⁷

5.1.5 Aboriginal and Torres Strait Islander people

On average, Aboriginal and Torres Strait Islander Australians die a great deal younger than the wider Australian community and have much higher rates of poor health outcomes. Aboriginal and Torres Strait Islander people have the lowest life expectancy of any minority in a developed country. Only 2.6 per cent of the Aboriginal and Torres Strait Islander population will pass the age of 65.²⁶⁸ Understanding and demonstrating respect for the beliefs of the patient and their family will assist with developing trust and rapport.²⁶⁹

Unexpected deaths in this Aboriginal and Torres Strait Islander community are common. In addition, delivering a diagnosis and prognosis to Aboriginal and Torres Strait Islander patients can be difficult considering the cultural and communication barriers.

Aboriginal and Torres Strait Islander peoples are not an homogenous group. Like the many nations of Europe, Aboriginal and Torres Strait Islander peoples comprise a large number of diverse, culturally different communities. Each community has its own unique customs, cultural beliefs and associated ceremonies. Although there are degrees to which Aboriginal and Torres Strait Islander people are connected to their traditions, the concept of community and the central place of land and family obligations are common underpinning values within and across Aboriginal and Torres Strait Islander communities throughout Australia. Family extends to distant relations, with obligations and responsibilities to all members and others within the community. 'Family' members may not be related according to the mainstream notion of blood relatives, but be related through traditional kinship or cultural groupings. Therefore, there are differences between non-Indigenous and Aboriginal and Torres Strait Islander Australians' perspectives on healthcare, wellbeing, death and dying. A common contrast in perspective is the meaning of a hospital admission.²⁷⁰

- For non-Indigenous people the hospital is a place to heal, to fix health problems, and to rehabilitate.
- For Aboriginal and Torres Strait Islander people, the hospital may be seen as a place one goes to die.

Having to move from isolated communities to regional or metropolitan centres for treatment or care can result in significant impact and trauma, not only for the Aboriginal and Torres Strait Islander individual, but also for their families. Flexible models of health care for those at the end of life should allow Aboriginal and Torres Strait Islander people the choice to return to their place of birth. Care which may make the Aboriginal and Torres Strait Islander peoples more comfortable may be less of a priority than the cultural and family support needed for spiritual wellbeing. Many Aboriginal people and Torres Strait Islander people use the 'classificatory system of kinship.' This is a strong relationship-based kinship system inherited by collective groups that provides the social structuring of family and the community (language group, nation or clan).²⁷¹

In discussions about end of life matters, information given to the Aboriginal and Torres Strait Islander people and/or their family/community should include the range of choices available to them. Knowing the choices and positives/negatives of the choices will assist the Aboriginal and Torres Strait Islander people and/or family to:

- make an informed decision about what is best for them – even if it means not accessing available services
- plan for time away from home
- plan for family members to accompany the patient
- prepare for what is likely to happen in relation to the illness.

The National Palliative Care Program also provides important resources to discuss end of life matters with Aboriginal and Torres Strait Islander people.²⁷² They raise the notion of 'cultural safety' as an important aspect of discussing medical treatment with Aboriginal and Torres Strait Islander people. Cultural safety is practice which respects, supports and empowers the cultural identity and wellbeing of an individual, and empowers them to express identity and have their cultural needs met. Cultural safety recognises that every person brings a set of values and beliefs to all interactions with other people and all that they do. Each clinician will bring values and perspectives from their own culture to the situation. Sometimes these can be obvious; sometimes they are so subtle the clinician may not even be aware there can be an impact on the patient. A guideline prepared by Queensland Health provides awareness about broader issues around patient care for Aboriginal and Torres Strait Islander people.²⁷³

5.1.6 People from other cultures

The Australian Bureau of Statistics (ABS) 2011 Census shows Queensland's population grew in the five years between 2006 and 2011, and that migrants have had a major role in this growth. There is continuing growth in cultural diversity across Queensland, including a notable growth in South East Queensland. Queensland is an increasingly multicultural society being home to people who speak more than 220 languages, hold more than 100 religious beliefs and come from more than 220 countries.²⁷⁴ The Queensland Government Statistician's Office also produces regular overseas migration figures for Queensland.²⁷⁵

Culture, for the purpose of this guideline, may be defined as: ‘a complex, learned, shared system of human behaviour, rituals and symbolism’. Despite the difference between cultures, there are usually common interests that may serve as starting points for discussion. In most cultural groups, the family has traditionally been the main source of security, assisted by adherence to their religious or spiritual beliefs. Migration from the country of birth cuts off many support systems and reduces the recognition and celebration of symbolic events. This can increase the sense of alienation and helplessness at times where difficult decisions are required.

People from other cultures arrive in Australia for a variety of reasons.²⁷⁶ Mostly the decision to relocate is voluntary, but sometimes it is not. Once living in Australia, people who are displaced from their birth country tend to live in the same vicinity to retain their traditional community support. It is to this community support that people often turn to if they are faced with difficult end of life decision-making.²⁷⁷

Generally, many cultural groups approach religion and spirituality very seriously. There are a number of religions that cross language and cultural boundaries, so it is important when working with a person facing a life-threatening illness and their family to not assume anything, and to understand where religion fits within the spectrum. There are many for whom religion in the context of their life in Australia does not have as significant a role as it may have in their homeland. However, when faced with a life-threatening illness and the possible or subsequent death of a family member or friend, religious practices, rituals and beliefs may resume their importance.

The sometimes startling differences in approaches to death and dying for the various multicultural groups means that clinicians treating patients who identify with another culture must be mindful about how the subject can be approached with the family.

It is important for health professionals and others to acquire some knowledge about these issues to ensure a sensitive approach when working with people facing terminal illness, their family and friends. Cultural factors shape patients’ preferences around decision-making, receiving bad news and end of life care. The developed world’s emphasis on patient autonomy, informed consent and truth telling is often at odds with the beliefs and values of some cultural groups, who may place greater value on family involvement in decision making as opposed to individual autonomy. For example, in some cultures, discussing death is actively discouraged as it is viewed as an indication of disrespect, likely to extinguish hope, invite death, and/or cause distress, depression and anxiety.²⁷⁸

The notion of ‘cultural safety’ is often referred to in recent literature about health care for people from other cultures. Cultural safety acknowledges that the culture of the provider can adversely impact on the recipient if there is a power imbalance. People from all cultural backgrounds may feel disempowered for many reasons, including:

- lack of medical knowledge
- lack of understanding of the illness and/or treatment/support care strategies
- not being involved in care planning
- unfamiliarity with the care environment (for example, a hospital/hospice)
- perceived social inequality
- differences in lifestyle
- lack of literacy/numeracy skills (for example, understanding medicine dosage)
- previous negative experiences with health care, and
- having heard negative stories from relatives about their experiences with health care.

Source: Clark & Phillips (2010)

5.1.7 People from the LGBTIQ communities

LGBTIQ is an acronym that is used to refer to people of diverse sexualities, relationships, genders and bodies. LGBTIQ people experience some issues which are uniquely related to their social experience and identity. LGBTIQ refers to issues broader than sexuality. People who are transgender, gender diverse or intersex may describe themselves as heterosexual and therefore not a minority sexual group. Intersex is also not a gender. Some people with Intersex variations may self-identify as male or female, as intersex or as non-binary. Some people who have intersex variations may describe themselves as transgender.

However, according to some researchers, there is little understanding in Australia of the special issues faced by gay, lesbian, bisexual and transgender people in end-of-life care and advance care planning.²⁷⁹ While many of the experiences of LGBTIQ people in receiving end-of-life care are similar to those of non- LGBTIQ people, some particular challenges facing LGBTIQ people in accessing end-of-life care have been identified in prior literature:²⁸⁰

At the end of their lives, GLBT Australians face the possibility of discrimination and inappropriate care. Advance care planning can help mitigate discrimination, particularly in ensuring that same-sex partners and other members of 'families of choice' are involved in end-of-life care and decision making. As in the wider population, however, significant barriers to advance care planning exist. How GLBT people experience these barriers may reflect their unique experiences and community history, as well as the additional pressure of dealing with services that fail to properly acknowledge gender and sexual diversity.

More recently, a 2016 systematic review examined evidence around the bereavement experience of partners of LGBTIQ people through thirteen relevant studies. All of them highlighted additional barriers faced by bereaved LGBTIQ people, beyond the pain experienced after losing a partner:²⁸¹

1. Anticipating discrimination: People access palliative care services late or not at all, either because they anticipate stigma or discrimination or they think the service is not for them
2. Complexities of religion and LGBT end of life care: Anecdotal evidence suggests that palliative and end of life care services may not always ensure LGBT patients and their families have the same spiritual needs addressed at end of life as any other patient.
3. Assumptions about identity and family structure: Health and social care staff often make assumptions about people's sexuality or gender identity that have an impact on their experience of palliative and end of life care. Evidence suggests that some clinicians do discriminate on the basis of sexual orientation.
4. Varied support networks: LGBT people at the end of life may choose to be surrounded by close friends and support groups which represent constructed support networks alongside biological ones. LGBT people can also feel concerned that their loved ones will not be respected and recognised as next of kin.
5. Unsupported grief and bereavement: Partners feel isolated or unsupported during bereavement because of their sexuality.
6. Increased pressure on LGBT carers: There is increased pressure on informal carers, because people are accessing palliative and end of life care services late or not at all. LGBT people may also experience barriers to palliative care because they are:
 - three times more likely to be single
 - less likely to have children
 - far more likely to be estranged from their birth families (though many LGBT people will have alternative family structures in place)
 - significantly more likely to experience damaging mental health problems.

These factors are likely to lower the chances of stable, ongoing informal care for some LGBTIQ people. Informal care, particularly from a partner, plays a vital role in ensuring someone gets access to palliative care. However, further research is needed on how being single influences access to health and social care services at the end of life, and on how adaptable hospice and palliative care services are to alternative family structures.²⁸²

5.2 Organ and tissue donation

Organs for transplantation are currently derived from three main sources: living donors, brain-dead donors and donors whose hearts have, at least briefly, stopped. Although research shows around seventy per cent of Australians support organ and tissue donation, only thirty per cent have registered to become donors.²⁸³ Forty per cent of those registered to become donors never donate because their family do not consent to organ donation. One reason for the discrepancy between supporters and actual donors is the fear that medical personal will not 'give it their all' if they know someone is a registered donor.

There is a popular fear that doctors will prematurely withdraw treatment if the patient is an organ donor. The idea that a potential donor will be sacrificed for multiple recipients in a utilitarian fashion is an unfortunate misconception.

In 2015, 435 organ donors gave 1,241 Australians a new chance in life. The number of organ donors and transplant recipients in 2015 was the highest since national records began.²⁸⁴ A 'potential donor' is usually identified after all measures to preserve life and to assist the patient in making a meaningful recovery have been attempted, and unfortunately the patient fails to recover. Unless the family or patient raises the issue of donation prior to patient death, the next of kin are usually approached for consent once the formal diagnosis of death has been made. The person best qualified to liaise with next of kin is either the senior doctor caring for the patient or the donor transplant coordinator.

Treating doctors of the 'potential donor', the transplant team and the treating doctors of the 'potential recipient' remain separate entities. It is important that they remain as such for public and patient confidence and trust in medical professionals and the delivery of medical care. It is paramount that at all times the intentions and interests of each professional body are transparent, so that confidence in our medical system remains.

In terms of the legal context, the *Transplantation and Anatomy Act 1979* regulates donation of blood and tissue and the *Guardianship and Administration Act 2000* deals with, among other things, consent from QCAT for live adult tissue donation for adults without capacity.

Organ and tissue donation is one consideration among many that may face families of patients at the end of life. Careful and sensitive communication about the potential for organ and tissue donation is conducted by donor coordinators who are experienced in and passionate about this area. The Australian Government aims to improve access to life-transforming transplants for Australians through a sustained increase in the donation of organs and tissues by implementing a nationally coordinated approach to organ and tissue donation. Further information and contact details are available from the Queensland section of the [Donate Life website](#).

Special Considerations – Summary Points

1. It is Queensland Health's policy that decisions to withhold or withdraw life-sustaining measures must be made on a case by case basis, and age or race or lifestyle must never be used to qualify these decisions.
2. Because a person has a disability, it should not be assumed they are unable to contribute to decision-making about end of life choices.
3. Major depression should be treated before a patient is asked to undertake advance care planning. If doubt exists about a patient's capacity, or where it is believed major depression is present, psychiatric consultation should be arranged.
4. Having to move from isolated communities to regional or metropolitan centres for treatment or care can result in significant impact and trauma, not only for the Aboriginal and Torres Strait Islander individual, but also for their families.
5. Although there are degrees to which Aboriginal and Torres Strait Islander people are connected to their traditions, the concept of community and the central place of land and family obligations are common underpinning values within and across Aboriginal and Torres Strait Islander communities throughout Australia.
6. While many of the experiences of LGBTI people in receiving end-of-life care are similar to those of non-LGBTI people, some particular challenges facing LGBTI people in accessing end-of-life care have been identified, such as assumptions about identity and family structure: Health and social care staff often make assumptions about people's sexuality or gender identity that have an impact on their experience of palliative and end of life care.
7. The sometimes startling differences in approaches to death and dying for the various multicultural groups mean that clinicians treating patients who identify with another culture must be mindful about how the subject can be approached with the family.
8. The diagnosis of a life-threatening condition in a person who lives with a decision-making disability, or the progression of an existing condition, may bring the person into new care settings where knowledge of his or her disability and how they live with it are limited or non-existent.

6.0 Advance care planning

While advance care planning is not the focus of these guidelines, it is important to include for completeness in the discussion about care at the end of life. When these guidelines were first published in 2009, a formal advance care planning program in Queensland Health was in its infancy. As part of the implementation process for the Acute Resuscitation Plan (ARP), advance care planning was introduced to provide a more 'acceptable' basis for which to initiate resuscitation planning.

Advance care planning is the umbrella term that captures the anticipatory planning elements for treatment and care at the end of life, including: resuscitation planning with a hospital doctor, general practitioner or allied health professional; arranging care and financial matters; thinking about, deciding upon and communicating preferences for treatment and care; transitioning to and being supported by specialist palliative care; formalising end-of-life decisions in enduring documents; making funeral arrangements; and fulfilling end-of-life wishes. Advance care planning is just that; planning in advance for care at the end of life, and therefore should be initiated as soon as practicable and appropriate where there is any one or a combination of the following:

- diagnosis of a chronic life-limiting illness such as cancer, heart disease, COPD, CKD or dementia
- increasing frailty and dependence on others for physical, social and emotional support
- unplanned hospital admissions due to progressive disease
- patient and family raise concerns about the future
- presence of other modifiable lifestyle factors in conjunction with progressive disease
- other factors, such as a recent death of someone close to patient or family history of chronic or life-limiting disease
- advancing age in conjunction with other comorbidities
- patient's prognosis is uncertain, but progressing toward deterioration of all or most indicators of their condition
- patient has a likely prognosis of less than 24 months.²⁸⁵

Queensland Health statewide [Advance Care Planning Clinical Guidelines](#) are now available. This document provides high level guidance to clinicians across all HHSs in the development of local policies and procedures to progress and expand the uptake of ACP for all ages and life stages across all service settings. [Appendix 7](#) provides list of possible triggers to initiate advance care planning and is a stand-alone resource named the ACP Quick Guide. Appendix 7 contains another stand-alone resource, the '[Six-step advance care planning process](#)'.

