Guideline

End of Life Care and Decision-Making

Summary The Guideline is particularly relevant for situations where the patient may lose decision-making capacity before their wishes have been determined. It is intended to provide useful advice for NSW Health staff about a process for negotiating end of life decisions. It also contains information on specific issues such as children and young people, artificial hydration and nutrition, and Advance Care Directives. The Guideline also recommends minimum standards for documentation of decisions about withholding, or withdrawal of, treatment, and dispute resolution for patients, families and staff.

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END OF LIFE CARE AND DECISION-MAKING

GUIDELINE SUMMARY

Dying patients can be any age and are cared for in many settings including emergency departments, intensive care units, hospital wards, palliative care units, paediatric wards, residential aged care facilities, supported disability accommodation and the home. This Guideline provides useful advice for NSW Health staff about the process for navigating complex end of life decisions wherever that care is delivered.

NSW Health places a high priority on health practitioners working collaboratively with patients, their families and carers, as well as each other, throughout all phases of end of life care. This guideline sets out a process for reaching end of life decisions, in a way that safeguards both patients and health practitioners, through open and compassionate communication, appropriate treatment decisions and fairness.

KEY PRINCIPLES

Building consensus

A large part of this document focuses on building consensus, particularly where patients do not have the capacity to engage in the decision-making process about the role of life-sustaining treatment for themselves.

Respect for life and care in dying

A primary goal of medical care is preservation of life, however when life cannot be preserved, the goal is to provide comfort and dignity to the dying person and to support the person's family and/or carers in doing so.

The right to know and to choose

People relate to death and dying differently, often based on personal experience, culture and history.

Appropriate withholding and withdrawal of life-sustaining treatment

The goals of care shift to ensuring comfort and dignity, whereby withholding or withdrawal of life-sustaining medical interventions are often appropriate in the best interests of the patient or in accordance with a patient's Advance Care Directive (ACD).

A collaborative approach to care

The person responsible, families, carers and health practitioners have an obligation to work together to make compassionate decisions for patients who lack decision-making capacity.

Transparency and accountability

In order to preserve the trust of those receiving health care and to ensure that decisions are fairly made, the decision-making process, the decisions made and likely outcomes should be clear to the participants and accurately documented.

Non-discriminatory care

Everyone in NSW should be able to access quality end of life care when it is needed, regardless of their geographic location, age, condition, disability, socio-economic needs, cultural and religious background, gender identity, sexual orientation or languages spoken.

Rights and obligations of health practitioners

Adults have a right to accept or decline care and health practitioners have a responsibility to practice in accordance with community and professional norms and legal standards.

Continuous improvement

Health practitioners must strive for ongoing improvement in standards of end of life care.

USE OF THE GUIDELINE

This Guideline is designed for use by NSW Health staff who are part of the treating team involved in end of life care.

This Guideline should form the basis of local policy on end of life decision-making, considering local conditions and resources Local policy development is recommended for:

- minimum standards for documentation of decisions about withholding, or withdrawal of, treatment
- providing culturally safe and responsive end of life services
- dispute resolution for patients, person responsible, families, carers and staff.

Local policy may expand on this Guideline by, for example, identifying relevant persons or contacts within the hospital/local health district/specialty health network who may serve certain roles.

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March-2005 (GL2005_057)	Deputy Secretary and Chief Health Officer	Initial Document

ATTACHMENTS

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1 BACKGROUND

1.1 About this document

This Guideline is to provide information for NSW Health staff who are part of the treating team involved in end of life care. This may include medical specialists, general practitioners, nurses, Aboriginal Health Workers and allied health professionals such as social workers, physiotherapists, dieticians and occupational therapists.

Dying patients can be any age and are cared for in many settings including emergency departments, intensive care units, hospital wards, palliative care units, paediatric wards, residential aged care facilities, supported disability accommodation and the home. This guideline provides useful advice for NSW Health staff about the process for navigating complex end of life decisions wherever that care is delivered.

NSW Health places a high priority on health practitioners working collaboratively with patients, their families and carers as well as each other throughout all phases of end of life care. These phases include from the time a patient is diagnosed with a terminal illness up to their imminent death. Care is dependent on open and early communication in an environment of trust. This Guideline sets out a process for reaching end of life decisions, in a way that safeguards both patients and health practitioners, through open and compassionate communication, appropriate treatment decisions and fairness.

Ideally, patients determine their own decisions for end of life care. Some aspects of this Guideline apply to these patients who have decision-making capacity or have documented their wishes. Often, however, patients lose decision-making capacity before their wishes are determined. In those situations the treating team, person responsible, family and/or carer need to collaborate on a plan of care that considers the patient's best interests: reflecting the patient's wishes and values and avoiding both inappropriate over- and under-treatment. This guideline is relevant to all situations where a consensus-building approach is recommended.

The *End of Life and Palliative Care Framework 2019-2024* (the Framework) sets out the vision and future direction for palliative and end of life care for people across NSW. The Framework describes how people and services can work together to provide accessible, high quality end of life and palliative care.

1.2 Key definitions

Advance Care Directive

An Advance Care Directive (ACD) is a way a person can document what healthcare treatments they would like to have or refuse, should they find themselves in a position where they are unable to make or communicate decisions about their treatment and care.

In NSW, an ACD can be spoken or written. There is not a specific form that must be used. An ACD can only be made by an adult with decision-making capacity and if it is valid, it must be followed. Health practitioners and persons responsible have no authority to override a valid ACD. Further information about making an ACD can be found online at - https://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf

Advance Care Plan

An Advance Care Plan can be made by the individual or together with people that they trust and/or who are important to them. Where the individual is not able to make decisions, the Advance Care Plan can be made by their family/carer with a health practitioner. An Advance Care Plan is not a legal document.

Advance Care Planning

Advance Care Planning involves a person thinking about what care they would like should they find themselves in a position where they cannot make or communicate decisions about their treatment or care. It can include the person talking with family, carers and/or health practitioners, developing an Advance Care Plan, appointing an Enduring Guardian or making an Advance Care Directive.

Capacity

The ability for a person to make their own decisions is called 'capacity'. When a person has capacity, they can make their own decisions about things that happen in their life. Broadly speaking, a person has capacity to make a particular decision, when they are able to do all of the following:

- understand the facts involved
- understand the main choices
- weigh up the consequences of the choices
- understand how the consequences affect them
- communicate their decision.

It is important to always presume that a person has the capacity to make all decisions for themselves. Capacity is decision specific, which means if there is doubt about a person's capacity then there will need to be an assessment of the person's capacity for each decision.

Carer

A carer is an individual who provides unpaid, informal support and care to a family member, friend or neighbour who needs assistance because of disability, terminal illness, chronic illness and/or mental illness. The carer may or may not live with the individual.

End of life

For the purposes of this Guideline, this refers to the timeframe when a patient is clearly approaching the end of their life and is living with/impaired by a life-limiting illness. This includes:

- the patient's last weeks or days of life, when deterioration is irreversible and
- when a patient is assessed as likely to die in the next 12 months

End of life care

End of life care is delivered to improve the quality of life for people who have a life-limiting illness, as well as their families and carers. It ensures the appropriate support and

palliative needs are provided to the person so they live as well as possible until their death.

Enduring Guardian

An Enduring Guardian is the person an individual legally appoints to make decisions about their health and lifestyle in the event they cannot make these decisions for themselves.

Family

Family is an all-encompassing term that refers to the people who are closest to the individual and with whom the individual has an ongoing, personal relationship. This may or may not include immediate biological family, family of acquisition, blended families, same sex-partners, and family and friends of choice.

Life-sustaining treatment

Life-sustaining treatment is any medical intervention, technology, procedure or medication that is administered to forestall the moment of death, whether or not the treatment is intended to affect life-threatening diseases or biological processes. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation, dialysis or certain medications (including antibiotics).

Palliative care

The World Health Organisation defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial or spiritual.

Patient

For the purposes of this document, the patient describes the person receiving end-of-life care in a setting such as an emergency department, intensive care unit, hospital ward, palliative care unit, paediatric ward, residential aged care facility, supported disability accommodation or the home.

Person responsible

If a person is not capable of consenting to their own treatment, the health practitioner should seek consent from their ‘person responsible’. This is required by the *Guardianship Act 1987*.

Under section 33A(4) of the *Guardianship Act 1987*, there is a hierarchy of people who can be the person responsible. A person responsible is one of the following people in order of priority:

i. Guardian – an appointed guardian (or enduring guardian) who has been given the right to consent to medical and dental treatments, or

ii. Spouse or partner – if there is no guardian, a spouse, de-facto spouse or partner where there is a close continuing relationship, or

iii. Carer – if there is no spouse or partner, an unpaid carer who provides or arranges for domestic support on a regular basis, or

iv. Relative or friend – if there is no carer, a friend or relative who has a close personal relationship, frequent personal contact and a personal interest in the person's welfare, on an unpaid basis.

The person responsible for a child (a person less than 18 years) is the person having parental responsibility (within the meaning of the *Children and Young Persons (Care and Protection) Act 1998*) for the child. However, if the child is in the care of the Minister, then the Minister is the person responsible, or if the child is in the care of the Secretary then the Secretary is the person responsible. These circumstances are determined by the *Children and Young Persons (Care and Protection) Act 1998*.

Treating team

The treating team is the multidisciplinary team of health professionals involved in the patient's management and care. This may include medical specialists, general practitioners, nurses, Aboriginal Health Workers, Aboriginal Health Practitioners, Aboriginal Liaison Officers, allied health professionals such as social workers, physio therapists, dieticians and occupational therapists, lived experience professionals, patient advocates, chaplains or pastoral care workers.

Treatment limitation decisions

Treatment limitation decisions are those that involve the reduction, withdrawal or withholding of life-sustaining treatment.

1.3 Developing local policy

This Guideline should form the basis of local policy on end of life decision-making, considering local conditions and resources. Local policy should be developed in collaboration with key stakeholders including consumer representatives, Aboriginal Health Workers and Aboriginal Health Practitioners. Local policy development is recommended for:

- minimum standards for documentation of decisions about withholding, or withdrawal of, treatment
- providing culturally safe and responsive end of life services
- dispute resolution for patients, person responsible, families, carers and staff.

Local policy may expand on this Guideline by, for example, identifying relevant persons or contacts within the hospital/local health district/specialty health network who may serve certain roles.

Quality improvement activities for end of life care should be developed to guide future practice including self-audits and other sources of performance feedback such as complaints and commendations.

1.4 Training and education

NSW Health has online training modules for health practitioners on My Health Learning which aim to raise awareness and competency in end of life conversations and good

practice. All relevant and current modules are part of the End of Life Learning Pathway, including the 'Introduction to Advance Care Planning' and 'SHAPE: End of Life Conversations'.

2 PRINCIPLES

2.1 Building consensus

A large part of this document focuses on building consensus, particularly where patients do not have the capacity to engage in the decision-making process about the role of life-sustaining treatment for themselves. Consensus building is the most inclusive process for determining what is the best treatment for that individual, at that time, and in that place. A consensus view about appropriate treatment is ethically justified when it is in accordance with the guiding principles outlined below.

2.2 Respect for life and care in dying

A primary goal of medical care is preservation of life, however when life cannot be preserved, the goal is to provide comfort and dignity to the dying person and to support the person's family and/or carers in doing so. Health practitioners will work collaboratively to ensure services and support are culturally safe and responsive to the unique needs of the person where they may require additional support in accessing end of life care.

2.3 The right to know and to choose

People relate to death and dying differently, often based on personal experience, culture and history. Everyone receiving healthcare has a right to be informed about their condition and their care options and have access to good quality health information, in a format and language that is culturally responsive and that they can understand. People have a right to accept and decline life-sustaining treatment. Health practitioners have an ethical and legal obligation to acknowledge and honour these stated choices and preferences.

2.4 Appropriate withholding and withdrawal of life-sustaining treatment

Appropriate end of life care should aim to provide the best possible treatment and care in line with the patient's wishes and values at that time. The goals of care shift to ensuring comfort and dignity, whereby withholding or withdrawing life-sustaining medical interventions are often in the best interests of the patient or in accordance with a patient's Advance Care Directive (ACD).

2.5 A collaborative approach to care

The person responsible, families, carers and health practitioners have an obligation to work together to make compassionate decisions for patients who lack decision-making capacity. They need to take into account previously expressed patient wishes where these wishes are known or are documented in an ACD or Advance Care Plan. Health practitioners in the treating team play a role in fostering a collaborative approach and ensuring support is culturally safe and responsive to the unique needs of the patient and their family and/or carers.

2.1 Transparency and accountability

In order to preserve the trust of those receiving health care and to ensure that decisions are fairly made, the decision-making process, the decisions made and likely outcomes should be clear to the participants and accurately documented. Information and guidance in accessible formats (e.g. designed for culturally and linguistic diverse audiences, Easy Read versions, or with pictures) should be made available.

Easy Read and video resources for people with disability regarding going to hospital, care coordination, palliative care and Advance Care Planning can be found at https://www.health.nsw.gov.au/disability/covid-19/Pages/going-to-hospital.aspx.

Health practitioners must engage professional health care interpreters for patients, person responsible, families and carers who are not fluent in spoken English, hard of hearing, or living with disability. More information can be found at www.health.nsw.gov.au/multicultural/Pages/health-care-interpreting-and-translating-services.aspx.

2.6 Non-discriminatory care

Everyone in NSW should be able to access quality end of life care when it is needed, regardless of their geographic location, age, condition, disability, socio-economic needs, cultural and religious background, gender identity, sexual orientation or languages spoken. Therefore, treatment decisions at the end of life should be non-discriminatory and dependent only on factors that are relevant to the patient's medical condition, values and wishes.

Treatment decisions may be unintentionally or unknowingly discriminatory because a person has a disability or mental illness. This may occur when assumptions are made about people with disability, or when their needs and preferences are not adequately taken into account. Further guidance can be found at https://www.health.nsw.gov.au/disability/Pages/policies-and-guidelines.aspx

2.7 Rights and obligations of health practitioners

Adults have a right to accept or decline care and health practitioners have a responsibility to practice in accordance with community and professional norms and legal standards. For children see 7.2.

Health practitioners are under no obligation to provide treatments that are futile. That is, treatment that is unreasonable and offers negligible prospect of benefit to the patient's medical condition.

2.8 Continuous improvement

Health practitioners must strive for ongoing improvement in standards of end of life care. End of life care and palliative care requires continuing education and support for those health professionals caring for dying patients, their person responsible, families and/or carers This should include feedback for consumers.

3 ADVANCE CARE PLANNING

Health outcomes for patients, their families and carers improve when they can talk through their concerns, preferences, choices and decisions with health practitioners.

Ideally, these conversations start when the patient is well and should continue throughout their health care journey. The patient's wishes, values, goals and priorities should be documented to help their person responsible, family, carer and health practitioners make decisions about the patient's end of life care when they are no longer able to do so.