Appendices

Appendix 1

End of life care in Queensland: a brief snapshot⁶

In 2014-15, of the almost 30,000 people who died in Queensland, over half (15,678) died in hospital; 70.8 per cent in public hospitals and 29.2 per cent in private hospitals.²⁸⁶ In 2015, people aged 60 and over represented 84.6 per cent of all deaths in Queensland, ten years before the same population accounted for 82.9 per cent of deaths. Over the last 135 years, life expectancy for Queenslanders has almost doubled: from 41.3 years for males and 49.8 for females in 1881 to 80.0 for males and 84.3 for females in 2015.²⁸⁷

Table 1 – 2015 top ten causes of deaths of Queenslanders (including children)²⁸⁸

All causes	Number	Age specific death rate ⁷
Ischaemic heart diseases (I20-I25)	3,866	80.9
Malignant neoplasms of digestive organs (C15-C26)	2,434	50.9
Cerebrovascular diseases (I60-I69)	2,031	42.5
Malignant neoplasms of respiratory and intrathoracic organs (C30-C39)	1,770	37.0
Organic, including symptomatic, mental disorders (F00-F09)	1,707	35.7
Chronic lower respiratory diseases (J40-J47)	1,539	32.2
Other forms of heart disease (I30-I52)	1,512	31.6
Diabetes mellitus (E10-E14)	850	17.8
Malignant neoplasms of lymphoid, haematopoietic and related tissue (C81-C96)	829	17.3
Intentional self-harm (X60-X84)	746	15.6
Total	29,782	

Source: Australian Bureau of Statistics: 3303.0 Causes of Death, Queensland, 2015.

The most recent Health of Queenslanders Report (2016) contains a statistical snapshot of death and dying which highlights the following:²⁸⁹

Health of Queenslanders Report: Ten quick facts for death and dying

1. One-third of all deaths are due to lifestyle related chronic conditions.
2. Indigenous Queenslanders were four times as likely to die before 50 years of age as non-Indigenous
3. Queenslanders—37% died before 50 years compared with 8.7% of non-Indigenous.
4. Cancers and cardiovascular diseases are the leading broad causes of death in Queensland, followed by respiratory conditions and injuries.
5. The majority of deaths (60%) occur in people aged 75 years and older—40% are premature.
6. Death rates are decreasing for the major conditions, indicative of the benefits of prevention, screening, early diagnosis and effective treatment.
7. There are many opportunities to reduce early deaths and improve end of life experience which will contribute to longer life expectancy, fewer years lived in ill-health, reduced costs and greater social wellbeing.
8. There is substantial variation in death outcomes across the regions, with better outcomes in the more populous HHSs. The northern and western HHSs generally have poorer outcomes, but improvement is evident with declining death rates particularly for lifestyle related conditions.
9. There were 18,048 deaths of older people (75 years and older) in 2014, accounting for 63% of all deaths.
10. Many people die in hospital—about two-thirds of those aged 65–74 years in 2014, however, that proportion declines in older age groups to about 40% of those aged over 85 years.

Source: Health of Queenslanders Report (2016)

To obtain a more accurate picture of Queensland's end of life population we need to turn to hospital activity data, in particular statistics about admitted patient activity, outpatient services, community and aged care. Most often, end-of-life populations are characterised as those who receive palliative care services, but this represents only part of the picture. The research shows that people approaching the end of life can experience deterioration long before being referred to palliative care services.²⁹⁰ In fact, the outcomes of research in this area overwhelmingly recommend that advance care planning should identify end-of-life populations long before they are referred to palliative care. Over the years, various attempts have been made to identify this population, not only in Queensland, but also in other jurisdictions nationally and internationally.

This task is not without challenge; capturing data around deterioration in the last two years or so before a person dies is difficult to verify for a host of reasons. These include, but are not limited to, duplication and fragmentation of services, coding anomalies as a result of patients alternating between health specialties, admitted and non-admitted services, private and public separations, and services received in the community. In addition, presence of a life-limiting condition does not preclude the provision of curative medical treatment when a patient is first diagnosed. Persons who elect to continue curative treatment even though their death may occur within a year or more could well be excluded from data sets that identify end-of-life populations. Largely, for these reasons, researchers turn to palliative care data to obtain the most accurate picture of services for the dying to determine how the experience for those patients and their families may be improved.

It is recognised that by the time a patient is referred to palliative care services they are usually well along their disease trajectory and have likely opted for treatment and care that is primarily for quality of life. Nevertheless, examination of palliative care statistics is useful to identify and better understand that part of the population who are receiving those services and are close to death. Because most palliative care patients usually receive their care in the 'admitted patient setting' (hospice, palliative care or other hospital ward), the role that hospitals play in providing end-of-life care has become crucial for those living with chronic progressive debilitating conditions. In the hospital setting, inpatient palliative care is provided through designated palliative care units/beds and 'general' beds as well as through outpatient consultations in ambulatory settings.

In 2013–14, a total of 10,400 palliative hospitalisations were recorded in Queensland; 77.4 per cent in public hospitals and 22.6 per cent in private hospitals.²⁹¹ Over the five years from 2009–10 to 2013–14, admitted palliative patient care across Australia increased 11 per cent; in comparison, Queensland recorded an increase in palliative care related hospitalisations of 36 per cent across both public and private hospitals.

Table 2 - Palliative care-related hospitalisations, Queensland and Australia, public and private hospitals, 2009-10 to 2013-14²⁹²

Hospitals	2009-10	2010-11	2011-12	2012-13	2013-14	Av. annual % change
Queensland Public	5,953	6,599	7,333	8,404	8,051	7.8
Australia Public	47,345	45,713	48,772	52,071	52,058	2.4
Queensland Private	1,696	1,715	2,005	1,946	2,349	8.5
Australia Private	8,638	8,753	8,842	9,525	10,106	4.0
Queensland all hospitals	7,649	8,314	9,338	10,350	10,400	8.0
Australia all hospitals	55,983	54,466	57,614	61,596	62,164	2.7

Source: Australian Institute of Health and Welfare 2014.

Table 3 - Queensland palliative care related hospitalisations percentage by mode of discharge, public and private, 2013-14

Discharge or transfer to:	Public	Private	All hospitals
Another acute hospital	7.8	1.9	6.4
Residential aged care	2.5	1.0	2.2

Discharge or transfer to:	Public	Private	All hospitals
Other health care accommodation	1.2	0.8	1.1
Statistical discharge	1.9	2.3	2.0
Left against medical advice	0.2	0.0	0.2
Died	58.0	59.7	58.4
Other (includes own residence)	28.4	34.2	29.7
Total	100.0	100.0	100.0

Source: Australian Institute of Health and Welfare 2014²⁹³

The number of readmissions patients encounter prior their death, together with the length of each admission also provides some indication about how care at the end of life may be experienced. The table below shows the number of admissions for persons who died in 2015–16 and were hospitalised in Queensland in the last six months prior to death in relation to palliative care received. For completeness, the table includes columns for episodes and percentages for renal dialysis, transplants and same day chemotherapy (highlighted in orange).

Table 4 - Summary statistics for persons who died in 2015-16 and were hospitalised in Queensland in the last 6 months prior to their death

Key Statistics				(Includes episodes for renal dialysis, transplants and same day chemotherapy)		
No. of patients		21,993		22,042		
No. of patients who died in hospital		14,673		14,680		
No. of patients who had palliative care episodes		7,181		7,181		
Of all patients, how many died in hospital and had palliative care?						
In-hospital death status	No palliative care episode	Had palliative care episode	Total	No palliative care episode	Had palliative care episode	Total
Did not die in hospital	6,610	710	7,320	6,652	710	7,362
Died in hospital	8,202	6,471	14,673	8,209	6,471	14,680
Total	14,812	7,181	21,993	14,861	7,181	22,042
Of the patients who died in hospital what was their episode type?						
Care type in the episode the patient died in:	Public	Private	Total	Public	Private	Total
Palliative	4,989	1,236	6,225	4,989	1,236	6,225
Acute	5,166	2,935	8,101	5,172	2,936	8,108
Other	310	37	347	310	37	347
Total	10,465	4,208	14,673	10,471	4,209	14,680
Of patients who died in hospital and had at least one palliative episode of care, how many died in palliative episode?						
Care type episode the patient died in	Public	Private	Total	Public	Private	Total
Palliative	4,989	1,236	6,225	4,989	1,236	6,225
Acute	159	52	211	159	52	211
Other	33	2	35	33	2	35
Total	5,181	1,290	6,471	5,181	1,290	6,471

Source: Statistical Services Branch, Data Request: based on QHAPDC extracted 7 December 2016, Queensland Death Registry extracted 7 December 2016 and Statistical Services Branch Master Linkage File (Vers.1269) (NB: excludes persons under 16 years, boarders, posthumous organ procurement, unqualified neonates, obstetrics, paediatrics, and trauma)

Of the just over 22,000 Queenslanders hospitalised six months prior to their death in 2015–2016, 66.7 per cent (14,680 patients) died in hospital. While there are subtleties around capturing the episode of care in which patients die, figures show that of those who died in hospital, 42.2 per cent (6,225 persons) were under a palliative care-type service at the time of their death. Patients who did not access palliative care services in the six months before their death and died in hospital represented 55.9 per cent (8,209) of the total number of patients who died in hospital. This generally accords with the figure of 55.3 per cent of patients (8,108) at the time of their death being registered under an ‘acute care type’, which is likely to have precluded palliative care services.

The average length of stay for palliative care services across both public and private hospitals in Queensland in 2013-14 was reported to be 9.4 days.²⁹⁴ In comparison, recent data suggests that in 2015–16, the average length of stay for admissions for those in the last six months of life is 24.5 days, while the average length of stay in the last admission for those who died in hospital is 14.1 days. Meanwhile in 2014-15, for all admissions across all hospitals in Queensland (excluding same day separations), the average length of stay was 5.2 days.²⁹⁵

Table 5 - Number of admissions to Queensland hospitals in the last 6 months of life for those who died in 2015–16

Number of admissions	Count	%	Count	%
1	8,243	37.5	8,018	36.4
2	5,167	23.5	4,768	21.6
3	3,249	14.8	2,901	13.2
4	2,020	9.2	1,788	8.1
5+	3,314	15.1	4,567	20.7
Total	21,993	100.0	22,042	100.0
Average length of stay				
Average length of stay in last 6 months	23.2		24.5	
ALOS in the last admission	12.6		12.5	
ALOS in the last admission for those who died in hospital	14.1		14.1	

Source: Statistical Services Branch, Data Request: based on QHAPDC extracted 7 December 2016, Queensland Death Registry extracted 7 December 2016 and Statistical Services Branch Master Linkage File (Vers.1269) (NB: excludes persons under 16 years, boarders, posthumous organ procurement, unqualified neonates, obstetrics, paediatrics, and trauma)

The principal diagnosis for palliative episodes ending in death of the patient in hospital also reveals that 57.7 per cent (3,595 out of 6,225) of patients die from some form of cancer, either with or without other co-morbidities. This compares to recent Australian statistics which states that in 2013-14, of the 23,155 people who died of some form of cancer in Australian hospitals, 76.4 per cent had received some form of palliative care related services – 5,462 people who died were not recorded as being under palliative care services.²⁹⁶ For all other non-cancer related deaths, 29.4 per cent had received palliative care related services; that is, 14,993 out of 51,066 patients who died of non-cancer related diseases were receiving or had received some form of palliative care-related services prior to their death. Therefore, a patient is three times more likely to receive palliative care services before their death if their principal diagnosis is cancer-related.

Latest figures for palliative care episodes across all HHSs from July 2016 to June 2017 indicate that palliative care represents 0.70 per cent of all admitted patients to public facilities (8,379 episodes). Palliative care patient days in all Queensland public facilities from July 2016 to June 2017 represented 2.04 per cent (68,994) total patient days.

Table 6 - Principal diagnosis for palliative episodes of care ending in in-hospital death for persons who died in 2015-16 and hospitalised in the last 6 months prior to death

Condition	Count	%	Count	%
Heart Failure	215	3.5	215	3.5
COPD	155	2.5	155	2.5
Coronary heart disease	73	1.2	73	1.2
Renal failure	151	2.4	151	2.4
Neoplasm	3,593	57.7	3,593	57.7
Other	2,038	32.7	2,038	32.7
Total	6,225	100.0	6,225	100.0

Source: Statistical Services Branch, Data Request: based on QHAPDC extracted 7 December 2016, Queensland Death Registry extracted 7 December 2016 and Statistical Services Branch Master Linkage File (Vers.1269) (NB: excludes persons under 16 years, boarders, posthumous organ procurement, unqualified neonates, obstetrics, paediatrics, and trauma)

This brief snapshot reveals that while Queenslanders are living longer, the demand for end-of-life care, in particular palliative services, is increasing in Queensland, more than in Australia as a whole. Statistics also show that being able to access palliative care services at least six months prior to death significantly decreases the possibility of dying in acute care-type settings. An important message to be taken from this brief analysis is the need to optimise care at the end of life by raising awareness of the importance of advance care planning. That, combined with key actions and deliverables within the *Statewide strategy for end-of-life care 2015* to raise the public profile of advance care planning and provide resources for clinicians and the public will over time, go towards ensuring that discussions around life-sustaining measures become routinized in all clinical practice.

An understanding of the demand for end-of-life services should also inform Hospital and Health Service health service planning activities for future supply of services such as specialist palliative care and promotion of a palliative approach. Conversations about life-sustaining measures should not be deferred until the patient is clearly dying, and decisions are required in a crisis without knowing what the patient would have wanted. Resuscitation planning should happen within the context of advance care planning to ensure there is agreement about the overall treatment plan for the adult patient and those closest to them. An important aspect of this conversation should be limit the potential for unnecessary and unwanted treatment at the end of life.

Appendix 2

Guiding Principles from the National Consensus Statement: essential elements for safe and high-quality end-of-life care.²⁹⁷

1. Dying is a normal part of life and a human experience, not just a biological or medical event.
2. Patients must be empowered to direct their own care, whenever possible. A patient's needs, goals and wishes at the end of life may change over time.
3. Providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs.
4. Recognising when a patient is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care.
5. The prognosis and the way that people respond to medical treatment will vary between individuals. This means that there is potential for ambiguity and uncertainty at the end of life. This must be honestly and openly acknowledged, and discussed with patients, substitute decision-makers, families and carers.
6. Safe and high-quality end-of-life care is patient and family-centred. Whenever possible, it should be aligned with the values, needs and wishes of the individual, and their family or carers. Such care should consider the patient's expressed wishes regarding the circumstances, environment and place in which they wish to die.
7. Safe and high-quality end-of-life care requires the availability of appropriately qualified, skilled and experienced interdisciplinary teams.
8. Safe and high-quality end-of-life care requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams, within and between settings, and across multiple episodes of care.
9. Care of the dying is urgent care. Timely recognition of a patient's transition to the terminal phase of life must be documented and communicated to patients, families, carers and other health professionals by the interdisciplinary team. The care plan must be specifically revised to meet the unique needs of the patient, family and carers during this phase.
10. End-of-life decision-making should be shared between the interdisciplinary team and the patient. Substitute decision-makers, families and carers should be involved, in accordance with the patient's expressed wishes and/or jurisdictional legislation.
11. The interdisciplinary team has a responsibility to:
 - provide timely and accurate information regarding the patient's clinical condition and its severity or stage, the expected disease trajectory, the available treatments, and the likelihood of response to such treatments
 - clearly communicate information to support patients (or substitute decision-makers, families and carers) to make decisions about care, and to check that they understand the implications, consequences and risks associated with such decisions
 - invite patients to participate in the process of advance care planning, and create opportunities for patients to make decisions and to communicate their values, goals and wishes regarding their end-of-life care
 - offer support, expert opinion and advice so that patients (or substitute decision-makers, families and carers) can participate in fully informed, shared (or supported) decision-making
 - identify existing advance care plans and provide care in accordance with the patient's expressed wishes

- document, communicate and hand over the agreed plan of care and any limitations of medical treatment to other clinicians involved in the patient's care.
12. For ethical reasons, it is important not to harm patients approaching the end of life by providing burdensome investigations and treatments that can be of no benefit.
 13. Patients have the right to refuse medical treatments. Decisions regarding treatment may be made in advance and remain valid unless the patient (or substitute decision-maker, family and carers) state otherwise.
 14. Unless required by law, doctors are not obliged to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the patient's quality of life.
 15. Care of the deceased person, and care for families and carers extends to the period after the patient has died.

Appendix 3

End-of-life component from the Medical Board of Australia's Good medical practice: a code of conduct for doctors in Australia²⁹⁸

Doctors have a vital role in assisting the community to deal with the reality of death and its consequences. In caring for patients towards the end of their life, good medical practice involves:

1. Taking steps to manage a patient's symptoms and concerns in a manner consistent with their values and wishes.
2. Providing or arranging appropriate palliative care.
3. Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.
4. Understanding that you do not have a duty to try to prolong life at all cost. However, you do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.
5. Accepting that patients have the right to refuse medical treatment or to request the withdrawal of treatment already started.
6. Respecting different cultural practices related to death and dying.
7. Striving to communicate effectively with patients and their families so they are able to understand the outcomes that can and cannot be achieved.
8. Facilitating advance care planning.
9. Taking reasonable steps to ensure that support is provided to patients and their families, even when it is not possible to deliver the outcome they desire.
10. Communicating bad news to patients and their families in the most appropriate way and providing support for them while they deal with this information.
11. When your patient dies, being willing to explain, to the best of your knowledge, the circumstances of the death to appropriate members of the patient's family and carers, unless you know the patient would have objected.

Appendix 4

General Principles²⁹⁹

1 Presumption of capacity

An adult is presumed to have capacity for a matter.

2 Same human rights

(1) The right of all adults to the same basic human rights regardless of a particular adult's capacity must be recognised and taken into account.

(2) The importance of empowering an adult to exercise the adult's basic human rights must also be recognised and taken into account.

3 Individual value

An adult's right to respect for his or her human worth and dignity as an individual must be recognised and taken into account.

4 Valued role as member of society

(1) An adult's right to be a valued member of society must be recognised and taken into account.

(2) Accordingly, the importance of encouraging and supporting an adult to perform social roles valued in society must be taken into account.

5 Participation in community life

The importance of encouraging and supporting an adult to live a life in the general community, and to take part in activities enjoyed by the general community, must be taken into account.

6 Encouragement of self-reliance

The importance of encouraging and supporting an adult to achieve the adult's maximum physical, social, emotional and intellectual potential, and to become as self-reliant as practicable, must be taken into account.

7 Maximum participation, minimal limitations and substituted judgment

(1) An adult's right to participate, to the greatest extent practicable, in decisions affecting the adult's life, including the development of policies, programs and services for people with impaired capacity for a matter, must be recognised and taken into account.

(2) Also, the importance of preserving, to the greatest extent practicable, an adult's right to make his or her own decisions must be taken into account.

(3) So, for example—

(a) the adult must be given any necessary support, and access to information, to enable the adult to participate in decisions affecting the adult's life; and

(b) to the greatest extent practicable, for exercising power for a matter for the adult, the adult's views and wishes are to be sought and taken into account; and

(c) a person or other entity in performing a function or exercising a power under this Act must do so in the way least restrictive of the adult's rights.

(4) Also, the principle of substituted judgment must be used so that if, from the adult's previous actions, it is reasonably practicable to work out what the adult's views and wishes would be, a person or other entity in performing a function or exercising a power under this Act must take into account what the person or other entity considers would be the adult's views and wishes.

(5) However, a person or other entity in performing a function or exercising a power under this Act must do so in a way consistent with the adult's proper care and protection.

(6) Views and wishes may be expressed orally, in writing or in another way, including, for example, by conduct.

8 Maintenance of existing supportive relationships

The importance of maintaining an adult's existing supportive relationships must be taken into account.

9 Maintenance of environment and values

(1) The importance of maintaining an adult's cultural and linguistic environment, and set of values (including any religious beliefs), must be taken into account.

(2) For an adult who is a member of an Aboriginal community or a Torres Strait Islander, this means the importance of maintaining the adult's Aboriginal or Torres Strait Islander cultural and linguistic environment, and set of values (including Aboriginal tradition or Island custom), must be taken into account.

Notes—

1 **Aboriginal tradition** has the meaning given by the *Acts Interpretation Act 1954*, schedule 1.

2 **Island custom** has the meaning given by the *Acts Interpretation Act 1954*, schedule 1.

10 Appropriate to circumstances

Power for a matter should be exercised by a guardian or administrator for an adult in a way that is appropriate to the adult's characteristics and needs.

11 Confidentiality

An adult's right to confidentiality of information about the adult must be recognised and taken into account.

Health Care Principle³⁰⁰

- (1) The **health care principle** means power for a health matter, or special health matter, for an adult should be exercised by a guardian, the public guardian, the tribunal, or for a matter relating to prescribed special health care, another entity—
 - (a) in the way least restrictive of the adult's rights; and
 - (b) only if the exercise of power—
 - (i) is necessary and appropriate to maintain or promote the adult's health or wellbeing; or
 - (ii) is, in all the circumstances, in the adult's best interests.

Example of exercising power in the way least restrictive of the adult's rights—

If there is a choice between a more or less intrusive way of meeting an identified need, the less intrusive way should be adopted.

- (2) In deciding whether the exercise of a power is appropriate, the guardian, the public guardian, tribunal or other entity must, to the greatest extent practicable—
 - (a) seek the adult's views and wishes and take them into account; and
 - (b) take the information given by the adult's health provider into account.

Note—

See section 76 (Health providers to give information).

- (3) The adult's views and wishes may be expressed—
 - (a) orally; or
 - (b) in writing, for example, in an advance health directive; or
 - (c) in another way, including, for example, by conduct.
- (4) The health care principle does not affect any right an adult has to refuse health care.
- (5) In deciding whether to consent to special health care for an adult, the tribunal or other entity must, to the greatest extent practicable, seek the views of the following person and take them into account—
 - (a) a guardian appointed by the tribunal for the adult;
 - (b) if there is no guardian mentioned in paragraph (a), an attorney for a health matter appointed by the adult;
 - (c) if there is no guardian or attorney mentioned in paragraph (a) or (b), the statutory health attorney for the adult.

Appendix 5

Supreme Court cases on best interests and life-sustaining treatment for adults who lack capacity³⁰¹

Application of Justice Health; Re a Patient (2011) 80 NSWLR 354; [2011] NSWSC 432 (Justice Health) The New South Wales Supreme Court declared that life-sustaining treatment for a prisoner with end-stage lung cancer, who lacked capacity and was expected to live for only a matter of days or weeks, was futile and need not be given.

Slaveski v Austin Health [2010] VSC 493 (Slaveski) The Victorian Supreme Court held that continuing artificial ventilation for a 71-year-old man in a coma from a catastrophic stroke was burdensome and not in the man's best interests. The medical team did not need to provide treatment despite family requests.

Australian Capital Territory v JT (2009) 4 ACTLR 68; [2009] ACTSC 105 (JT) The ACT Supreme Court held that artificial nutrition and hydration was not futile for a 69-year-old man with a psychiatric illness manifesting in religious obsessions which led to extreme fasting. The court declined to make the declaration sought by the government that it would be lawful to stop this treatment.

Melo v Superintendent of Royal Darwin Hospital (2007) 21 NTLR 197; [2007] NTSC 71 (Melo) The Northern Territory Supreme Court held that treatment for a 29-year-old man with catastrophic injuries sustained in a motor vehicle accident, including high-level fractures of the cervical spinal cord and brain damage, was futile. Despite family requests, the court did not require continued treatment.

In the Matter of Herrington; Re King [2007] VSC 151 (Herrington) The Victorian Supreme Court declined to order that active treatment (including the administration of fluids) be continued for a woman with hypoxic brain damage who had been in a vegetative state for 6 months. It held that the medical team should progress with palliative care despite family request for more active treatment.

Queensland v Astill (unreported, Supreme Court of Queensland, Muir J, 18 January 2006) (Astill) The Queensland Supreme Court ordered blood transfusions be given to a woman injured in a motor vehicle accident despite her possessing a "no blood" card. This card did not comply with formalities of Queensland legislation and so did not operate. Treatment was ordered to promote the patient's welfare.

Messiha v South East Health [2004] NSWSC 1061 (Messiha) The NSW Supreme Court held that active treatment for a 75-year-old man, who suffered severe brain damage after he collapsed at home and his brain was deprived of oxygen for 25 minutes, was futile, burdensome and intrusive and should not be continued. The court did not accept the family's view that treatment was in the patient's best interests.

Northridge v Central Sydney Area Health Service (2000) 50 NSWLR 549; [2000] NSWSC 1241 (Northridge). The NSW Supreme Court reinstated active treatment for a man with brain damage following a drug overdose. The court held that the diagnosis that he was in a "chronic vegetative state" and the decision to withdraw treatment were premature, contrary to the hospital's own guidance, and not in the patient's best interests.

Withholding and withdrawing life-sustaining measures

Legal considerations for adult patients

Consent to withhold/withdraw life-sustaining measures

- Queensland guardianship legislation provides a consenting framework for adults with impaired capacity, through the use of Advance Health Directives (AHD) and substitute decision-makers (SDMs). EXCEPT IN EMERGENCY SITUATIONS, consent is required to withhold and/or withdraw life-sustaining medical treatment (including those measures considered to be “futile”).
- Under the law, patients with capacity provide their own consent (and may refuse life-sustaining treatment, even if this results in their death or would cause it to happen sooner).
- The guardianship law provides for a COLLABORATIVE APPROACH to obtaining consent and includes a legal requirement to DOCUMENT the decision-making pathway.
- Good medical practice and clinical judgement will determine the best approach to the consenting process, with the objective of obtaining CONSENT TO THE OVERALL TREATMENT PLAN.
- Consent is NOT A CONTRACT. There is no “legal” offer and acceptance, but rather a CONVERSATION to ensure information is provided and broad understanding is obtained. This is to avoid criminal and civil action (ASSAULT).
- CONVERSATION = (discussion of) CONDITION + PROGNOSIS + OVERALL TREATMENT PLAN.
- COMMUNICATION IS KEY: The overall treatment plan should be discussed in the context of what can and can’t be done (within reasonable limits of what is achievable) for the patient in a sensitive, yet honest way. This conversation may include discussion, in broad terms, of AVAILABLE treatment options, palliative care and other support measures. The conversation should occur as early as practicable to avoid decisions being made in a crisis.
- COMMUNICATION IS TWO-WAY: Silence or ambivalence from patients or SDMs is not consent. Ensure overall treatment plan is UNDERSTOOD.
- SDMs MUST adhere to the General Principles and the Health Care Principle, and act in best interests of adult (if not => the facility’s dispute resolution process activates and => Public Guardian or court as a last resort).
- If the patient lacks capacity, consent is not required to provide comfort cares (minor/ uncontroversial health care). In these cases, the doctor must reasonably consider this is to promote the patient’s health and wellbeing.



Futile medical treatment

- Concept difficult, controversial and term is best avoided in end-of-life discussions with patients and SDMs. Guardianship law definition linked to “good medical practice” (medical and ethical standards). AHPRA (Medical Board of Australia) provides a [code of conduct for doctors](#) on good medical practice, with specific guidance on end-of-life care.
- Doctors are only required to OFFER what is clinically appropriate and available to the patient, but doctors must still have the consenting conversation (see above).
- Doctors are only required to PROVIDE what is clinically appropriate and available to the patient in accordance with good medical practice.
- Doctors do NOT have to provide, nor accede to demands by patients and their families for clinically inappropriate medical treatment (i.e. futile treatment). THINK dispute resolution.
- Where no AHD, a consent to the withholding or withdrawal of life-sustaining measures (LSM) by a SDM cannot operate unless the doctor reasonably considers PROVIDING the measures would be INCONSISTENT with good medical practice, that is PROVIDING LSMs would be potentially futile.
- Doctors can override directions in AHDs in very limited circumstances (e.g. different circumstances



Withholding and withdrawing life-sustaining measures

Legal considerations for adult patients

apply to directions in AHD; also, a direction to withhold or withdraw LSMs cannot operate in an AHD unless - the patient is in a coma, or is terminally ill with less than 1 year to live, or has no prospect of regaining capacity for health matters, and the treating doctor believes that PROVIDING the measures would be INCONSISTENT with the standards of good medical practice, in other words providing LSMs would be futile).

- An objection by the patient to withhold and/or withdraw LSMs is awkwardly dealt with in the guardianship legislation, but is considered rare in reality. An OBJECTION to a clinical decision to withhold and/or withdraw LSMs = DEMAND for futile treatment (see Acute Resuscitation Plan [ARP] Quick Guide). QH policy position is that objections must be expressed directly to the treating doctor (NOT through a family member).
- The position in legislation is that if the objection is expressed to the doctor, consent will be needed to withhold and/or withdraw treatment.

Clinical management, coordination and responsibility

- Medical technology and the medicalisation of dying has increased demands on the health care system, particularly in ICUs. Queensland Health has to respond by ensuring its approach is both practical and capable of balancing competing interests. Shifting the focus to a more realistic expectation of dying and providing patients with appropriate treatment can reduce unnecessary and unwanted invasive measures and transfers to ICUs.
- Starting point is ALWAYS clinical. When completing an ARP, DOCTORS: What is good medical practice in THIS situation? What can realistically be offered? What can YOU provide this patient to improve their life and health? What would YOU do if the patient arrests? What would YOU want an attending team to do if the patient arrests?
- Remember – Clinical is followed by the legal: Legal does NOT determine the clinical.

- Medical treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to withdraw treatment which has commenced.
- Do not create ‘artificial’ emergencies to avoid obtaining consent, if there is time to do so.
- If clinical doubts or uncertainties, the decision must favour life. Seek a second opinion from an experienced clinician.

Clinical leadership

- Clinical leadership is required to ensure only clinically necessary and available treatment is offered and provided to patients. (DOCTORS: Should the patient be referred to palliative care? If not now, when?)
- If patients are being transferred inappropriately to ICU, must resolve with other specialty.
- Conducting advance care planning (ACP) discussions with the patient and/or their decision-makers as early as appropriate can assist with this process. Ideally, ACP discussions should commence long before a patient has a need for an ARP.
- Documentation of all decisions around life-sustaining measures must be clear & thorough (legal requirement).
- Completing the ARP which was designed to be used in acute emergency situations assists to:
 - identify earlier those patients for whom life-sustaining measures (such as CPR) are clinically inappropriate;
 - identify those patients who refuse medical treatment (e.g. do not want “heroic” LSMs);
 - ensure the appropriate decision-making process is documented and followed (clinical, ethical, legal);
 - initiate dispute resolution when needed; and
 - avoid the “11th hour” crisis and commencement of clinically inappropriate treatment.
- Policy and process compliance => protections under law and indemnity from Queensland Health.

Queensland Health guiding principles for decision-making about life-sustaining measures

Principle 1:	All decision-making must reflect respect for life and the patient’s right to know and choose.
Principle 2:	All decision-making must meet the standards of good medical practice.
Principle 3:	All efforts must be made to obtain the appropriate consent through a collaborative approach.
Principle 4:	There must be transparency in and accountability for all decision-making.