Currently in NSW, people can plan for end of life care by:

- discussing their preferences for life-sustaining treatment with their person responsible, family and/or carer while they are well
- writing an Advance Care Directive (ACD) if they are an adult with decision-making capacity, noting that an ACD can also be oral (which should be documented)
- formally appointing and/or informing an Enduring Guardian (where the person has decision-making capacity)
- developing an Advance Care Plan (ACP) in conjunction with their health practitioners, person responsible, family and/or carer

The critical element for effective advance care planning by any of the above approaches is discussion between the patient and their person responsible, family and/or carer, as well as their treating team.

An ACP may be developed by the individual (regardless of their capacity) and/or by their person responsible, family and/or carer on their behalf, in consultation with their treating team. An ACP is not a legal document.

However, an ACD in NSW can only be made by an adult with decision-making capacity. An ACD can be spoken or written in NSW. It does not need to be on a specific form to record their wishes. This means that all ACDs must be respected, including ACDs from other states and territories.

NSW Health has developed the *Making an Advance Care Directive* package which includes an ACD form and an information booklet to help complete the form.

The My Health Record allows a person to upload an ACP and/or an ACD as part of their health information under the 'Advance Care Planning Documentation' section. Guidance on access procedures for ACDs/ACPs on My Health Record in both emergency and non-emergency settings can be found on the NSW Health website at https://www.health.nsw.gov.au/patients/acp/Pages/access-procedures-mhr.aspx.

4 FOUNDATION FOR SOUND DECISION-MAKING

The following section discusses a number of factors that support a sound process for end of life decision-making. The process itself is discussed in more detail in section 5.

These factors include:

- respecting the principles of this Guideline
- the changing context of treatment decisions at the end of life
- the relationship between the treating team/health care professional and the patient with decision-making capacity
- holistic assessment and the importance of multi-professional input including allied health reviews, interpreting services, disability supporter or advocate, and Aboriginal liaison
- the collaborative nature of the treating team/health practitioners and the patient and/or person responsible, family and/or carer
- supported decision-making tools as required, for example support to access and understand the information and resources needed to make a decision for themselves. This is particularly relevant for people with disability.
- the consensus building model where the patient has no decision-making capacity
- accountability
- the importance of palliative care.

4.1 The changing context of treatment decisions at end of life

Because planning for end of life care usually takes place in the context of ever-changing circumstances, it is useful to follow the cyclic feedback process as set out in section 5 (see 5.1).

One reason for this constant change is the difficulty in predicting, with certainty, an individual's response to a particular treatment or prognosis of their disease. Often life-sustaining treatment will be commenced while further investigations are carried out, or information sought, in order to make a more accurate prognosis. When all available information has been collected the appropriateness of continuing the treatment is reviewed with the treating team/health practitioner, patient and/or their person responsible, family and/or carer.

The patient's wishes may also change as they develop an appreciation of their clinical condition. This process of review, decision-making and treatment trial may be repeated a number of times as the patient's condition improves or deteriorates. These decisions are often based on probabilities, rather than certainties.

4.2 The relationship between the treating team/health practitioner and the patient with decision-making capacity

Under NSW law, every person has the right to the presumption of capacity. Capacity or lack of capacity should not be assumed on the basis of a patient's diagnosis or condition. Any concern about a person's capacity to understand or participate must be assessed on an individual basis.

A person's decision-making capacity may be adversely affected by chronic or acute illnesses. As a result, a patient's decision-making capacity may vary over time and therefore necessitate periodic re-assessment.

Disability and mental illness can also impact a person's decision-making capacity. Health practitioners should consider how the patient can be supported in their decision-making.

An adult patient with decision-making capacity may accept, refuse or withdraw life-sustaining treatment, even where that decision may lead to serious deterioration in health or death. It is crucial that the patient is properly informed of the consequences of refusing such treatment. A patient may make choices about treatment consistent with their own values, even where these values differ from those of the treating team/health practitioner, their person responsible, family and/or carer. A patient with decision-making capacity has autonomous decision-making authority and the treating team/health practitioner acts in an advisory capacity to the patient, enabling the patient to make choices regarding their treatment options.

It is essential that health practitioners continue to keep patients (and/or their person responsible, family and/or carer) informed about their medical condition as they improve or deteriorate, and as the patient's decision-making capacity fluctuates. Patients should be given the opportunity to participate in treatment decisions consistent with their decision-making capacity.

Note that where the patient is a young person (between 14 and under 18 years) their consent may be sufficient, in most cases, but it is good practice to include the parents or guardian in the decision-making and consent process.

Where a minor has insufficient understanding (likely 13 years and under) consent from a parent or guardian must be obtained they should be included in the process.

The general principles regarding consent for medical treatment apply in relation to the treatment of dying patients, as they do for other patients. Health practitioners must be familiar with *NSW Health Consent to Medical and Healthcare Treatment Manual* (Consent Manual) .

4.3 The collaborative nature of the treating team

The treating team involved in end of life care, either through direct decision-making or in supportive roles, may include medical specialists, general practitioners, nurses, Aboriginal Health Workers, Aboriginal Health Practitioners, Aboriginal Liaison Officers, allied health professionals such as social workers, physiotherapists, dieticians and occupational therapists, lived experience professionals, patient advocates, chaplains or pastoral care workers.

Individual members of the treating team may have closer or prolonged involvement with the patient and may be aware of the patient's values and wishes, and what is culturally appropriate. Other team members may be involved periodically on an 'as needed' basis or 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. Junior nurses and doctors, as well as general practitioners working with community-based patients, should not be excluded where end of life decisions are considered.

Reaching agreement within the treating team about appropriate care is an important initial step in a collaborative approach, particularly where the patient no longer has decision-making capacity.

Nurses play a significant role in providing clinical and social information to the patient, person responsible, family and/or carer in the potential initiation of treatment limitation discussions and as managers of the dying process. Nurses are included in the collaborative process whereby the treating team develops a management plan with patients and/or their person responsible, families and/or carers.

4.4 A consensus-building model when the patient has no decision-making capacity

Where the patient lacks decision-making capacity the treating team should confirm if there is a valid Advance Care Directive (ACD) so that decisions can be made in accordance with the patient's ACD.

When a patient lacks decision-making capacity and it is not an emergency, all health practitioners are required by law to consult and seek consent to treatment from the 'person responsible'.

Where the patient has a legally appointed guardian (including Enduring Guardians), they can make decisions about treatment being withheld or withdrawn only if they have been expressly given such a power in their appointment. In this case, the guardian is the decision-maker and the health practitioner acts in an advisory capacity, just as they would have if the patient had decision-making capacity. It is important for health practitioners to review the terms on which guardians are appointed.

In the absence of a suitably authorised guardian, other persons responsible do not have the express power to consent to withholding or withdrawing treatment, but they should be consulted when end of life decisions are being made.

A person responsible can provide a consent to active medical treatments such as pain management and/or end of life care symptoms.

When the patient cannot be supported to make their own informed decision about their care, a consensus-building approach to end of life decision-making is recommended. This collaborative process aims to draw on the person responsible, family and/or carer and treating team's knowledge and understanding of the patient's personal values and medical condition.

A consensus is sought within the treating team, and between the treating team and family and/or carer, about a plan of care that is as consistent with the patient's wishes and

values as much as possible. This approach supports the family and/or carer in the degree of involvement they wish to have.