Please note:

This resource is designed primarily for health professionals treating and caring for those at or approaching the end of life. More detailed information can be found in the *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients* or at <https://www.health.qld.gov.au/careatendoflife>

A multidisciplinary guide to identify those who may benefit from advance care planning (ACP Quick Guide)

Triggers that suggest a person may benefit from advance care planning (ACP):

- 1 The "surprise question" – would you be surprised if the person were to die in the next year?
- 2 The person is experiencing symptoms and signs that indicate declining health
- 3 The person is experiencing indicators of decline related to their specific disease or condition
- 4 The person reaches or experiences a significant milestone e.g. advancing age (i.e. aged >65 years or older, or >55 years if an Aboriginal or Torres Strait Islander person), retirement, bereavement, admission to community or aged care facility
- 5 The person, family member or carer raises ACP with a health professional

Symptoms and signs of declining health:

- Advancing disease—unstable, deteriorating, complex symptom burden
- Decreasing response to optimal treatments, decreasing reversibility
- Repeated unplanned (emergency) hospital admissions
- General physical decline and often unwell; prolonged recovery periods
- Declining functional performance status (e.g. Palliative Care Outcomes Collaboration (PCOC) indicators (RUG-ADL, SAS and AKPS), reduced mobility, increasing dependence in activities of daily living
- Presence of other risk factors (e.g. social determinants of health – smoking, obesity, diabetes, depression)
- Resident of or about to enter Residential Aged Care Facility
- Presence of an increasing burden of comorbidities (comorbidity is regarded as the biggest predictor of mortality and morbidity)
- Deteriorating physical and mental status following a significant event, e.g. serious fall, retirement on medical grounds
- Choice to discontinue medical treatments and focus on quality of life
- Progressive unplanned unexplained weight loss in last 6 months (>10%) or failure to regain weight lost

Indicators of decline related to specific diseases/ conditions:

Cancer	Heart and peripheral vascular disease	Neurological disease including dementia
<ul style="list-style-type: none"> • Diagnosis of malignancy • Person is becoming less able to manage usual activities and symptoms getting worse • Metastatic disease (spread to other organs) • Persistent symptoms despite optimal therapy • Refer to Cancer Prognosis tools for further information (e.g. PiPs, Pap, PPI, PPS) 	<ul style="list-style-type: none"> • Diagnosis of moderate to severe: <ul style="list-style-type: none"> – atherosclerosis – myocardial infarction – valvular heart disease – cardiomyopathy – lung disease • Frequent ischaemic chest pain • Short of breath when resting, moving or walking a few steps • Increasing heart failure (HF) symptoms despite maximum tolerated HF therapy, including diuretics, ACE inhibitors and beta-blockers • Intractable peripheral oedema • Worsening or irreversible end-organ damage (including cardiac cachexia) • Repeated hospital readmissions with deteriorating HF, ventricular arrhythmias or cardiac arrest • Peripheral ischaemia (claudication) 	<ul style="list-style-type: none"> • Diagnosis of any progressive neurodegenerative disease, e.g. Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis, stroke or dementia. <ul style="list-style-type: none"> – deteriorating physical health or cognitive function – declining mobility or falls – deteriorating speech/communication – progressive dysphagia • Recurrent aspiration pneumonia • Residual paralysis following a stroke • Inability to care for self without assistance • Urinary and faecal incontinence • Poor outcomes in PCOC indicators (e.g. SAS) • Plus any of the following: weight loss, recurrent sepsis, pressure injury or reduced oral intake
Kidney disease	Liver disease	Frailty
<ul style="list-style-type: none"> • Moderate to late stage (3b, 4 or 5) chronic kidney disease (eGFR < 45ml/min) • Kidney failure complicating other life-limiting conditions or treatments • Non-compliance with recommended treatment • Decision to withhold or withdraw dialysis, whether by patient or doctor, and in whatever circumstances 	<ul style="list-style-type: none"> • Deterioration in past year with complications such as: <ul style="list-style-type: none"> – ascites – hepatic encephalopathy – renal impairment – recurrent infections – oesophageal varices – spontaneous bacterial peritonitis • Diagnosis of cirrhosis with one or more complications in the last year, including: diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome • Alcohol-related liver disease • Liver transplantation options unlikely 	<ul style="list-style-type: none"> • Multiple co-morbidities with significant impairment in day-to-day activities and: <ul style="list-style-type: none"> – deteriorating functional performance status – combination of at least three of the following symptoms: weakness, slow walking speed, significant weight loss, exhaustion, low physical activity • Decreasing appetite and oral intake • Levels 6-9 using the Clinical Frailty Scale
Lung disease		
<ul style="list-style-type: none"> • Disease assessed to be moderate to severe (e.g. from GOLD II - FEV1 50-79% predicted to GOLD IV - FEV1 <30% of predicted) • Recurrent hospital admissions (≥ 3 in last 12 months due to COPD) • Fulfils criteria for long-term oxygen therapy • MRC dyspnoea scale grade 3-5 (levels of breathlessness after activity) • More than 6 weeks of systemic steroids for COPD in preceding 6 months • Persistent symptoms despite optimal therapy, with surgery becoming more risky. 		

[Adapted from: Gold Standards Framework. *Proactive Identification Guidance* (FIG) 6th Ed. 2016; University of Edinburgh. *Supportive and Palliative Care Indicators SHIP tools*; Alsaad A. Melhus et al. A tool for prediction of risk of rehospitalisation and mortality in the hospitalised elderly: secondary analysis of clinical trial data. *BMJ Open* 2015;5:e007259. doi:10.1136/bmjopen-2014-007259; Australian Commission on Safety and Quality in Health Care. *Safety and Quality of End-of-Life Care in Acute Hospitals: A Background Paper*. Sydney: ACSQHC, 2013].

Please see reverse for purpose of this guide and recommendations for further steps to carry out ACP



Queensland
Government

Identifying people who will benefit from advance care planning (ACP)

(Purpose of this guide and recommendations for further steps to carry out)

What is the purpose of the ACP Quick Guide?

The purpose of this multidisciplinary ACP Quick Guide is to assist clinicians to identify when a person may benefit from ACP earlier in the course of their illness. It may also assist to identify those who may be approaching the end of life before significant deterioration of their condition occurs.

Why do we need a guide to identify people who may benefit from ACP?

According to the Australian Commission on Safety and Quality in Health Care, "(C)linicians and patients should identify opportunities for proactive and pre-emptive end-of-life care discussions, to increase the likelihood of delivering high-quality end-of-life care aligned with the patient's values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations."¹

National and international research agrees that predicting mortality and the timing of decline can be difficult, even for experienced clinicians. A single page of broad indicators supports health professionals to identify whether the person in their care is approaching the end of their life and the potential for further decline. While it is never too early or too late to commence ACP, evidence is growing that people benefit most from carrying out ACP as early as possible in their disease trajectory. People who are identified as being at risk of deterioration are more likely to participate actively in their current and future treatment and care.

It is most beneficial for patients, their families² and the multidisciplinary healthcare team to commence ACP before the person suffers a loss of capacity and becomes unable to express and/or document their own preferences and choices about end-of-life care. Early identification of those who may benefit from ACP provides opportunities to actively involve the person and those closest to them in their current and future treatment and care.

Who can use the ACP Quick Guide?

Any healthcare professional who is looking for more guidance to identify those who will benefit from ACP can use this guide. While experienced clinicians may be aware of their patient's declining health, there are times when guidance is needed to make a more holistic assessment of whether the person may benefit from ACP. Caring for patients who are approaching the end of life offers opportunities for the multidisciplinary healthcare team to identify their patient's needs, coordinate and review their goals and plan of care, and consider how best to align care with their expressed values, goals and wishes.

Documenting decisions and potential decision-makers is also an important part of the ACP process, and the responsibility of all involved in the treatment and care of the person.

What happens when a person is identified by the ACP Quick Guide?

If a person is identified as likely to benefit from ACP, the range of health professionals involved in their care should initiate an appropriate ACP process leading to a multidisciplinary review of their treatment plans. After a more thorough clinical assessment of the person's condition, ongoing discussion, coordination and review with the multidisciplinary healthcare team can assist the person and their family to prepare for treatment and care when their condition deteriorates (refer to the [ACP Clinical Guidelines](#) or [ACP flip cards](#) for more information).

What happens if a person falls outside the purpose of the ACP Quick Guide?

A person may fall outside the purpose of these guidelines if they are well. It is never too early to undertake ACP and this can occur by following the six steps in the ACP process, as explained in the [ACP Clinical Guidelines](#). Healthy people may decide to engage in ACP and this should be encouraged. Sometimes initiating ACP may be triggered by exposure to literature, posters and conversations that promote ACP in the well community.

Quality of life and comfort for the person and those closest to them will be the focus in the last days and hours of life through palliative care. The [Care plan for the dying person](#) (CPDP) is designed for those patients who are actively dying in the terminal phase of their disease. Most people who are near to dying should have been identified without the need to refer to the ACP Quick Guide; however that does not preclude their engaging in ACP for what may, in reality, be a limited range of choices.

When in doubt, it is best to initiate ACP in the context of a general discussion about the person's health and well-being. In this way, consent can be obtained and the ACP process followed. No harm can come from initiating ACP early. (Refer to the [ACP Clinical Guidelines](#) or [ACP flip cards](#) for more information, including the ACP process, clinician responsibilities, and legal issues around obtaining and documenting consent).

Where does the ACP Quick Guide fit with other ACP documents?

This guide is Appendix 2 in the [ACP Clinical Guidelines](#) and was developed to support the identification of those at or approaching the end of life, representing step 1 (identify) of the 6 step ACP Process.

1. Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: essential elements for safe and high-quality end-of-life care*. Sydney: ACSQHC, 2015. p. 11.

2. Please note in this ACP Quick Guide the term family is used as the most likely support for the person identified as being at the end of life. Close family members are usually, but not always, substitute decision-maker/s. Where legal consent is required, ensure the person's decision-maker/s is consulted. Refer to the [ACP Clinical Guidelines](#) for further information.

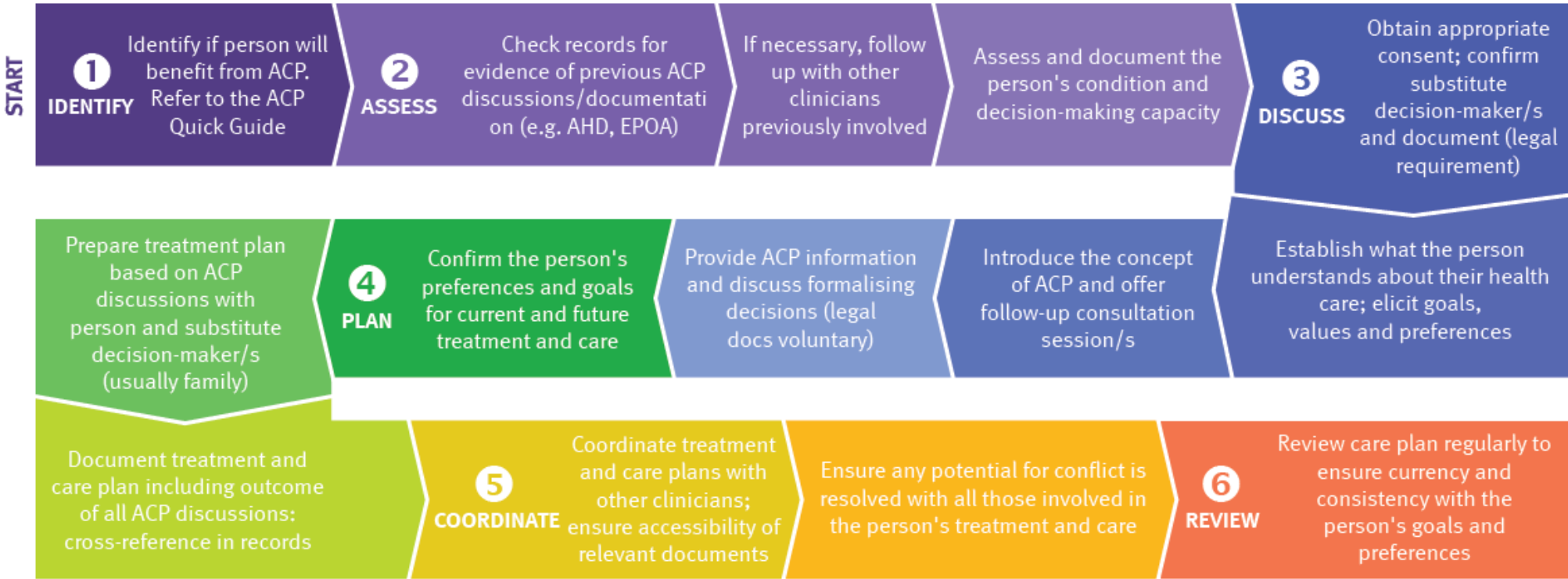


6 Step Advance Care Planning Process

Advance care planning (ACP) is a person-centred approach for planning current and future health and personal care that reflects the person’s values, beliefs and preferences. The process of ACP is collaborative and coordinated. It aims to develop an understanding of the person’s treatment and care goals in order to assist health professionals to better meet their needs.

Effective ACP involves ongoing communication between the person, those closest to them, and a multidisciplinary healthcare team to optimise the person’s current treatment, care, and quality of life. ACP can be carried out at any time and will be driven by the person’s care needs and their willingness to participate.

ACP is an iterative process and should be integrated into clinical practice and routine care. ACP plans should be reviewed regularly to ensure plans remain consistent with the person’s values, beliefs and preferences for health and personal care.



ACP is an iterative process and can commence at any stage. Repeat stages as required. Carefully document to ensure all clinicians can access.

Please note:
This resource is designed primarily for health professionals treating and caring for those at or approaching the end of life.
More information about the 6 step ACP process can be found in the *ACP Clinical Guidelines*, or at <https://www.health.qld.gov.au/careatendoflife>

6 Step Advance Care Planning Process - Considerations

ACP can include:

- assessing the person's current condition and likely prognosis
- establishing the person's health and personal goals, values and preferences
- discussing current and future treatment and personal care options
- identifying the person's decision-makers for a time when they might lack capacity
- documenting treatment and care plans and ensuring they are appropriately communicated and available when needed
- assisting the person to formally document their wishes if they choose to do so
- coordinating treatment and care to reflect the person's goals, values and preferences.

1

IDENTIFY



- Identify those who are most likely to benefit from ACP. Key groups broadly recognised as benefitting most include those: for whom the "surprise question" applies (i.e. would you be surprised if the person were to die in 12 months?), experiencing symptoms and signs of declining health, reaching or experiencing life's milestones (e.g. advancing age, retirement, bereavement)
- Check for general indicators of decline and disease specific indicators related to particular conditions
- Refer to the ACP Quick Guide (Appendix 2 of the [ACP Clinical Guidelines](#))

2

ASSESS



- Check the person's clinical record for evidence of previous ACP discussions/documents - ensure enduring documents (e.g. Advance Health Directive [AHD], Enduring Power of Attorney [EPOA]) are valid (e.g. apply to the current circumstances, up to date)
- Follow up with other clinicians previously involved, particularly if other specialties are involved
- Assess the person's capacity for decision-making - (it is an established legal principle that all adults are presumed to have capacity unless assessed they do not)
- Assess the person's current condition and determine likely prognosis, options and uncertainties for treatment; document
- Consider the need for other decision-makers to be involved if the person has impaired capacity; take any disabilities into consideration

3

DISCUSS



- Obtain the person's consent – this need not be framed as "Will you consent to this discussion?" Rather, expressed as an invitation for the person to talk about their health and personal goals, their experience of illness and what they understand about their current condition; ensure the person remains comfortable to continue the discussion
- Obtain the person's consent to involve others in discussions (part of confidentiality requirements)
- Confirm substitute decision-maker/s and document consenting discussions (part of the legal requirement to document the decision-making pathway)
- Discuss diagnosis, prognosis and realistic treatment options; explain the uncertainties of predicting recovery
- Elicit the person's goals, values and preferences about proposed medical treatment and ongoing care
- Consider/discuss symptom control, pain relief, and other treatment options in the context of changing and deteriorating disease or condition
- Introduce the concept of ACP by describing it without using technical jargon – explain a key step is to identify substitute decision-maker/s in the event of impaired capacity
- If appropriate, introduce resuscitation planning – this is not the sole focus of ACP discussions and should not be forced; be alert for signs of distress
- Provide appropriate ACP information to the person/decision-maker/s – this may include brochures and/or references to ACP websites
- Discuss possibility of person formalising their decisions in legal documents, e.g. EPOA or AHD – ensure people are aware completing legal documents is voluntary
- If the person has impaired capacity, ACP discussions can also be held with their substitute decision-maker/s

4

PLAN



- Ensure open communication is maintained with the person and their substitute decision-maker/s while developing treatment and care plan
- Provide any further information as appropriate, such as for clinical specialty/ community support or other spiritual/cultural support networks
- Based on the person's goals of care and preferences, prepare a care plan that considers current and future treatment and care; build in review mechanisms
- Consider whether the treatment plan provides a realistic balance between active/curative measures and palliative and other support therapies
- Complete appropriate paperwork to support the person's treatment and care plan (e.g. Acute Resuscitation Plan [ARP], Statement of Choices [SoC], Care Plan for the Dying Person [CPDP])
- Ensure treatment and care plan is appropriately documented and communicated to ensure access by multi-disciplinary team

5

COORDINATE



- Involve other teams as appropriate, such as social workers, aged care, spiritual carers, and cultural representatives
- As the person's condition/prognosis deteriorates, coordinate with community care and/or palliative care teams for ongoing support as appropriate
- Any potential for misunderstanding or dispute should be resolved by this stage - involve senior clinicians and/or escalate to facility management
- Ensure processes are in place to manage place of dying and bereavement, including emotional, cultural, spiritual & social support to those closest to the person

6

REVIEW



- Revisit treatment and care goals, and discuss with the person and their family; escalate if any disputes remain unresolved
- Revisit resuscitation planning to ensure earlier decisions about cardiopulmonary resuscitation (for example), reflect person's current goals for treatment and care
- Review previous ACP discussions if, for example: person's circumstances change, hospital admission, unplanned surgery, deterioration in medical condition etc
- Review paperwork to ensure all relevant documents remain valid, current and accessible (e.g. AHD, EPOA, ARP, SoC)

Appendix 8

Possible triggers for initiating an Acute Resuscitation Plan (ARP)⁸

SURPRISE QUESTION	
Would it be a surprise if the patient were to die within 12 months? Or Would it be a surprise if the patient were to survive beyond 12 months?	
AGE	
Over 65 years Over 55 years if an Aboriginal and Torres Strait Islander person	
HOSPITALISATIONS	
Admitted via emergency this hospitalisation Repeat ICU admission at this or previous hospitalisation Hospitalisations in the last 12 months (≥3) RRT calls in last 12 months (as part of this admission, or from elsewhere)	
MET CALLING CRITERIA	
Decreased LOC: Glasgow Coma Score change >2 or AVPU=P or U Systolic blood pressure <90 mm Hg Respiratory rate <5 or >30 Pulse rate <40 or >140 Hypoglycaemia: BGL	Need for oxygen therapy or known oxygen saturation <90% Repeated or prolonged seizures Low urinary output (<15 mL/h or <0.5 mL/kg/h) MEW or SEWS score >4
DISEASE/CONDITION RISK FACTORS	
Cancer	
<p>Metastatic cancer</p> <p>Functional ability deteriorating due to progressive cancer</p> <p>Pain levels more difficult to manage</p> <p>Multi-morbidities or not responding to treatment – if spending more than 50% of time in bed/lying down, prognosis estimated in months</p> <p>Cancer Prognosis tools available e.g. PiPs, Pap, PPI, PPS</p> <p>Also refer to Clinical Prioritisation Criteria resources under Oncology and Malignant Haematology (biopsy proven new diagnosis of lymphoma, breast cancer, colorectal cancer, head and neck cancer, lung cancer, Lymphadenopathy for investigation, multiple myeloma, testicular cancer).</p> <p>Symptoms associated with advanced cancer states:</p> <ul style="list-style-type: none"> • anorexia and weight loss • cognitive impairment • dyspnoea • dysphagia <p>Cancer syndromes with short median survival rates:</p> <ul style="list-style-type: none"> • pancreatic and most biliary tract cancers • metastatic adenocarcinomas of unknown primary • untreated small cell lung cancer • multiple metastases to brain, liver or lung • ongoing bleeding from tumour or bone marrow failure without transfusion • malignant ascites • malignant bowel obstruction unable to be surgically bypassed • malignant pericardial effusion 	

⁸ Please note that a project is underway to develop a tool based on these indicators.

Chronic kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min)

Kidney failure complicating other life limiting conditions or treatments

Patients choosing to discontinue dialysis or not opting for dialysis

Symptomatic renal failure – nausea and vomiting, anorexia, pruritis, reduced functional status, intractable fluid overload

The 'surprise question' applies

Patient chooses the 'no dialysis' option, discontinuing dialysis or rejects dialysis if their transplant has failed

Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy

Commencement of dialysis in end stage renal disease (ESRD) with poor functional status

Failure of multiple vascular access and/or modalities for renal replacement therapy

Deliberate non-compliance with recommended treatment.

MELD score that predicts high mortality risk³⁰²

Chronic heart failure

Identifiers of patients with advanced heart failure and poor prognosis:

- Patient with consistent NYHA class III/IV HF
 - unable to undertake physical activity without discomfort
 - symptoms of chronic HF present at rest
 - severe chronic HF

AND

- Not suitable for any further procedures, such as:
 - revascularization with coronary bypass surgery
 - coronary angioplasty
 - valve surgery
 - cardiac resynchronization therapy (biventricular pacing [BiV-P])

PLUS, AT LEAST ONE OF:

- increasing HF symptoms despite maximum tolerated HF therapy, including diuretics, ACE inhibitors and beta-blockers, as indicated
- worsening or irreversible end-organ damage (including cardiac cachexia)
- repeated hospital readmissions with deteriorating HF, ventricular arrhythmias or cardiac arrest
- Extensive, untreatable coronary artery disease with breathlessness or chest pain at rest or on minimal exertion³⁰³
- Severe, inoperable peripheral vascular disease.

(ACE, angiotensin-converting enzyme; HF, heart failure; NYHA, New York Heart Association)

Chronic obstructive pulmonary disease

Recurrent hospital admissions based on COPD

The American Thoracic Society (ATS) provides criteria for staging the severity of airflow obstruction (ratio of FEV₁ to forced vital capacity [FEV₁/FVC]) and its severity as measured by % of predicted FEV₁. ATS and the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria for assessing the severity of airflow obstruction (based on % of predicted post-bronchodilator FEV₁ when the FEV₁/FVC is < 70%) are as follows:

- GOLD I (mild) - FEV₁ 80% or greater of predicted
- GOLD II (moderate) - FEV₁ 50-79% of predicted
- GOLD III (severe) - FEV₁ 30-49% of predicted
- GOLD IV (very severe) - FEV₁ less than 30% of predicted

GOLD combined assessment of COPD incorporates assessment of the severity of airflow obstruction, symptom assessment and history of exacerbations.³⁰⁴

The Australian and New Zealand guidelines for the management of COPD (COPD-X) were developed by the Thoracic Society of Australia and New Zealand (TSANZ) and Lung Foundation Australia (LFA). The classification of severity of COPD is outlined in the following table:

	MILD	MODERATE	SEVERE
Typical Symptoms	Few symptoms Breathlessness on moderate exertion Recurrent chest infections Little or no effect on daily activities	Increasing dyspnoea Breathlessness walking on level ground Increasing limitation of daily activities Cough and sputum production Infections requiring steroids	Dyspnoea on minimal exertion Daily activities severely curtailed Experiencing regular sputum production Chronic cough
Lung Function	FEV ₁ ≈ 60-80% predicted	FEV ₁ ≈ 40-59% predicted	FEV ₁ ≈ < 40% predicted

FEV₁ ≈ = forced expiratory volume in one second

[Table adapted from: Lung Foundation Australia's Stepwise Management of Stable COPD available at Lung Foundation Australia (Stepwise Management of Stable COPD)]

The 2011 American College of Physicians/American College of Chest Physicians/American Thoracic Society/European Respiratory Society (ACP/ACCP/ATS/ERS) guideline for diagnosis and management of stable COPD indicates a history of more than 40 pack-years of smoking was the best single predictor of airflow obstruction; however, the most helpful information was provided by a combination of the following 3 signs:³⁰⁵

- Self-reported smoking history of more than 55 pack-years
- Wheezing on auscultation
- Self-reported wheezing.

Other factors for COPD or other chronic respiratory conditions include:

- Weight loss (Body Mass Index below 18)
- Respiratory failure (PaCO₂ > 50mmHg)
- Right sided heart failure
- Worsening shortness of breath
- Pulmonary hypertension
- Fulfils long term oxygen therapy criteria (PaO₂ ≤55 mm Hg on room air)
- 6 weeks steroids in preceding 6 months
- requires palliative medication for breathlessness.

Moderate/severe liver disease

Advanced cirrhosis with one or more complications in the past 12 months:

- diuretic resistant ascites
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Neurological diseases

Diagnosis of any progressive neurodegenerative disease (e.g. Parkinson's disease, motor neurone disease, multiple sclerosis)

General indicators:

Progressive deterioration in physical and/or cognitive function despite optimal therapy

Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure

Symptoms which are becoming increasingly complex and difficult to control

Speech problems: increasing difficulty in communications and progressive dysphasia
Mobility problems and falls

Parkinson's Disease

Drug treatment less effective or increasingly complex regime of drug treatments
Increasing "off" periods even with the use of complex drug regimes
Cognitive impairment notably the onset of dementia-
Weight loss
Dyskinesias and mobility problems
Psychiatric symptoms (depression, anxiety, hallucinations, psychosis)

Motor Neurone Disease

Increasing cognitive difficulties
Rapid decline in physical status
Low vital capacity (below 70% predicted spirometry), or initiation of NIV
Weight loss

Multiple Sclerosis

Dysphagia + poor nutritional status.
Communication difficulties e.g., Dysarthria + fatigue.
Cognitive impairment notably the onset of dementia.

Frailty

See the [clinical frailty score tool](#)

Multiple co morbidities
Significant impairment in day to day living
Musculoskeletal disease (arthritis or osteoporosis)
Partial stroke paralysis
Unable to dress, walk or eat without some assistance
Eating and drinking less combined with swallowing difficulties
Unintentional or unexplained weight loss (≥ 5 kg in last 12 months)
Deteriorating functional score e.g. performance status – Barthel/ ECOG/ Karnofsky
Recurrent hospital presentations to emergency departments or admissions to acute settings
Combination of at least three of the following symptoms:

- weakness (low grip strength for writing or handling small objects, difficulty or inability to lift heavy objects ≥ 5 kg)
- slow walking speed (walks 4.5 m in ≥ 7 s)
- significant weight loss
- exhaustion
- low physical activity
- depression

Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers that may indicate a person is entering the later stages include any combination of the following:

- Unable to walk without assistance
- Urinary and faecal incontinence
- No consistently meaningful conversation
- Unable to do achieve activities of daily living
- Barthel score < 3
- Recurrent urinary tract infections
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake and significant weight loss
- Aspiration pneumonia
- Behavioural alterations

Difficulties in achieving acceptable levels of other functional variables derived from the Rosow-Breslau Functional Health Scale and the Nagi Index, including:	
<ul style="list-style-type: none"> • getting up from a chair • walking several blocks • pushing or pulling heavy objects • climbing a flight of stairs • stooping, kneeling, or crouching 	<ul style="list-style-type: none"> • picking up a coin • reaching above one's shoulders • lifting 10 lb • using a map • vigorous physical activity
Self-reported symptoms	
<p>Daily activity level reported to be moderately reduced but out of bed more than half the day</p> <p>Able to do some of the things could do 12 months ago, but not everything</p> <p>Pain experienced is reported to be moderate to constant</p> <p>Burdens to carers and family reported to be most days to all day, every day</p> <p>Impacts on finances reported as moderate to significant</p> <p>Pleasure and interest in doing things reported as some days to none of the time</p> <p>Feelings of anxiousness and hopelessness occur many days to all of the time.</p>	
Lifestyle/ behavioural factors	
<p>Also take other lifestyle/ behavioural factors into consideration which contribute to symptoms in association with chronic disease and other comorbidities, such as:</p> <ul style="list-style-type: none"> • current tobacco use • body mass index (obesity) • diabetes • presence of chronic pain • harmful use of alcohol or other drugs • physical inactivity • oral health diseases • mental health disorders and depressive states. 	

Figure 4 – Potential triggers for initiating an Acute Resuscitation Plan (ARP)³⁰⁶

Appendix 9

Useful functional scores

Karnofsky Performance Status Score³⁰⁷

The *Karnofsky score for performance status calculator* scale runs from 100 to 0 where 100 means the patient's condition is normal and 0 indicates death. While evaluating the patient symptoms with the KPS, each clinician assigns a performance score which describes different symptom stages in increments of 10. The Karnofsky score can be used to compare effectiveness of different therapies and to assess the prognosis in individual patients.

100 - Normal; no complaints; no evidence of disease.

90 - Able to carry on normal activity; minor signs or symptoms of disease.

80 - Normal activity with effort; some signs or symptoms of disease.

70 - Cares for self; unable to carry on normal activity or to do active work.

60 - Requires occasional assistance, but is able to care for most of their personal needs.

50 - Requires considerable assistance and frequent medical care.

40 - Disabled; requires special care and assistance.

30 - Severely disabled; hospital admission is indicated although death not imminent.

20 - Very sick; hospital admission necessary; active supportive treatment necessary.

10 - Moribund; comatose, fatal processes progressing rapidly.

0 - Dead.

Karnofsky performance scores are sometimes put in three states which are described as levels of performance and functionality.

A (100 – 80) Able to carry on normal activity and to work; no special care needed

B (70 – 50) Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed

C (40 – 0) Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.

The Palliative Care Outcomes Collaboration (PCOC) also provides a range of ready to use evidence-based assessment tools, education material and toolkits on their [website](#). PCOC is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. The PCOC data set provides four clinical assessment tools:

1. [Palliative Care Phase, Palliative Care Problem Severity Score \(PCPSS\)](#)
2. [Symptom Assessment Scale \(SAS\)](#)
3. [Australia-modified Karnofsky Performance Status \(AKPS\) scale](#)
4. [Utilisation Groups – Activities of Daily Living \(RUG-ADL\)](#).

WHO/ ECOG Performance Status³⁰⁸

The ECOG Scale of Performance Status is a standard criteria for measuring how disease impacts upon a patient's daily living abilities (known to health professionals and researchers as a patient's performance status). It describes a patient's level of functioning in terms of their ability to care for themselves, daily activity, and physical ability (walking, working, etc.). The scale was developed by the Eastern Cooperative Oncology Group (ECOG), now part of the ECOG-ACRIN Cancer Research Group, and published in 1982.

- 0 Fully active, able to carry on all pre-disease performance without restriction
- 1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, eg., light housework, office work
- 2 Ambulatory and capable of self-care but unable to carry out work activities: upright more than 50% of waking hours
- 3 Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
- 4 Completely disabled, cannot carry on any self-care, totally confined to bed or chair
- 5 Dead

Notes:

Comparing the ECOG Performance Status to the Karnofsky Performance Status

The ECOG Performance Status and the Karnofsky Performance Status are two widely used methods to assess the functional status of a patient. Both scales have been in the public domain for many years as ways to classify a patient according to their functional impairment, compare the effectiveness of therapies, and assess the prognosis of a patient. The Karnofsky index, between 100 and 0, was introduced in a textbook in 1949.³⁰⁹ Key elements of the ECOG scale first appeared in the medical literature in 1960.³¹⁰ There are several ways to map the two scales. The table below displays one commonly used comparison.

ECOG Performance Status	Karnofsky Performance Status
0 Fully active, able to carry on all pre-disease performance without restriction	100 Normal, no complaints; no evidence of disease 90 Able to carry on normal activity; minor signs or symptoms of disease
1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work	80 Normal activity with effort, some signs or symptoms of disease 70 Cares for self but unable to carry on normal activity or to do active work
2 Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours	60 Requires occasional assistance but is able to care for most of personal needs 50 Requires considerable assistance and frequent medical care
3 Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours	40 Disabled; requires special care and assistance 30 Severely disabled; hospitalization is indicated although death not imminent
4 Completely disabled; cannot carry on any selfcare; totally confined to bed or chair	20 Very ill; hospitalization and active supportive care necessary 10 Moribund, comatose
5 Dead	0 Dead

Charlson Comorbidity Index (CCI) Score³¹¹ (age adjusted)

The original Charlson Index was developed with 19 categories in 1987. The CCI assesses the ten year survival/mortality risk in patients with several comorbidities based on a scoring system. This instrument is used to categorize comorbidities of patients and uses the International Classification of Diseases (ICD) diagnosis codes.