The approach of shared decision-making is recommended due to the risk that sole decision-making by any one party may fail to achieve the best possible treatment decision. A consensus approach with appropriate involvement from both treating team and family and/or carer:

- avoids placing a senior treating clinician in a position of assuming a patient's wishes concerning end of life treatment without the participation of others, or withholding or withdrawing treatment
- is consistent with a desire by many patients that if they are not able make decisions then their family and/or carer can be involved in end of life decisions
- reduces the potential of imposing possible additional stress on a family and/or carer who may perceive that they carry the burden of decision-making and which may later contribute to feelings of guilt
- minimises inappropriate input to decisions where concerns arise about conflict of interest within a family or a family or carers understanding of medical care.

A consensus approach can be facilitated by a senior treating clinician and members of the treating team through the person responsible, family and/or carer conferencing to discuss the illness, prognosis, goals of care and potential outcomes, impacts of decisions, patient's values and wishes.

The treating team and senior treating clinician should offer recommendations for the patient's management plan based on their understanding of the patient's medical condition and prognosis. They should allow time for discussion and reflection, while continuing to work with, and support, the family and/or carer and reach a consensus decision.

The person responsible, families and carers should be provided with a contact point for appropriate members of the treating team, hospital or community-based staff after the patient's death to discuss unanswered questions. This may be beneficial in eliminating guilt or uncertainties.

Elements that are critical to the success of this approach and options for resolving disagreements are discussed in section 5.

4.5 Accountability

As the leader of the treating team, the senior treating clinician is accountable to the patient, the person responsible, the family and/or carer, the employing health authority, and ultimately the courts, for the process whereby a consensus about end of life decisions is sought and the reasonableness of the planned course of action.

Following the process set out in this Guideline and developing adequate documentation of that process will ensure that the senior treating clinician and the treating team meet the obligations required for accountability in end of life treatment decisions.

4.6 Importance of palliative care

The provision of palliative care for patients should be introduced early and continue throughout all phases of a life-limiting illness, especially during the dying phase. The treating team should ensure services and support are culturally safe and responsive to the unique needs of the patient, family and/or carer.

This care should encompass optimising the quality of life, reducing suffering, promoting dignity, providing relief from pain and other distressing symptoms, as well as providing emotional and psychological support in preparation for death.

During discussions about end of life care, patients can raise other issues such as relief of psychological suffering, spiritual care, choice around place of death, and addressing any unresolved issues that they may have.

Offering support systems help the person responsible, family and/or carer cope during the patient's illness. This could include personal and home care, counselling and respite as well as offering support through their own bereavement and grieving journey.

The specific details of palliative care should be documented (See section 7.3).

More information on providing accessible, high quality end of life and palliative care can be found in the *End of Life and Palliative Care Framework 2019-2024*.

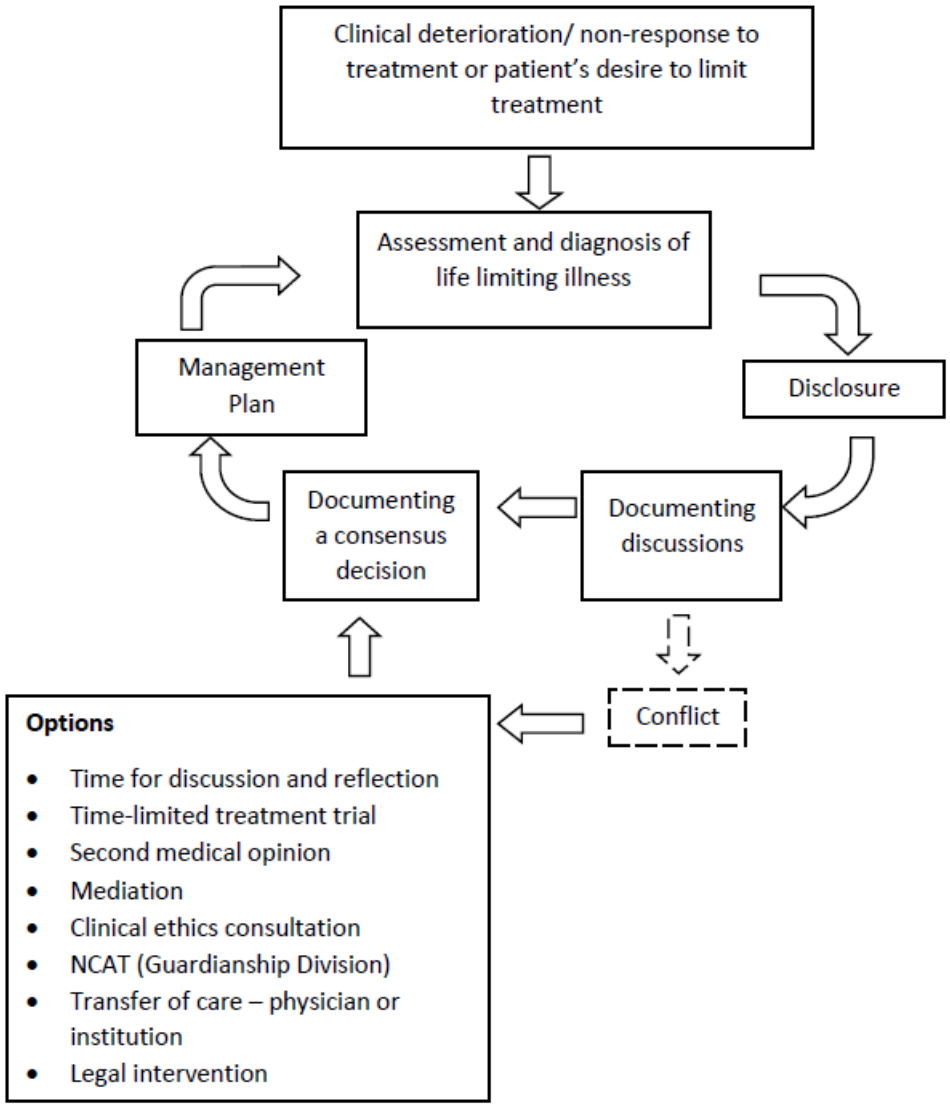
5 DEVELOPING A MANAGEMENT PLAN

Planning end of life care is an iterative or cyclic process based on holistic, comprehensive assessment, disclosure, discussion and consensus building with the patient and/or their person responsible, family and/or carer and the treating team.

This process can take place over a short period, such as hours, where the patient suddenly or unexpectedly deteriorates, but it can also extend over weeks or months. End of life discussions may be included in discharge plans to facilitate follow up and discussion with their General Practitioner (GP). This may be particularly relevant for aged and frail people, or those living with a chronic condition or receiving palliative care.

The key points in each step of this process (section 5.1) are discussed in the following sections.

5.1 Process of end of life decision-making



5.2 Assessment

A sudden or unexpected deterioration, or uncertainty about prognosis, usually requires efforts to stabilise the patient so that a complete assessment can be undertaken and potential reversibility of the condition be established.

Development of an end of life management plan should be considered and discussed if:

- the patient's recovery is uncertain
- if the treating clinician asks him or herself, 'Would I be surprised if this patient were to die in 6 to 12 months?' and the answer is 'No'
- if the patient clinically deteriorates or is anticipated to do so
- or if the patient's condition is considered high risk.

The treating team should undertake this assessment at the earliest appropriate time. Life-sustaining treatment that has already commenced may be subsequently withdrawn if it is deemed no longer appropriate upon assessment of the patient's wishes or clinical condition. The treating team should document all of the information used to support their decision-making process.