Comorbidity is the term given to the presence of one or more additional conditions existing simultaneously, independently or not (with or without a causal effect) with a disease considered primary. It also suggests the effect of one or more additional conditions on the primary disease.

The CCI calculates for age groups and condition and each are awarded a specific number of points, some conditions weighing more than others, based on the adjusted risk of mortality. The more points given, the more likely the predicted adverse outcome.

To calculate the Charlson Probability (10 year mortality)

1. Calculate $Y = e^{(i * 0.9)}$
2. Calculate $Z = 0.983^Y$
3. where Z is the 10 year survival

Various online tools calculate the Charlson Comorbidity Index. While they provide a resource for clinicians, they should not be used as a substitute for thorough clinical assessment and clinical judgement based on the person's unique circumstances. More information about calculating the CCI can be found in a number of articles.³¹²

Age	Points	Patient	NOTES
≥40	0		
≥50	1		
≥60	2		
≥70	3		
>80	4		
Myocardial infarction	1		
Congestive heart failure	1		
Peripheral vascular disease	1		
Cerebrovascular disease	1		
Dementia	1		
Chronic pulmonary disease	1		
Connective tissue disease	1		
Peptic ulcer disease	1		
Chronic liver disease	1		
Diabetes mellitus with end organ damage	2		
Moderate to severe kidney disease (CKD)	2		
Hemiplegia	2		
Solid tumour	2		
Lymphoma	2		
Leukaemia	2		
Moderate to severe liver disease	3		
Metastatic solid tumour	6		
Acquired immunodeficiency syndrome (AIDS)	6		
Totals			

APACHE II³¹³

The APACHE score is one of the most well-known and widely used and validated scoring systems for ICU. The original APACHE score was developed in 1981 to classify groups of patients according to severity of illness and designed as a mortality prediction tool.

The APACHE II score is calculated at the beginning of the ICU admission to help determine the patient's mortality risk for the admission. APACHE II was released in 1985 and reduced the number of variables from 34 to 12; it is the sum of acute physiology score, age and chronic health score. The APACHE II scoring system is measured during the first 24 hours of ICU admission with a maximum score of 71. A score of 25 represents a predicted mortality of 50% and a score of over 35 represents a predicted mortality of 80%.

Physiologic Variable	High Abnormal Range					Low Abnormal Range				
	+4	+3	+2	+1	0	+1	+2	+3	+4	Points
Temperature, core (°C)	≥41	39-40.9		38.5-38.9	36-38.4	34-35.9	32-33.9	30-31.9	≤29.9	
Mean Arterial Pressure (mm Hg)	≥160	130-159	110-129		70-109		50-69		≤49	
Heart Rate (ventricular response)	≥180	140-179	110-139		70-109		55-69	40-54	≤39	
Respiratory Rate	≥50	35-49		25-34	12-24	10-11	6-9		≤5	
Oxygenation (a) F10 ₂ ≥ 0.5: use A-aDO ₂ (b) F10 ₂ < 0.5: use PaO ₂	≥500	350-499	200-349		<200 >70	61-70		55-60	<55	
Arterial pH (preferred)	≥7.7	7.6-7.69		7.5-7.59	7.33-7.49		7.25-7.32	7.15-7.24	<7.15	
HCO ₃ (mEq/l)	≥52	41-51.9		32-40.9	22-31.9		18-21.9	15-17.9	<15	
Serum Na (mmol/L)	≥180	160-179	155-159	150-154	130-149		120-129	111-119	≤110	
Serum K (mmol/L)	≥7	6-6.9		5.5-5.9	3.5-5.4	3-3.4	2.5-2.9		<2.5	
Serum Creatinine (mg/dL) (double points for acute renal failure)	≥3.5	2-3.4	1.5-1.9		0.6-1.4		<0.6			
Haemocrit (%)	≥60		50-59.9	46-49.9	30-45.9		20-29.9		<20	
TLC (10 ³ /cc)	≥40		20-39.9	15-19.9	3-14.9		1-2.9		<1	
GCS (Score = 15 minus actual GCS)	GCS → Points: 15=0; 14=1; 13=2; 12=3; 11=4; 10=5; 9=6; 8=7; 7=8; 6=9; 5=10; 4=11; 3=12									
A. Total Acute Physiology Score (sum of 12 variables above)										
B. Age points (years): ≤44=0; 45 to 54=2; 55 to 64=3; 65 to 74=5; ≥75=6										
C. Chronic Health Points (5 points for nonoperative or emergency postoperative patients; 2 points for elective postoperative patients)										
TOTAL APACHE II SCORE (add the points together from A + B + C)										

Katz Index of Independence in Activities of Daily Living³¹⁴

The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is an instrument to assess functional status as a measurement of a person's ability to perform activities of daily living independently. Clinicians typically use the tool to detect problems in performing activities of daily living and to plan care accordingly. The Index ranks adequacy of performance in the six functions of *bathing, dressing, toileting, transferring, continence, and feeding*. Persons are scored yes/no for independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment. The instrument is most effectively used among older adults in a variety of care settings, when baseline measurements, taken when the person is well, are compared to periodic or subsequent measures. The following table is adapted from the Hartford Institute for Geriatric Nursing, New York University, College of Nursing.

Activities Points (1 or 0)	Independence (1 Point)	Dependence (0 Points)
	NO supervision, direction or personal assistance.	NO supervision, direction or personal assistance.
BATHING Points: _____	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity.	(0 POINTS) Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
DRESSING Points: _____	(1 POINT) Get clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
TRANSFERRING Points: _____	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transfer aids are acceptable.	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE Points: _____	(1 POINT) Exercises complete self-control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder.
FEEDING Points: _____	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.
TOTAL POINTS: _____ SCORING: 6 = High (<i>patient independent</i>) 0 = Low (<i>patient very dependent</i>)		

Figure 5 - Useful functional scores* and measures³¹⁵

[* Please note that some websites provide a basic electronic scoring system for some of the more well-known indicators. These repositories are not validated; however, the calculators can serve as a general resource for clinicians, but must not replace clinical judgement.]³¹⁶

Appendix 10

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Queensland Government

Acute Resuscitation Plan (ARP)
For adults at risk of an acute deterioration

Facility: _____

URN: _____ (Affix patient identification label here)

Family name: _____

Given name(s): _____

Address: _____

Date of birth: _____ Sex: ☐ M ☐ F ☐ I

Clinical assessment and appropriate treatment options should be guided by good medical practice, which includes discussions with the patient and/or their substitute decision-maker(s).

- This ARP form is for use in all Queensland Health facilities (e.g. hospitals, aged care and other residential facilities).
- The Quick Guide attached to this form contains important information and should be read prior to completing the form.
- If there is insufficient room on this form to record information, please cross-reference with the progress notes.

1. Clinical assessment

Record details/assessment of relevant medical conditions, relating to the patient's physical and mental health. This section may include clinical reasons why resuscitation planning is necessary.

2. Capacity assessment

☐ I believe that the patient has capacity* to consent to and/or refuse medical treatment.

☐ I believe that the patient does not have capacity to consent to and/or refuse medical treatment.

If there is a change in capacity, this form must be reviewed.

Details of assessment: _____

*A patient with capacity can understand information about their medical treatment and treatment options, weigh up the benefits, risks and burdens of each choice and freely and voluntarily make and communicate a decision. Please refer to the Capacity Assessment Clinical Guideline for further information.

3. Resuscitation management plan

If an acute deterioration or critical event occurs, it is clinically indicated to:

Provide e.g. ventilation, IV fluids, supportive therapies

Not provide e.g. defibrillation, intubation, antibiotics

There is further documentation in the progress notes on the following dates: _____

If a cardiac or respiratory arrest occurs, it is clinically appropriate to:

CPR ☐ Provide ☐ Do not provide

A decision not to provide CPR does not limit other treatment or care

If the Resuscitation management plan differs from the choices of the patient (see Section 4) regarding future medical treatment, record the details in the progress notes or on this form and follow an appropriate resolution process (see Section 4 in the Quick Guide).

Form continues over page

General

- The ARP form replaces 'not for resuscitation' (NFR) orders and documents resuscitation planning.
- An ARP form should be completed where it is reasonably expected that an adult patient (≥18) may suffer an acute deterioration or critical event (e.g. cardiac or respiratory arrest) in the foreseeable future and require resuscitation planning. Particular consideration should be given to adult patients who are terminally ill and/or are expected to die within 12 months. For further information on prognostic indicators, please refer to the Implementation Guidelines Part 1.

Communicating with patients

- Completing an ARP form is only one aspect of the advance care planning process.
- Open, honest and sensitive communication with the patient and/or their substitute decision-maker(s) about end-of-life choices is vital when a patient is diagnosed with a life-threatening illness or condition.
- People approaching the end of life have a right to be informed of their available treatment options and to have their views and wishes for care respected, including choices for resuscitation.
- For patients with chronic or terminal illnesses, discussing resuscitation planning with them on each admission may be unduly distressing and inappropriate. In these situations, it is unlikely that many of the details on the ARP form will change, even across admissions.
- For further information about communicating with patients and their families, see Advance Care Planning Online Training Modules (Module 6 - Communication Strategies).

Legal considerations

- The law requires a collaborative approach between health providers and patients and/or their substitute decision-maker(s) about providing, withholding or withdrawing life-sustaining measures, and appropriate documentation of this. The ARP form prompts this approach.
- An ARP form is a clinical record and does not in itself give consent to provide, withhold or withdraw life-sustaining measures. Legal authority comes from obtaining consent to the Resuscitation management plan from the appropriate decision-maker. The ARP form does, however, provide clinical authority to act on its resuscitation planning instructions, provided those instructions are clear.
- An ARP form is not the same as, nor does it replace, an AHD.
- The law expects health providers to adhere to clinical and ethical standards through 'good medical practice' (GMP). In meeting these standards, medical officers are under no obligation to offer, provide or continue treatments that on balance would have the potential to cause harm and offer no benefit to the patient (i.e. futile).
- GMP also requires informed consent. When active treatments are no longer appropriate, this should be sensitively explained (in specific or broad terms) to patients and/or their substitute decision-maker(s), and available end-of-life treatment and care options discussed.
- In some emergency situations, while all reasonable efforts should be made to obtain consent, it may be inappropriate to continue to maintain life while attempts are made to obtain consent. Emergency situations are characterised by the need for an immediate decision to be made about maintaining the life and health of a patient.
- Medical treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to withdraw treatment which has been commenced.
- Legal protections and indemnity are provided to staff who comply with Queensland Health policy on the withholding and withdrawal of life-sustaining measures.
- See Flowchart below: Withholding and Withdrawing Life-sustaining Measures.

Capacity

- Under the law, all patients are presumed to have capacity. The law differentiates between patients with capacity and without capacity in terms of consenting to health care.
- A patient with capacity is entitled to refuse any or all medical treatment, even if this results in their death. The treating medical officer should ensure the patient receives adequate information about the nature of the proposed treatment measures.
- The law regarding consent for patients without capacity is contained in the Powers of Attorney Act 1998 and the Guardianship and Administration Act 2000 (GAA).
- A substitute decision-maker(s) must consider the patient's best interests, the patient's views and wishes and medical opinion when providing consent. See Health Care Principle and General Principles, Schedule 1, GAA.

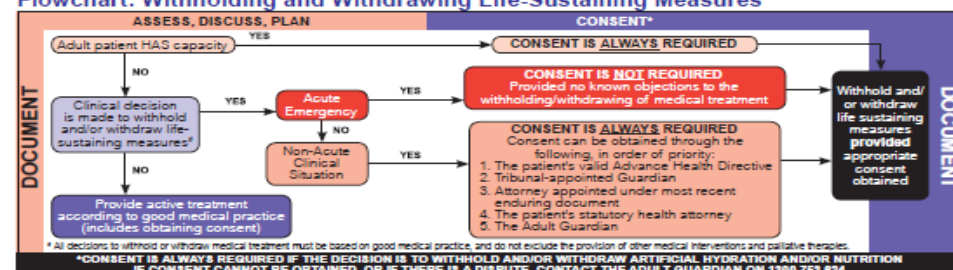
Patient objections

- The law recognises that a person can object to life-sustaining measures being provided, withheld or withdrawn. Queensland Health's policy position is that direct knowledge of an objection is required from the patient, rather than hearsay (e.g. from a family member). The patient's objection should have been expressed directly to the treating medical officer as close as possible to the acute deterioration or event.
- For the withholding or withdrawal of medical treatment, an objection may be expressed by the patient as a verbal request to "do everything" or "don't let me die", or by their conduct, or in formal terms through an Advance Health Directive.

Effect of objection by patient to withholding or withdrawing life-sustaining measures

	Emergency	Non-emergency
Capacity	<ul style="list-style-type: none"> Objection = demand for treatment Patient cannot demand clinically inappropriate treatment Discuss with patient Commence dispute resolution process, including: second opinion, family conference, referral to hospital executive Document decision-making pathway 	<ul style="list-style-type: none"> Time to manage objection/ demand for treatment Patient cannot demand clinically inappropriate treatment Discuss with patient Commence dispute resolution process, including: second opinion, family conference, referral to hospital executive Document decision-making pathway
Impaired capacity	<ul style="list-style-type: none"> MOs cannot override patient objection. Need consent from substitute decision-maker (legal position) All reasonable efforts should be made to obtain consent If consent cannot be obtained in time available, or decision-maker(s) demands clinically inappropriate treatment, withhold/withdraw medical treatment if consistent with GMP (policy position) Document decision-making pathway (legal requirement) 	<ul style="list-style-type: none"> Time to manage objection/ demand for treatment Objection can be overridden by MO on grounds the patient: <ul style="list-style-type: none"> has no/minimal understanding of what is involved; and will suffer temporary or no distress Need consent from substitute decision-maker to withhold/withdraw treatment If no consent, or decision-maker demands clinically inappropriate treatment, commence dispute resolution process Document decision-making pathway (legal requirement)

Flowchart: Withholding and Withdrawing Life-Sustaining Measures



Quick guide to completing an Acute Resuscitation Plan (ARP)

Remove these instructions before filing this ARP form. It is recommended that the original form be filed at the front of the patient's medical record, but individual facilities can decide on the most prominent place to file the form.

This Quick Guide should be read in conjunction with the *Withholding and Withdrawing Life-Sustaining Measures Policy and Implementation Standard*, and the *Implementation Guidelines – End-of-life care: decision-making for withholding and withdrawing life-sustaining measures from adult patients – Part 1 and Part 2*.

Section 1. Clinical assessment

- If there are doubts or uncertainties about the patient's medical condition, a second opinion should be obtained.

Section 2. Capacity assessment

- If there are doubts or uncertainties about the patient's capacity (e.g. fluctuating or episodic capacity), seek a second opinion and/or arrange a mental health assessment.
- See the Capacity Assessment Clinical Guideline for further information.

Section 3. Resuscitation management plan

- Record the treatment and care that should, and should not be, provided. Examples given on the ARP form are for illustration only and do not substitute for clinical judgement.
- Patients may still benefit from a range of treatments and therapies that contribute to quality end-of-life care.
- If it is not clinically appropriate to provide CPR, clearly state any other treatments and care that are to be provided.
- Completion of this section does not exclude the provision of other treatments which are not specifically mentioned (e.g. palliative therapies, management of pain, suffering and discomfort).