If there is reasonable doubt within the treating team about the medical assessment, they should seek advice from other senior clinicians, if possible, with experience in the condition. Any second opinions should be documented.

Assessment should also include evidence of the patient's preferences and values where available from the patient, as documented in their ACD, or by their person responsible, family and/or carer if the patient has no capacity.

A patient's preferences for life-sustaining treatment are not static over time and should be regularly reviewed by the treating team. Patient decision-making capacity may be impacted by many things including demoralisation, distress, or depression. Effective management of a patient's situation and symptoms should be addressed in conjunction with the decision-making process.

A patient's preferences regarding direct communication and information must be respected, documented and accessible to the treating team. The patient also has the choice to nominate someone to receive information on their behalf, or to exclude family members and/or a carer from discussions, decision-making processes and access to information.

The desire for autonomous decision-making or the preference for a collective or delegated approach to end of life decisions may vary among patients from culturally diverse or religious backgrounds. This aspect should be explored on an individual basis to avoid inappropriate clinical decisions and poor interaction with patients, their families and/or carers. The treating team should engage with appropriate cultural health workers, such as Aboriginal Health Workers, to ensure services and support are culturally safe and responsive to the unique needs of the patient, their family and/or carer.

The informal use of untrained interpreters such as other family members or a carer should be avoided when communicating essential or clinical information. Failure to work

with a health care interpreter or engaging an untrained interpreter (including family or friends) poses a risk to both the patient and the health practitioner.

Failure to demonstrate any improvement over an extended period or deterioration in clinical condition should generate discussion and questions about further initiation or continuation of treatment. The patient, the person responsible, family and/or carer, or the treating team may initiate such discussions.

5.3 Disclosure

Accurate information in Plain English should be provided to patients, their person responsible, families and/or carers so they can participate meaningfully in decisions about end of life care. Where required, this information should be provided in a culturally appropriate way, for example engaging with Aboriginal Health Workers to create a culturally appropriate end of life pathway. Information should be provided in accessible formats if needed including translations into languages other than English, Easy Read or pictures.

Assistive technology (e.g. touch screen devices, Text-To-Speech software/apps, dedicated speech devices, etc) may facilitate communication between the treating team and the patient, person responsible, family and/or carer. This is particularly relevant when communicating with a person with disability.

Uncertainty about prognosis or likely response to treatment should be communicated to patients, their person responsible, their families and carers. Prognostic information is ideally given by a health practitioner who is respected as an expert.

Patients, the person responsible, families and/or carers may be caught off guard when conversations about the goals of care and possible treatment limitations occur suddenly, very late, without preparation, or when they have not received a balanced picture of the patient's prognosis.

Patients, their person responsible, families and/or carers should be engaged in open communication about possible outcomes early in treatment, especially where the patient is seriously or critically ill. This is to prevent unrealistic expectations about what can be achieved with treatment.

It is important to confirm that the patient, family and/or carer has understood the discussion. Early, honest and regular communication can also help create the trust needed for shared decision-making and to defuse tension.

5.4 Documenting discussions

Discussions with patients, their person responsible, families and/or carers about treatment limitation should ideally occur in stages over a period of time, preferably while the patient can determine the appropriateness of treatment or its withdrawal. It is recommended that nursing staff, or other key members of the treating team are present in these discussions to support and facilitate communication between the treating team, the person responsible, family and/or carer.

Strategic opportunities for the treating team to initiate or revisit discussion about end of life care may include recent hospitalisation with severe, progressive illness or repeated

recent admissions, enquiries from the patient or family and/or carer about palliative care or an expression by the patient of a wish to die.

Having the same person/s communicate with the patient, the person responsible, family and/or carer on behalf of the treating team throughout this process can be useful, as minor differences in explanation of the patient's condition or progress can seem to patients, families and carers like major disagreements or discord in the team. Ideally, this health practitioner should be experienced in conducting such discussions, should have earned trust before treatment limitation is discussed, and should be able to discuss prognostic information.

The phrases 'do everything' or 'do nothing' are unproductive and should be avoided. Such terminology is a barrier to informed discussion regarding the benefits and burdens of certain courses of action. Where limitation of life-sustaining treatment is planned, ongoing care with the goal of providing comfort to the patient should be emphasised with the patient and their person responsible, family and/or carer.

Some local health districts and specialty health networks within NSW Health have established local clinical ethics committees. These committees variously provide education and local policy advice regarding ethical issues arising in their facilities and ethics case consultation. Should an impasse occur, a local clinical ethics committee could bring multidisciplinary expertise together with the person responsible, family and/or carer and the treating team to explore and assist with resolution.

5.5 Documenting a consensus decision

The agreed management plan for end of life care, and decisions about the use of life-sustaining treatment within that plan, should be documented and conveyed to all members of the treating team as well as the patient, their person responsible, family and/or carers This may include discussions and shared planning with health practitioners in other care settings, for example, with a patient's GP if they have chosen to die at home.

Such communication may be difficult where many staff care for the patient, however adequate documentation may assist in this regard. Where possible, alerts should be added regarding a patient's treatment preferences into their hospital record or ACD. The treating team (under the supervision of the senior treating clinician) is responsible for summarising discussions held with the patient, person responsible, family and/or carer and treating team in the patient notes.

These notes must clearly state:

- medical facts leading to the decision, including prognosis
- those involved in the discussion and if it was a family meeting
- the patient's wishes, where known and if documented in an ACP or ACD
- goals of treatment and care
- details about medical treatments to be provided, timeframe before review, or details about treatments to be withdrawn / withheld.

Management plans may cover a shorter or longer period of time, depending on the clinical situation of the patient. Decisions that involve withholding treatment should be regularly reviewed in accordance with fluctuations in the patient's condition. A change in the appropriateness of withholding treatment (such as cardiopulmonary resuscitation) needs to be re-documented (see also section 7.5).

Other appropriate treating team members should continue to document other aspects of care that will be maintained or enhanced, such as comfort measures.

Thorough documentation of decision-making processes and subsequent care enables greater transparency and accountability in the care provided and ensures that all health practitioners fulfil their professional and legal obligations.

6 RESOLVING DISAGREEMENTS

In most situations where a patient is dying, the patient, person responsible, family and/or carer and treating 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 disagreements between the treating team, the patient or the person responsible can be prevented by early, sensitive and proactive communication that clarifies goals of treatment, possible outcomes and the patient's values and wishes. That is where early engagement of the Specialist Palliative Care Team, culturally appropriate support services, and Aboriginal Health Workers may help.

6.1 Disagreement in the treating team

In circumstances where one team member disagrees with the others, the team should consider the basis for disagreement and seek the opinions of independent professionals from the same discipline as the disagreeing member. If support for this position cannot be found, it may be appropriate for the dissenting member(s) not to continue being involved in the treating team. As in other areas of clinical practice, a health practitioner may exercise conscientious objection and not participate in a practice which is contrary to their professional opinion or moral beliefs.

Counselling or other psychological support may be appropriate where disagreement occurs about the appropriateness of treatment limitation. This is particularly relevant for health practitioners and allied health workers who may be more acutely aware of the patient's distress.

6.2 When a patient's person responsible, family and/or carer disagree with a patient's decision

The wishes of the adult patient with decision-making capacity are paramount. If the patient's expressed wishes regarding active treatment, refusal or withdrawal of treatment prior to loss of decision-making capacity are known, then these wishes prevail over the wishes of the person responsible, family and/or carer.

Disagreements between the patient and their person responsible, family and/or carer may arise for many reasons including if they are not properly informed of the patient's wishes. Every effort should be made to respect the patient's preference regarding

communicating this information to the person responsible, family and/or carer, with services and support made available.

In cases where the clinician believes family and/or carers are making inappropriate requests and they suspect abuse of older people then they should consult their local protocols. Further information can be found in NSW Health Policy Directive *Identifying and responding to abuse of older people* (PD2020_001).

6.3 Inappropriate requests for continuing treatment

At times a patient, person responsible, family and/or carer, may request a test or intervention that appears unreasonable or inappropriate to the treating team. Such a request may appear inappropriate in the following scenarios:

- where the patient's condition continues to deteriorate even with optimal therapeutic interventions
- where tests will not assist with the patient's goals or management
- where the treatment would not be successful in producing the clinical effect for which it is ordinarily used
- where the treatment might successfully produce a clinical effect, but still fail to serve important patient goals such as independence from life-support devices, survival in order to leave hospital, or improvement from permanent unconsciousness.

A focus should be kept on the patient and their wishes where they are documented in an ACD. All requests for continuing treatment should be given due consideration before decisions about the appropriateness of treatments are made. Any request should lead to a review of the diagnosis and prognosis and the margins of certainty in each aspect. Health practitioners should initially endeavour to explain to the patient, person responsible, family and/or carer why they think the desired test or treatment is inappropriate.

The person responsible, families and/or carers of patients without decision-making capacity who request continued treatment in such situations might have unrealistic expectations about what can be achieved.

More often though, a person responsible, family and/or carer 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 and/or carer is not aware of the patient's ACD and/or early engagement in treatment planning prior to the onset of the dying process (see 5.2) or where guilt may be associated with fractured or distant relationships within the family.

Where the treating team considers these requests for life-sustaining treatment to be of negligible clinical benefit, consent to withhold or withdraw treatment is not required. However, consultation is important in determining what is in a patient's best interests.

The efforts of nursing and medical staff, pastoral care workers, social workers or other counsellors should be directed to supporting the person responsible, family members and carers and assisting them to resolve their difficulties in accepting the reality of the patient's impending death.

In such circumstances, it is preferable to continue treatment until conflict with relatives is resolved. However, time-critical situations pose extremely difficult choices and challenges. Clinicians may be required to seek additional support from their hospital administrators or executive when resolving such conflict (see 6.5).

6.4 Requests for withholding or withdrawal of treatment by the patient

Unrelieved pain, suffering or depression may influence a patient's request to withhold or withdraw treatment. Under such circumstances, it is appropriate to:

- consider a patient's ACD if documented,
- explore the patient's feelings possibly with the assistance of a qualified professional (for example, palliative care or acute pain service), and
- address any issues that may be resolvable.

It may be appropriate to:

- request a palliative care consultation for symptom management and assessment,
- negotiate an agreed plan of continuing treatment with the patient and schedule further discussion in the near future, while acknowledging that sustained wishes for treatment refusal in the competent patient are ultimately paramount.

6.5 Options for resolving disagreement

The following approaches are possible avenues for resolving disagreements in the end of life care setting. Not all options will be available in all clinical contexts. However, the simple approaches should be taken first.

6.5.1 Timing and discussion

Unless decisions about life-sustaining treatment need to be made urgently, giving the person responsible, families and/or carers time to come to terms with the impending death of the patient may be sufficient to resolve outstanding issues. The treating team should consider scheduling time for further discussion with them or others providing support.

6.5.2 Second medical opinion

The patient, person responsible, family and/or carer may request a second medical opinion. Offering a second opinion may also be appropriate if the person responsible, family and/or carer is displaying anxiety or uncertainty regarding diagnosis or prognosis. It is the responsibility of the senior treating clinician to facilitate any second medical opinion. This opinion should be from a health practitioner with relevant expertise in the patient's condition and who is demonstrably independent from the treating team.

6.5.3 Time-limited treatment trial

A time-limited treatment trial may be undertaken to clarify prognostic uncertainty or resolve disagreement about prognosis, provided the trial is in the best interests of the patient or consistent with their wishes. It may be advisable to clarify with the treating team and person responsible, family and/or carer what treatments are being commenced

or continued, the criteria for assessment and the timeframe for review before possible continuation or withdrawal.

6.5.4 Facilitation

Involvement of a third party may assist in clarifying and addressing the concerns of the patient, person responsible, family and/or carer, or in finding agreement where an impasse has occurred between the person responsible, family, carer and the treating team. The third party may be a senior member of the hospital administration and/or hospital executive team, a senior health practitioner, or another person agreed upon by those involved. The person should have sufficient seniority, be respected by all parties, and be demonstrably independent of the treating team. Where available, a clinical ethics committee could be accessed to explore and assist with resolution.

6.5.5 Patient transfer

If these steps have not resolved the situation and a dispute remains between the patient, person responsible, family and/or carer and the treating team or the relationship has broken down, then the practicality of transferring the care of the patient should be investigated with those involved. This should be facilitated by the responsible senior treating clinician in consultation with the patient, person responsible, family and/or care. The transfer could be to another institution or home, or to another suitable treating clinician within the same institution.

6.5.6 Guardianship Division of the NSW Civil and Administrative Tribunal

The Guardianship Division of the NSW Civil and Administrative Tribunal (the Tribunal) has the jurisdiction to make orders as to whether medical/dental treatment of a patient should proceed if the patient lacks the capacity to provide their own consent.

Any application for such an order must set out evidence of the person's diminished capacity, the proposed treatment, details of alternative treatments (if any), and the nature and degree of any significant risks associated with either the proposed treatment or the alternatives.

The Tribunal can also hear applications seeking the appointment of a guardian to make ongoing medical and/or end of life decisions for a patient with diminished capacity. A family member/friend of the patient can be appointed as guardian, or alternatively, the Public Guardian of NSW.

More information about the Tribunal can be found at https://www.ncat.nsw.gov.au/

6.5.7 Legal intervention

The NSW Supreme Court has jurisdiction to hear matters relating to treatment limitation decisions. If the child or young person is under 18 years of age, then the Family Court of Australia has jurisdiction. Senior treating clinicians or their delegates may consider initiating a Court action when they are unsure if the proposed treatment or treatment limitation is in accordance with their duties, and if all of the above steps have failed to resolve their concerns.

Before initiating a Court action, the senior treating clinician should have:

- contacted the Ministry of Health's Legal and Regulatory Services Branch to discuss the matter
- informed the hospital executive of the proposed approach
- obtained a second specialist's medical opinion in writing
- received advice from their health service's executive team
- discussed this course of action with the person responsible, family and/or carer.

Where this option is taken, continued consultation should take place with the person responsible, family members and/or carer to assist in clarifying the issues and to determine whether a legally acceptable solution in the best interests of the patient can be reached.

The Ministry of Health's Legal and Regulatory Services Branch can be contacted at (02) 9391-9606 or by email at NSWH-legalmail@health.nsw.gov.au.

Persons responsible, family members or carers may decide to independently initiate a Court action if they have concerns regarding end of life decisions where the patient lacks decision-making capacity. Persons responsible, family members or carers should be specifically informed that they have this option.

7 SPECIFIC ISSUES

7.1 Euthanasia/assisted suicide

Euthanasia and assisted suicide involve deliberate acts or omissions that are undertaken with the intention of ending a person's life.