Section 4. Patient choices

- Where a patient with capacity has strong views about their end-of-life care, they should be encouraged to complete an Advance Health Directive (AHD).
- A patient may have already completed an AHD. Any inconsistency between a valid AHD and the patient's stated choices will need to be resolved with the patient and/or their potential substitute decision-maker(s). Where the patient has capacity they should be encouraged to review their AHD.
- Cross-reference any previous advance care planning.

When patient choices differ from the Resuscitation management plan

- Where a patient's choices differ from the Resuscitation management plan, this could represent a recognised objection under the law, even in an acute emergency (see Objections).
- If the patient or their potential substitute decision-maker(s) requests treatment that differs from the Resuscitation management plan, the medical officer must make all efforts to explain why the request does not meet the standards of good medical practice and is not in the patient's best interests.
- Involvement of all members of the health care team is recommended in these situations. The medical officer may also seek a second opinion from and/or involvement of a more experienced clinician. Other resolution options can be found in the Implementation Guidelines Part 1.
- All efforts should be made to resolve the situation. If unsuccessful, the medical officer must refer the matter to executive level.
- For a patient with impaired capacity. If the medical officer believes the substitute decision-maker(s) is not adhering to the Health Care Principle and the General Principles, it is recommended the matter be referred to the Adult Guardian as soon as possible. See Legal considerations and Capacity.
- Clear and detailed documentation is vital at all stages of discussions held.

Section 5. Consenting details

- Under the law, all patients with impaired capacity have a substitute decision-maker(s). This includes the Adult Guardian when no other substitute decision-maker is available.
- For patients with capacity, this section identifies a potential substitute decision-maker(s) prior to any loss of capacity.
- Consent must be obtained to act on the Resuscitation management plan (except in some emergency situations). Consent from a substitute decision-maker(s) must be based on the General Principles and the Health Care Principle. See Legal considerations and Capacity.

- Consent from patients or their substitute decision-maker(s) can be verbal. This should be documented. Verbal consent given by the Adult Guardian will be confirmed in writing.
- The ARP form is not a consent form. There is no requirement for the patient or their substitute decision-maker(s) to sign the ARP form.
- Consent should be obtained from the patient or their substitute decision-maker(s) as close as possible to the acute deterioration or event. If consent is obtained earlier the medical officer must, at the time of an acute deterioration or event, ensure the patient or their substitute decision-maker(s) continues to understand what they have consented to.

Section 6. Clinician authorisation

- The most senior medical officer available should complete and sign the ARP form. This is particularly relevant where patient choices differ from clinical recommendations about CPR and future medical treatment.
- In limited circumstances (e.g. in remote communities), it may be appropriate for a more junior doctor or other health professional to complete and sign the form. In these circumstances, the ARP form must be authorised by the most senior medical officer available (this can be done over the phone, by fax or email). Note that this carries an element of risk.
- If a medical officer does not fully complete/sign/authorise the ARP form, and the patient suffers an acute deterioration or critical event, attending clinicians are required to exercise their clinical judgement based on the circumstances and document this.
- It may be appropriate to record details of when the ARP form should be reviewed. It is recommended that long-term ARP forms be regularly reviewed as part of good medical practice.

Voiding the ARP form

- If changes are required or the form has lapsed, it must be marked as void under the authority of a medical officer.
- To void the form, draw two lines diagonally across the front and back pages, write 'VOID' between the lines and sign and date this notation. Retain the voided ARP form in the patient's medical record.
- A medical officer is responsible for deciding whether an existing ARP form should be voided as a result of changes and whether a new ARP form is required.

Patient transfers and copies

- If a patient is being transferred to another facility, a copy of the ARP form (active, voided or lapsed) should be accompanied by an ARP Cover Sheet.
- The original ARP form must be retained in the patient's medical record.
- Record the contact details of the transferring facility, person or team in the space provided on the Cover Sheet. This information may assist the receiving team or facility to develop appropriate resuscitation planning for the patient.
- Non-Queensland Health facilities are responsible for following their own processes and procedures for documenting or acting on resuscitation planning decisions. This includes the Queensland Ambulance Service while the patient is in transit.
- It is recommended that the patient's GP receive a copy of the patient's ARP form (active, voided or lapsed) for their records.

For further information and resources, contact

Access Improvement Service:

Email: QHealthethics@health.qld.gov.au

Website: www.health.qld.gov.au/advance-care-planning/

Family name:	Given name(s):	URN:
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4. Patient choices

The patient has the following views and wishes about their end-of-life care: (e.g. CPR, pain management options, living and visiting arrangements, spiritual and/or cultural support). Discuss the views and wishes of patients who have impaired capacity with their substitute decision-maker(s). Record the dates and times of discussions.

Has the patient participated in advance care planning? ☐ Yes ☐ No

5. Consenting details

Complete this section, irrespective of the patient's capacity.

Patients with capacity can provide their own consent. For patients with impaired capacity, consent must be obtained from a substitute decision-maker(s), in the order below.

The patient has:

1 Advance Health Directive (AHD)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
2 Tribunal-appointed Guardian	<input type="checkbox"/> Yes	<input type="checkbox"/> No
3 Attorney(s) for health matters under Enduring Power of Attorney or AHD	<input type="checkbox"/> Yes	<input type="checkbox"/> No
4 Statutory Health Attorney*	<input type="checkbox"/> Yes	<input type="checkbox"/> No
5 If no to all, the Adult Guardian must be contacted for consent. Ph: 1300 QLD OAG (753 624)		

Name/details of substitute decision-maker(s): (e.g. relationship to patient, phone number, location of original AHD)

Record the dates and times of discussions held with, and consent obtained from, the patient and/or substitute decision-maker(s). Cross reference with the progress notes.

Details of consenting discussions:

* A statutory health attorney is, in the following order: a spouse (including de facto and same sex partner) in a continuing relationship, an adult who has care of the person (not a paid carer), an adult who is a close friend or relation (not a paid carer), or a Power of Attorney Act 1998.

6. Clinician authorisation

This ARP form remains valid:

<input type="checkbox"/> For this admission	/ /
<input type="checkbox"/> Until date:	
<input type="checkbox"/> For this and subsequent admissions	

Medical officer's name:

--

Medical officer's signature:

--

Date:

--

Authorising medical officer's name*, if applicable:

--

Dr

* If required, the authorising medical officer will be a more experienced or senior medical officer and must be involved in all decisions to withhold/withdraw medical treatment.

Recommendations for review, if applicable:

Other clinicians involved in the development of this ARP form and/or provided with a copy: (e.g. GPs, allied health and nursing professionals)

If changes are required, this form must be voided and a new ARP form completed

Acute Resuscitation Plan Cover Sheet

Facility

Date

 / /

A copy of this patient's
Acute Resuscitation Plan is attached

(Affix patient identification label here)

URN:

Family name:

Given names:

Date of birth:

Sex: ☐ M ☐ F

This Cover Sheet is designed to accompany a copy of a patient's Acute Resuscitation Plan (ARP) form if they are transferred to another health care facility or during transit to that facility.

If a patient has a valid Advance Health Directive, this can be referred to for additional information.

For Queensland Health Facilities

- Queensland Health facilities may act on the instructions in a copy of the patient's ACTIVE ARP form.
- An ACTIVE ARP means that it is:
 1. Valid until a specified (future) date; or
 2. Valid for "this and subsequent admissions".
(this information is in Section 7 on page 2 of the ARP form)
- It is the responsibility of all facilities in receipt of the copy of the patient's ACTIVE ARP form to:
 1. Verify that both pages (sections 1 to 7) of the ARP copy are attached
 2. Check that the ARP copy is the most recent version
 3. Check the validity of the ARP form in Section 7 on page 2 of the form
 4. Verify that the consent details documented on the copy are current
 5. File the copy of the ARP form at the front of the patient's record, or in the most prominent position, according to hospital practice
 6. The treating Medical Officer in the receiving facility may, at their discretion:
 - a. Contact the previous authorising Medical Officer/signing Medical Officer/treating team from the facility where the original ARP was completed
 - b. Conduct any re-assessments of the patient, as appropriate
 - c. Discuss the patient's choices, appropriate to the circumstances ¹
 - d. Complete a new ARP form and/or void the copy received.
- If the copy of the ARP indicates that it is void or valid only for the current admission, a new ARP will need to be completed for the patient if resuscitation planning is required.

For Non-Queensland Health Facilities

- Facilities other than those managed by Queensland Health are responsible for following their own procedures and processes for documenting or acting on resuscitation planning decisions. This includes the Queensland Ambulance Service while the patient is in transit.

¹ In some cases it may be distressing for a patient and/or their substitute decision-maker to revisit resuscitation planning discussions already held at the previous facility.

Acute Resuscitation Plan Form – Information Sheet

General

- The ARP form applies to adult patients only.
- The ARP replaces 'not for resuscitation' (NFR) orders and aims to improve documentation of resuscitation planning.
- This form should be completed where it can be reasonably expected that an adult patient may suffer an acute event in hospital in the foreseeable future and require resuscitation planning.
- If changes are required to the form, it must be voided and a new ARP form completed. To void a form, draw two lines diagonally across the front page, write 'VOID' between the lines and sign and date this annotation. The voided form should be retained on the patient file.
- The ARP form applies to the emergent resuscitation of the patient with cardiac or respiratory arrest. If the patient is successfully resuscitated, the patient's condition should be re-evaluated to determine a management plan consistent with good medical practice. Ongoing organ support may or may not be indicated, depending on the cause for the deterioration and the patient's clinical status.
- Completion of an ARP form, particularly where CPR and other medical treatment are indicated, is neither a commitment, nor a prerequisite, to admit a patient to an intensive care or critical care unit.

Legal considerations

- An ARP form is a clinical record and does not provide legal consent to withhold or withdraw life-sustaining measures.
- An ARP form is different from a patient's Advance Health Directive (AHD). An AHD is a legal document formalising the patient's choices for end-of-life care. An AHD is only triggered when the patient lacks capacity for decision-making.

Patients with capacity

- Where a patient has capacity to make health care decisions, the patient's consent must be obtained to withhold or withdraw life-sustaining measures. Consent must be recorded in the progress notes.
- A patient with capacity is entitled to refuse any or all medical treatments, even if this results in their death. The authorising medical officer should ensure the patient has received adequate information about the nature of the proposed medical treatment.

Patients with impaired capacity

- Queensland's legislation refers to 'good medical practice' as something that must underscore all treatment decisions about withholding and/ or withdrawing medical treatment from adult patients who lack capacity.
- In meeting the standards of good medical practice, medical officers are under no obligation to initiate treatments known to be ineffective, nor to continue treatments that have become ineffective. Good medical practice also involves ethical considerations.
- Medical treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to withdraw treatment which has been initiated.
- Consenting details for a patient must be documented on this form and in the progress notes. Meticulous documentation of the decision-making pathway for withholding and withdrawing of life-sustaining measures is required by law.
- Blood transfusions do not qualify under the legislation as a 'life-sustaining measure', therefore, consent is always required.
- Consent must always be obtained to withhold or withdraw artificial hydration and/or nutrition, even in acute emergency situations.

Emergency situations

- Emergency situations are characterised by the need for urgent decisions to maintain the life and health of a patient.
- In providing life-sustaining medical treatment to a patient without capacity, the legislation recognises that it is not always practical to obtain consent in urgent health care situations.
- While all reasonable efforts to obtain consent should be made, in some emergency situations it may be inappropriate to continue to maintain life while attempts are made to obtain consent to withhold or withdraw treatment.
- In acute emergency situations, consent is generally not required to withhold or withdraw life-sustaining medical treatment (with the exception of artificial hydration and/or nutrition).
- Life-sustaining medical treatment may not be withheld or withdrawn without consent, even in an acute emergency, if the medical officer knows the patient has objected to the withholding or withdrawal of treatment (that is, the patient directed the medical officer to prolong their life before losing capacity).

For advice, contact Office of the Adult Guardian:

Phone: 1300 QLD OAG (753 624)
Email: adult.guardian@justice.qld.gov.au

Other resources, contact Clinical Policy Unit:

Email: clinicalpolicy@health.qld.gov.au
Internet: www.health.qld.gov.au/advance-care-planning/
Intranet: qheps.health.qld.gov.au/policybranch/html/ethicsteam.htm

Glossary

Term	Description
Acute Resuscitation Plan (ARP)	<p>The ARP form is a medical order or clinical tool that is completed when it can be reasonably expected that an adult patient might suffer an acute event in hospital in the foreseeable future. It replaces Not for Resuscitation (NFR) Orders. It is important to note that while the ARP provides clinical authority to act on its directions, it is not a legal consent form, and therefore is very different to the Advance Health Directive. In 2009, the ARP became an endorsed Statewide form and was implemented throughout the State. The ARP was designed to be a short form that is easily located and used in emergency situations.</p>
Advance Care Planning	<p>ACP is a person-centred approach for planning current and future health and personal care that reflects the person's values, beliefs and preferences. The process of ACP is collaborative and coordinated and aims to develop an understanding of the person's treatment and care goals in order to assist health professionals to better meet their needs. Effective ACP involves ongoing communication between the person, those closest to them, and a multidisciplinary healthcare team to optimise the person's current treatment, care, and quality of life. If the person becomes too unwell to participate in decision-making, the preparation gained through ACP will guide all those involved in the process to make decisions about health and personal care in the person's best interests.</p> <p>While anyone can carry out ACP at any time, the nature and timing of ACP will often be driven by the person's care needs and may be influenced by their willingness to participate.</p> <p>Ideally, ACP discussions should be initiated early for those with life-limiting illness to optimise the person's quality of life and minimise potentially burdensome and unwanted treatment.</p> <p>ACP can include:</p> <ul style="list-style-type: none"> • assessing the person's current condition and likely prognosis • establishing the person's health and personal goals, values and preferences • discussing current and future treatment and personal care options • identifying the person's decision-makers for a time when they might lack capacity for decision-making • documenting treatment and care plans and ensuring they are appropriately communicated and available when needed • assisting the person to formally document their wishes if they choose to do so • coordinating treatment and care to reflect the person's goals, values and preferences. <p>ACP should be integrated into clinical practice and routine care, and reviewed regularly to ensure plans remain consistent with the person's values, beliefs and preferences for health and personal care.</p>

Term	Description
Advance care plan	An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care, and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.
Advance Health Directive	An Advance Health Directive acts as the patient's decision-maker should they lose capacity for decision-making about health matters. An Advance Health Directive also formalises an adult's wishes about current and future health matters and may nominate one or more people to make decisions on their behalf should they become unable to do so. Queensland's Advance Health Directive is given force under both the <i>Powers of Attorney Act 1998</i> and the <i>Guardianship and Administration Act 2000</i> . The legal effect of a patient's Advance Health Directive is as if the patient gave the directions when they had capacity.
Artificial hydration and/or nutrition	Artificial nutrition and/or hydration refers specifically to techniques for providing nutrition and/or hydration because the patient is unable to swallow. It includes the use of nasogastric tube, percutaneous endoscopic gastrostomy (PEG feeding) or radiologically inserted gastrostomy (RIG) feeding tubes through the abdominal wall. PEG, RIG and nasogastric tube feeding also provide fluids necessary to keep patients hydrated. Artificial hydration includes intravenous or subcutaneous infusion of fluids (use of a 'drip'), and nasogastric tube feeding or administration of fluid. The term artificial nutrition and hydration does not refer to help given to patients to eat or drink, for example spoon feeding.
End of life	The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.
End-of-life care³¹⁷	Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with: <ul style="list-style-type: none"> • advanced, progressive, incurable conditions • general frailty and co-existing conditions that mean that they are expected to die within 12 months • existing conditions, if they are at risk of dying from a sudden acute crisis in their condition • life-threatening acute conditions caused by sudden catastrophic events.
Enduring Power of Attorney (EPOA)	An Enduring power of Attorney is a formal document used to appoint someone to make financial and personal decisions on behalf of a patient in circumstances where they are unable to do so themselves (i.e. lack of capacity). Queensland's Enduring Power of Attorney is given force under section 44(1) of the <i>Powers of Attorney Act 1998</i> .
Family	Those who are closest to the patient in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice.