In NSW both euthanasia and assisted suicide are crimes under the *Crimes Act 1900 (NSW)*. However, the following is permitted in NSW:

- The refusal of any or all life sustaining treatments by a person with decision-making capacity
- Competent patients to prepare an advance refusal of treatment for a time of future incapacity
- Decisions by doctors, in consultation with the guardian/ person responsible for incapacitated patients, to withhold or withdraw treatments that will not benefit the patient, to permit a peaceful death.

NSW Health strongly endorses patient autonomy and is committed to empowering patients in their choices, where the request is within the existing ethical and legal framework.

7.2 Neonates, children and young people

End of life decisions in neonates and children present many challenges and difficulties. This difficulty is because, unlike adults, neonates and children are often unable to understand or fully understand choices concerning life-sustaining treatments or functional states and the implications for decision-making. Children are also less likely to have expressed values that would be known by the family and inform treatment decisions.

Parents and the treating team may nevertheless consider that continued treatment is not appropriate where the child's condition is intolerable to the child or where the child is dying.

Older children and young people (that is, between 14 and under 18 years) may not make treatment limitation decisions solely by themselves, even where their capacity to make other medical decisions is not in doubt. Older children should be involved in discussions with their parents and the treating team regarding their prognosis and treatment, as appropriate to their level of understanding, emotional maturity and in accordance with their best interests.

Multidisciplinary support, as described below, may be necessary where a child's expressed wishes about end of life treatment is contrary to those of their parents.

Neonates, children and young people cannot have an ACD, however they can document their wishes in an ACP.

In addition to the strategies discussed in 6.5, the following strategies may be useful where the treating clinician and parents or guardian differ in their assessment of what is in the best interests of the patient, or where the parents disagree with each other:

- Appropriate multidisciplinary support for parents should be provided. The understandable anxieties of parents in relation to treatment limitation decisions may be complicated by potential feelings of guilt and responsibility for the child's death. This support may ultimately involve working with parents to refocus their hopes and goals.
- Assessment by a clinician with skills in working with distressed families (e.g. mental health practitioner, social worker, family therapist) that tries to understand the processes occurring in the family, especially as they may relate to the disagreement.
- Appointment of an appropriately qualified professional, such as a counsellor, in the treating team to advocate independently for the interests of the child.

The consensus-building approach to treatment limitation decisions outlined in this Guideline at 4.4 is also applicable in this setting. Where the process fails to bring a consensus about the appropriateness of treatment limitation, resolution will require application to the Court.

Where the child is subject to a care order conferring parental responsibility to the Minister under the *Children and Young Persons (Care and Protection) Act 1998 (NSW*) the law treats the Minister as the child's parent.

The treating clinician should consult with the Minister about the appropriateness of life-sustaining medical treatment by contacting the Department of Communities and Justice. Treatment should continue to be provided, time permitting, while consultation takes place. Disagreements between the treatment team and the Minister or Minister's delegate about the appropriate course of action should be resolved by the same processes as apply to other parents, as outlined in this guideline.

There are three Specialist Paediatric Palliative Care Services in NSW that provide a consultative service to health care teams, community staff and parents and/or carers to support them in their location of choice/goals of care. These services are provided by the

Sydney Children's Hospitals Network (The Children's Hospital at Westmead and the Sydney Children's Hospital, Randwick) and John Hunter Children's Hospital, Newcastle.

Further information on the services and their contact details can be found at www.nswppcprogramme.com.au.

7.3 Culturally appropriate and responsive care at end of life

Culturally appropriate care at end of life for people is supportive of personal, family and community needs. This may include palliative care in the home, return to community, cultural or ritual activities.

Aboriginal Health Workers, Aboriginal Health Practitioners and Multicultural Health Workers can work with the patient, family and/or carers to inform the various service providers about their specific needs.

The Lesbian, Gay, Bisexual, Transgender or Intersex (LGBTI) community may face additional barriers when accessing appropriate and responsive care at end of life. This may include experiences of discrimination in health care and other settings, and a lack of recognition of LGBTI families. As a result, it may be important for LGBTI patients to prepare clear advance care planning documents to protect their legal rights and end of life care preferences, particularly if their family and/or carer are not aware of or do not respect their sexual orientation, gender identity, intersex status or relationships.

People with disability may require additional supports to enable them to understand death, dying and end of life care, and to effectively make decisions about appropriate and responsive care. This may include the use of assistive technology, translated resources, or disability supporters/advocates. It is important not to underestimate the capacity of people with disability to understand and make decisions about their own health care.

Diagnostic overshadowing – attributing the symptoms of a disease to the disability and thereby failing to diagnose or treat it – can be a significant barrier to the timely introduction of palliative and end of life care. Where possible, the treatment team should include input from disability and mental health specialists.

7.4 Appropriate use of analgesia and sedation

Analgesia and sedation should be provided in proportion with clinical need by whatever route is necessary for the primary goal of relieving pain or other unwanted symptoms. Such administration will not be unlawful provided the intention of the clinician or authorised prescriber is the relief of symptoms, even if the medical practitioner is aware that the administration of the drug might also hasten death.

7.5 Artificial hydration and nutrition

Use of artificial hydration and nutrition is an intervention with its own possible burdens and discomforts, for example, those related to having tubes in situ or regularly replaced.

Withdrawal of artificial hydration and nutrition, like the withdrawal of other medical interventions, can be seen as a withdrawal of treatment decision that may be made in accordance with this Guideline. It is recognised that the provision of artificial hydration and nutrition may be a particularly sensitive matter for some in the community who believe that it must be continued, unless specifically refused by the patient. The offering

of food and fluids should be part of the care of dying patients as appropriate to their clinical condition or wishes, unless it presents a risk to the patient.

These decisions can be made and documented by the treating team which can include speech pathologists and/or dietitians who are skilled at providing assessment and guidance in a palliative care framework. Speech pathologists are also skilled at providing education and strategies on safe feeding strategies to minimise aspiration and/or discomfort to maximise quality of life.

7.6 Making Resuscitation Plans

Making a Resuscitation Plan is one step in the process of planning quality end of life care. It is a medically authorised order to use or withhold resuscitation measures and document other aspects of treatment relevant at end of life.

Resuscitation Plans are intended for patients 29 days and older in all NSW Public Health Organisations, including acute facilities, sub-acute facilities, ambulatory and community settings, and NSW Ambulance. For patients under 29 days of age, the Paediatric Resuscitation Plan may be used to guide discussions.

NSW Health Resuscitation Plans are not valid for community patients under the medical care of a doctor who is not a NSW Health staff member. General Practitioners with admitting rights are considered NSW Health staff. Decisions to withhold CPR and other resuscitation measures seek to avoid unwanted, excessively burdensome or insufficiently beneficial interventions for patients at the end of life. At some point in the course of life-limiting illness, a shift in the focus of care away from aggressive intervention and towards a palliative approach is often the agreed outcome.

The rationale for withholding resuscitation includes:

- Where there is a clearly stated, adequately informed and properly documented or verbally expressed refusal by a person with decision-making capacity. An ACD and ACP can inform decisions recorded in the Resuscitation Plan.
- Where the person has no capacity to make this decision, there is an adequately informed and properly documented decision to withhold resuscitation by the Attending Medical Officer in consultation with the person responsible, family and/or carer.
- Where the Attending Medical Officer judges that resuscitation offers no benefit or where the benefits are small and overwhelmed by the burden to the patient.

Not having a Resuscitation Plan does not necessarily mean that resuscitation is a default action that must be applied in all situations. A medical officer's clinical judgement should be used where resuscitation is manifestly inappropriate and/or the patient is deceased.