Term	Description
Futile medical treatment	<p>Futile medical treatment refers to interventions that are unlikely to produce any significant benefit for the patient. Two kinds of medical futility are often distinguished:</p> <ol style="list-style-type: none"> 1. Quantitative futility, where the likelihood that an intervention will benefit the patient is exceedingly poor, and 2. Qualitative futility, where the quality of benefit an intervention will produce is exceedingly poor. <p>While the medical community is largely conversant with the meaning of the term, there is variability in how the term is applied. The Australian Medical Association describes futile medical treatment as treatment that no longer provides a benefit to a patient or treatment where the burdens of treatment outweigh the benefits. Doctors are not required to offer treatment options they consider neither medically beneficial nor clinically appropriate.</p>
Goals of care	<p>The aims for a patient's medical treatment, as agreed between the patient, family, carers and healthcare team. Goals of care will change over time, particularly as the patient enters the terminal phase.</p> <p>Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient.</p> <p>The patient's goals of care may also include nonmedical goals – for example, returning home or reaching a particular milestone, such as participating in a family event.</p>
Good Medical Practice	<p>Good medical practice is good medical practice for the medical profession in Australia having regard to -</p> <ol style="list-style-type: none"> (a) the recognised medical standards, practices and procedures of the medical profession in Australia; and (b) the recognised ethical standards of the medical profession in Australia. <p>Good Medical Practice: A Code of Conduct for Doctors in Australia was released by the Medical Board of Australia in 2014 and has a specific component on end-of-life care.</p>
Health care ³¹⁸	<p>(1) Health care, of an adult, is care or treatment of, or a service or a procedure for, the adult—</p> <ol style="list-style-type: none"> (a) to diagnose, maintain, or treat the adult's physical or mental condition; and (b) carried out by, or under the direction or supervision of, a health provider. <p>(2) Health care, of an adult, includes withholding or withdrawal of a life-sustaining measure for the adult if the commencement or continuation of the measure for the adult would be inconsistent with good medical practice.</p> <p>Health provider</p> <p>Means a person who provides health care, or special health care, in the practice of a profession or the ordinary course of business. Examples are doctors, dentists, social workers, psychologists, nursing professionals.</p>

Term	Description
Informed consent ³¹⁹	Informed consent, in a legal sense, reflects that a patient has received the information relevant to them to make an informed decision and they have given permission for the healthcare to be provided. In an ethical sense the provision of informed consent by a patient reflects the end point of a process of engagement in which one or more health practitioners have supported the patient to come to an informed decision to agree to the healthcare offered.
Informed decision-making ³²⁰	Informed decision-making is the two-way communication process between a patient and one or more health practitioners that is central to patient-centred healthcare. It reflects the ethical principle that a patient has the right to decide what is appropriate for them, taking into account their personal circumstances, beliefs and priorities. This includes the right to accept or to decline the offer of certain healthcare and to change that decision. In order for a patient to exercise this right to decide, they require the information that is relevant to them.
Interdisciplinary team	A team of providers who work together to develop and implement a plan of care. Membership depends on the services required to identify and address the expectations and needs of the patient, carers and family. An interdisciplinary team might typically include one or more doctors, nurses, social workers, spiritual advisers, pharmacists and personal care workers. Other disciplines may be part of the team, depending on the needs of the patient and the resources available. Hospital volunteers, patients, carers and family members may also be considered as part of the interdisciplinary team.
Life-sustaining measure	The legislation defines a life-sustaining measure as health care intended to sustain or prolong life that maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation. ³²¹ Life-sustaining measures include, but are not limited to; cardiopulmonary resuscitation, assisted ventilation and artificial nutrition and hydration. Other life-sustaining measures might include; drug therapies, antibiotics and renal and liver failure treatments (eg., haemodialysis, peritoneal dialysis, hemofiltration). Life-sustaining measures do not include unusual or extraordinary forms of treatment taking into account the available facilities and resources available to provide for the patient's care.
Nonbeneficial treatment ³²²	Interventions that will not be effective in treating a patient's medical condition or improving their quality of life. Nonbeneficial treatment may include interventions such as diagnostic tests, medications, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Nonbeneficial treatment is sometimes referred to as futile treatment, but this is not a preferred term.

Term	Description
Objections to withholding or withdrawing of life-sustaining measures ³²³	<p>If an adult objects to the withholding or withdrawing of life-sustaining measures, they are effectively saying that they want them – that is they want the measures, believing they will save their life and health. This turns on the need for consent if an adult objects. Section 67 of the <i>Guardianship and Administration Act 2000</i> contains provisions around adults objecting to withholding or withdrawing of life-sustaining measures</p> <p>Effect of adult's objection to health care</p> <p>(1) Generally, the exercise of power for a health matter or special health matter is ineffective to give consent to health care of an adult if the health provider knows, or ought reasonably to know, the adult objects to the health care.</p> <p><i>Editor's note—</i></p> <p>Object is defined in schedule 4 (Dictionary). Note also the <i>Powers of Attorney Act 1998</i>, section 35(2)(a) (Advance Health Directives) provides that 'by an Advance Health Directive [a] principal may give a direction—</p> <p>(a) consenting, in the circumstances specified, to particular future health care of the principal when necessary and despite objection by the principal when the health care is provided'.</p> <p>(2) However, the exercise of power for a health matter or special health matter is effective to give consent to the health care despite an objection by the adult to the health care if—</p> <p>(a) the adult has minimal or no understanding of 1 of the following—</p> <p>(i) what the health care involves;</p> <p>(ii) why the health care is required; and</p> <p>(b) the health care is likely to cause the adult—</p> <p>(i) no distress; or</p> <p>(ii) temporary distress that is outweighed by the benefit to the adult of the proposed health care.</p> <p>(3) Subsection (2) does not apply to the following health care—</p> <p>(a) removal of tissue for donation;</p> <p>(b) participation in special medical research or experimental health care or approved clinical research.</p> <p>Object (Schedule 4 definition)</p> <p>object, by an adult, to health care means—</p> <p>(a) the adult indicates the adult does not wish to have the health care; or</p> <p>(b) the adult previously indicated, in similar circumstances, the adult did not then wish to have the health care and since then the adult has not indicated otherwise.</p> <p><i>Example—</i></p> <p>An indication may be given in an enduring power of attorney or advance health directive or in another way, including, for example, orally or by conduct.</p>
Overall benefit	<p>The term 'overall benefit' describes the ethical basis on which decisions are made about treatment and care for adult patients who lack capacity to decide. It involves an assessment of the appropriateness of treatment and care options that encompasses not only the potential clinical benefits, burdens and risks of those options, but also non-clinical factors such as the patient's personal circumstances, wishes, beliefs and values. Overall benefit also encompasses whether treatment is in the adult patient's best interests.</p>

Term	Description
Palliative care or palliative approach ³²⁴	<p>Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness.</p> <p>Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social. Because palliative care is based on individual needs, the services offered will differ but may include:</p> <ul style="list-style-type: none"> • Relief of pain and other symptoms e.g. vomiting, shortness of breath • Resources such as equipment needed to aid care at home • Assistance for families to come together to talk about sensitive issues • Links to other services such as home help and financial support • Support for people to meet cultural obligations • Support for emotional, social and spiritual concerns • Counselling and grief support • Referrals to respite care services <p>Palliative care is a family-centred model of care, meaning that family and carers can receive practical and emotional support.</p>
Resuscitation orders/plans	<p>Documents completed by a doctor to outline the plan of care in relation to emergency treatment of severe clinical deterioration.</p> <p>Queensland's Acute Resuscitation Plan (ARP) is an endorsed Statewide medical order that provides clinical authority to act on its instructions. Replacing NFR Orders from 2009, the ARP relates to decisions to provide or not provide life-sustaining measures, such as CPR, if the patient has a cardiac or respiratory arrest.</p>
Specialist palliative care	<p>Services provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate nonspecialist clinicians who are providing palliative care.</p>
Statement of Choices (SoC)	<p>The SoC is an advance care planning form developed by Metro South HHS. It records the views and wishes of a person about their end of life treatment and care. The SoC is not a legal document like an Advance Health Directive, but may be used to guide decision-making about end of life care. The SoC is currently being trialled and will be reviewed in 2017/18.</p>
Statutory Health Attorney ³²⁵	<p>(1) For a health matter, an adult's statutory health attorney is the first, in listed order, of the following people who is readily available and culturally appropriate to exercise power for the matter—</p> <ol style="list-style-type: none"> (a) a spouse of the adult if the relationship between the adult and the spouse is close and continuing; (b) a person who is 18 years or more and who has the care of the adult and is not a paid carer for the adult; (c) a person who is 18 years or more and who is a close friend or relation of the adult and is not a paid carer for the adult. <p><i>Note</i>— If there is a disagreement about which of 2 or more eligible people should be the statutory health attorney or how the power should be exercised, see the <i>Guardianship and Administration Act 2000</i>, section 42 (Disagreement about health matter).</p> <p>(2) If no-one listed in subsection (1) is readily available and</p>

Term	Description
	<p>culturally appropriate to exercise power for a matter, the public guardian is the adult's statutory health attorney for the matter.</p> <p>(3) Without limiting who is a person who has the care of the adult, for this section, a person has the care of an adult if the person—</p> <ul style="list-style-type: none"> (a) provides domestic services and support to the adult; or (b) arranges for the adult to be provided with domestic services and support. <p>(4) If an adult resides in an institution (for example, a hospital, nursing home, group home, boarding-house or hostel) at which the adult is cared for by another person, the adult—</p> <ul style="list-style-type: none"> (a) is not, merely because of this fact, to be regarded as being in the care of the other person; and (b) remains in the care of the person in whose care the adult was immediately before residing in the institution.
Substitute decision-maker	<p>A person appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. Substituted decision-making comes into effect when consent is required to provide health care to an adult with impaired capacity. The <i>Guardianship and Administration Act 2000</i> (s. 66 – Adult with impaired capacity-order of priority in dealing with health matter) provides a priority list of substitute decision-makers when consent is required:</p> <ol style="list-style-type: none"> 1. a valid Advance Health Directive 2. Tribunal-appointed Guardian 3. Attorney appointed under most recent enduring document (e.g. an Enduring Power of Attorney) 4. the person's statutory health attorney 5. the Public Guardian. <p>More than one substitute decision-maker may be appointed under an enduring document. The range of substitute decision-makers under the <i>Guardianship and Administration Act 2000</i> (section 9) are described as both formal (including tribunals and courts) and informal (including family members approved under section 154 of the same Act). There are essentially three categories of substitute decision-makers:</p> <ul style="list-style-type: none"> • substitute decision-makers chosen by the person (e.g. one or more enduring guardians appointed under a statutory advance care directive, or a nominated substitute decision-maker in a common law advance care directive) • substitute decision-makers assigned to the person by the law in the absence of an appointed substitute decision-maker, (e.g. statutory health attorney which could be a family member or carer or close friend) <ul style="list-style-type: none"> • substitute decision-makers appointed for the person (e.g. a guardian appointed by a guardianship tribunal).
Terminal condition	<p>A progressive condition that has no cure and that can be reasonably expected to cause the death of a person in the foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing. A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise. Palliative Care Australia recommends "living with an eventually fatal (or terminal) condition."</p>

Term	Description
<p>Urgent health care³²⁶ (also describes acute emergency situations)</p>	<p>Urgent health care</p> <p>(1) Health care, other than special health care, of an adult may be carried out without consent if the adult's health provider reasonably considers—</p> <ul style="list-style-type: none"> (a) the adult has impaired capacity for the health matter concerned; and (b) either— <ul style="list-style-type: none"> (i) the health care should be carried out urgently to meet imminent risk to the adult's life or health; or (ii) the health care should be carried out urgently to prevent significant pain or distress to the adult and it is not reasonably practicable to get consent from a person who may give it under this Act or the <i>Powers of Attorney Act 1998</i>. <p>(2) However, the health care mentioned in subsection (1)(b)(i) may not be carried out without consent if the health provider knows the adult objects to the health care in an advance health directive.</p> <p>(3) However, the health care mentioned in subsection (1)(b)(ii) may not be carried out without consent if the health provider knows the adult objects to the health care unless—</p> <ul style="list-style-type: none"> (a) the adult has minimal or no understanding of 1 or both of the following— <ul style="list-style-type: none"> (i) what the health care involves; (ii) why the health care is required; and (b) the health care is likely to cause the adult— <ul style="list-style-type: none"> (i) no distress; or (ii) temporary distress that is outweighed by the benefit to the adult of the health care. <p>(4) The health provider must certify in the adult's clinical records as to the various things enabling the health care to be carried out because of this section.</p> <p>(5) In this section—</p> <p>health care, of an adult, does not include withholding or withdrawal of a life-sustaining measure for the adult.</p>

References

- ¹ *Guardianship and Administration Act 2000, Powers of Attorney Act 1998, and Public Guardian Act 2014*
- ² Despite an increase in the absolute number of deaths, death rates have fallen in Australia. "From 1907 to 2013, the age-standardised death rate for males and females fell by 71% and 76% respectively..." However, "chronic diseases such as cancer, coronary heart disease and diabetes are becoming increasingly common in Australia due to a population that is increasing and ageing, as well as to social and lifestyle changes. Improvements in medical care have also enabled us to live longer with illnesses and diseases, and have provided access to treatments not available in the past." ([AIHW Australia's Health 2016](#), pages 10 & 12)
- ³ Part 7 of the [Hospital and Health Boards Act 2011](#) contains provisions around confidentiality of information for persons receiving public sector health services. Section 139A defines 'designated person' for the purposes of that Act and subdivision 1 of Division 2 in Part 7 deals with the prohibited disclosure of confidential information, including by health practitioners (s. 142A). Part 7 contains provisions about circumstances where it is permitted to disclose confidential information, for example where consent is obtained (s. 144) or where disclosure is required to lessen or prevent serious risk to life, health or safety (s.147), and disclosure to Commonwealth, another State or Commonwealth or State entity (s. 151) if certain criteria are met.
- ⁴ Queensland Department of Health. August 2014. [Indemnity for Queensland Health medical Practitioners](#). Human Resources Policy I2 (QH-POL-153). However, while the indemnity may pay for legal representation for a clinician, it will not prevent a claim being made or findings being made against a clinician.
- ⁵ See *Guardianship and Administration Act 2000*, s. 63 – Urgent health care. In particular, s. 63(4) – "The health provider must certify in the adult's clinical records as to the various things enabling the health care to be carried out because of this section."
- ⁶ AIHW. General Record of Incidence of Mortality (GRIM) books. [All causes combined](#). Accessed 13 December 2016.
- ⁷ Australian Bureau of Statistics. [Life Tables](#), States, Territories and Australia, 2014-2016 (Cat. 3302055001DO001_20142016) Released 18 October 2017. Accessed 15 November 2017.
- ⁸ AIHW 2005. [Mortality over the twentieth century in Australia: Trends and patterns in major causes of death](#). Mortality Surveillance Series no. 4. AIHW cat. no. PHE73. Canberra: AIHW. p. xxiii.
- ⁹ Swerissen H and Duckett S. 2015. What can we do to help Australians die the way they want to? *MJA* 201(1); 19 January 2015.
- ¹⁰ Swerissen H and Duckett S. 2014. *Dying Well*. Grattan Institute. p. 5
- ¹¹ Australian Institute of Health and Welfare, [Australia's health 2014: leading types of ill health](#). Accessed 15 October 2016.
- ¹² Commonwealth of Australia (2010) *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*.
- ¹³ Hales S, Zimmermann C and Rodin G. 2008. Cited in Swerissen H and Duckett S. 2014. *Dying Well*. Grattan Institute. p. 9.
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- ¹⁵ *Ibid.*, p. 2.
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