The general principles and process guiding the completion of a Resuscitation Plan are the same for children as for adults. Though the Paediatric Resuscitation Plan is not intended for use in Neonates (patients under 29 days), it may be used to guide discussions. For more information on Resuscitation Plans refer to NSW Health Policy Directive *Using Resuscitation Plans in End of Life Decisions* (PD2014_030) .

7.7 Advance Care Directives (ACDs)

The NSW Supreme Court has said that valid ACDs must be followed as they are part of a person's right to make decisions about their health. Health professionals and persons responsible have no authority to override an ACD.

The following conditions should be met before ACD treatment decisions are followed. The ACD:

- is intended to apply to the clinical circumstances that have arisen
- must be sufficiently clear and specific to guide clinical care
- should be made by an adult patient and should reflect their wishes, rather than the wishes of another person, and
- there must not be any reasonable evidence to suggest that the ACD does not reflect the current intentions of the patient, or was made as a result of undue influence

It is best practice, but not legally necessary, that the ACD:

- is periodically reviewed by the patient, for example after an illness, or following a change in health status
- should be available at the time decisions need to be made, for example, by ensuring the likely person responsible and primary healthcare provider have a copy and any of its revisions
- be signed and witnessed, if it is written
- is developed by a patient with involvement or assistance from a medical practitioner.

If there is doubt about whether the ACD applies, or if there are concerns that the ACD is not valid, health treatment should be provided until clarification can be sought from the Supreme Court. The Ministry of Health's Legal and Regulatory Services Branch should be contacted in these circumstances. If after hours, the clinician should elevate the matter to the Local Health Districts (Districts) executive who can contact the Ministry of Health's General Counsel.

See section 3 of this Guideline for more detailed information about ACDs and advance care planning.

7.8 Organ and tissue donation

Specialist organ donation doctors and nurses in hospitals will help identify potential organ donors and engage in donor conversations with the person responsible, family and/or carers. Where patients have registered their wishes about organ donation on the Australian Organ Donor Register (https://donatelife.gov.au/) or documented them in their ACD or previously informed their person responsible, family or carer, the treating team should inform the specialist organ donation team in their hospital.

7.9 Post-coma unresponsiveness (PCU)

The withholding or withdrawal of treatment for a severely brain-injured patient is a decision that should be made in accordance with this Guideline. Diagnosis of PCU is difficult and usually protracted, often taking months to confirm. The National Health and Medical Research Council has released ethical guidelines for the care of people in post-coma unresponsiveness or in a minimally responsive state. It is available at www.nhmrc.gov.au.

7.10 Emergency treatment

In circumstances where treatment is necessary as a matter of urgency, a treating clinician or health may provide medical treatment without consent (from either the patient or the person responsible). This may occur when a patient's condition suddenly deteriorates and his or her wishes or likelihood of recovery are unknown. This treatment may be to:

- save the patient's life,
- prevent serious damage to the patient's health; or,
- to alleviate significant pain or distress, except in cases of special medical treatment.

Special medical treatment is treatment requiring additional consent or approval pursuant to legislation.

This treatment should be no more than is reasonably required in the best interests of the patient. This does not apply, however, if the patient, when competent, has unequivocally refused the provision of such treatment in the applicable circumstances and the clinician is satisfied on the available evidence that such a direction has been made.

This emergency principle also applies to children and young people if the treatment is required urgently to save the life or prevent serious damage to the health of the child or young person.

Any treatment provided without consent in an emergency must be documented in the patient's Health Record.

More information on consent is available from the *NSW Health Consent to Medical and Healthcare Treatment Manual* *(Consent Manual)*http:///.

8 RESOURCES AND CONTACTS

NSW Ministry of Health

1. Policy Directive on Using Resuscitation Plans in End of Life Decisions

   www.health.nsw.gov.au/PDS/pages/doc.aspx?dn=PD2014_030

2. Information on access procedures to Advance Care Planning and/or Advance Care Directives on My Health Records

   www.health.nsw.gov.au/patients/acp/Pages/access-procedures-mhr.aspx

3. Information on Advance Care Planning for people with mental illness: a comprehensive guide

   www.health.nsw.gov.au/patients/acp/Pages/comprehensive-guide.aspx

4. Information on the Introduction to Advance Care Planning

   www.heti.nsw.gov.au/education-and-training/courses-and-programs

5. NSW End of Life and Palliative Care Framework 2019-2024

   www.health.nsw.gov.au/palliativecare/Publications/eol-pc-framework.pdf

6. Information and resources on palliative care:

   www.health.nsw.gov.au/palliativecare/Pages/easy-read-resources.aspx

7. NSW Paediatric Palliative Care Services

   www.nswppcprogramme.com.au/

   Sydney Children's Hospitals Network (The Children's Hospital at Westmead and the Sydney Children's Hospital, Randwick)

   www.schn.health.nsw.gov.au

   John Hunter Children's Hospital, Newcastle

   www.hnekidshealth.nsw.gov.au/site/jhch

8. Information on Supporting Health Professionals in Advance Care Planning and End of Life (SHAPE) Conversations

   www.heti.nsw.gov.au/education-and-training/courses-and-programs

9. Information on requirements for organ donation and autopsy

   www.health.nsw.gov.au/organdonation/Pages/policies-and-guidelines.aspx

   www.health.nsw.gov.au/humantissue/Pages/default.aspx

10. Information on informed consent requirements

    NSW Health Consent to Medical and Healthcare Treatment Manual

    www.health.nsw.gov.au/policies/manuals/Pages/consent-manual.aspx

11. NSW Health Care Interpreting Services

    www.health.nsw.gov.au/multicultural/Pages/health-care-interpreting-and-translating-services.aspx

Further information can be downloaded through NSW Health website www.health.nsw.gov.au/pubs

Other websites

12. NSW Planning Ahead Tools

    https://planningaheadtools.com.au/

13. Clinical Excellence Commission's End of Life Program

    www.cec.health.nsw.gov.au/keep-patients-safe/end-of-life-care

    The AMBER Care Bundle

    www.cec.health.nsw.gov.au/keep-patients-safe/end-of-life-care/amber-care

    Last Days of Life

    www.cec.health.nsw.gov.au/keep-patients-safe/end-of-life-care/last-days-of-life

14. Agency for Clinical Innovation's Palliative Care Network

    https://aci.health.nsw.gov.au/networks/palliative-care

15. Information on Palliative Care Standards and Guidelines:

    www.pallcare.org.au/publications/index

16. Information on capacity and the Capacity Toolkit:

www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/ds_capacity_tool.aspx

17. Information about Guardianship and the NSW Trustee and Guardian

    www.tag.nsw.gov.au/guardianship

18. Information on guardianship and the role of the Guardianship Division of the NSW Civil and Administrative Tribunal

    www.ncat.nsw.gov.au/ncat/how-ncat-works/ncat-divisions-and-appeal-panel/guardianship-division.html

    Fact sheet on consent to medical treatment, and Fact sheet on person responsible

    https://ncat.nsw.gov.au/ncat/publications-and-resources/fact-sheets/guardianship-division-fact-sheets.html#Consent3

8.1 Implementation checklist and compliance self-assessment

Organisation / Facility:	

Assessed by:	**Date of Assessment:**		
Key Requirements	**Not commenced**	**Partial compliance**	**Full compliance**
	❑	❑	❑
	Notes:		
	❑	❑	❑
	Notes:		
	❑	❑	❑
	Notes:		
	❑	❑	❑
	Notes:		
	❑	❑	❑
	Notes:		
	❑	❑	❑
	Notes:		