The Palliative Approach Toolkit

Module 2: Key processes
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The Palliative Approach Toolkit was developed as part of the Implementation of a comprehensive evidence based palliative approach in Residential Aged Care (cebparac) project funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program.

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The Palliative Approach Toolkit

The Palliative Approach (PA) Toolkit is designed to assist residential aged care facilities to implement a comprehensive, evidence-based palliative approach of care for residents. The PA Toolkit contains:

Module 1: Integrating a palliative approach
Module 1 focuses on policies, systems and resources to support a palliative approach in a residential aged care setting.

Education resources
- Three self-directed learning packages
  1. Nurse (Introduction)
  2. Nurse (Advanced)
  3. Careworker (Introduction)
- Two educational DVDs
  1. “A palliative approach in residential aged care: Suiting the needs”
  2. “All on the same page: Palliative care case conferences in residential aged care”
- Five educational flipcharts
  The flipcharts are for short sessional in-service education targeting careworkers and are mapped to the clinical care domains.

Resource materials
The PA Toolkit includes several important reference publications:
- “Guidelines for a Palliative Approach in Residential Aged Care - Enhanced Version”
- “Therapeutic Guidelines: Palliative Care, Version 3”
- “Now What? Understanding Grief” brochure
- “Understanding the Dying Process” brochure
- “Invitation and family questionnaire - Palliative care case conference”

Module 2: Key processes
Module 2 focuses on three key processes essential in implementing a palliative approach:
- Advance care planning
- Palliative care case conferences
- End of life care pathway

Module 3: Clinical care
Module 3 focuses on the assessment and management of five clinical care domains:
- Pain
- Dyspnoea
- Nutrition and hydration
- Oral care
- Delirium

For the purposes of this toolkit, nurse will refer to registered and enrolled nurse and careworker will refer to personal careworker, health careworker and assistant-in-nursing.
The Palliative Approach Toolkit
Throughout the module, we provide examples of assessment tools and forms. Printable versions can be downloaded from “PA Toolkit: Forms CD”.

A palliative approach aims to improve the quality-of-life for individuals with a life-limiting illness and their families by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.  

A palliative approach is not restricted to the last days or weeks of life.

A palliative approach offers many benefits to residents, their families and the residential aged care facility (RACF) team including:

• reducing potential distress to residents and their families caused by a transfer to an acute care setting
• reducing the admission and/or transfer of residents to acute care facilities as RACF staff develop the skills to manage the palliative care of residents
• increasing the involvement of the resident and their family in decision making about their care
• encouraging open and early discussion on death and dying
• facilitating advance care planning
• providing opportunities, especially for improved control of pain and other symptoms, in a setting that is familiar to the resident
• offering the resident and family consistent and continuous care by staff with whom they have developed a rapport and positive therapeutic relationship.  

Why a palliative approach in residential aged care?

In Australia, the proportion of people dying in residential aged care facilities has steadily increased over the last two decades. In addition, people entering residential care are increasingly frail, often highly dependent and with multiple co-morbidities. The complex needs of residents and their families have prompted recognition of the need for a palliative approach.

When should a palliative approach be implemented?

Estimated prognosis is used as a trigger for the key processes in a palliative approach. Three trajectories can be applied to all new and existing residents based on their estimated prognosis (Figure 1).

Residents in trajectory B have a prognosis of six months or less. They are in the palliative phase and require a palliative approach.

Residents in trajectory C have a prognosis of less than one week. They are in the final stages of their illness and require terminal care.

It is important that residents are assessed and identified early and that strategies are developed to address issues of pain management, symptom relief and spiritual and cultural needs.
Figure 1
Palliative approach trajectories

All new and existing residents

Trajectory A
Expected prognosis of greater than 6 months
Annual nurse led case conference including advance care planning
Review 6 monthly
Prognosis 6 months or less

Trajectory B
Expected prognosis of 6 months or less
Palliative care case conference including review of advance care planning
Assessment and management of palliative clinical symptoms
Review monthly
Prognosis less than 1 week

Trajectory C
Expected prognosis of less than 1 week
Commence Residential Aged Care End of Life Care Pathway
Review daily
If prognosis is greater than 1 week

Palliative phase

Terminal phase
**Trajectory A - Estimated prognosis greater than six months**

All new and existing residents should have the opportunity to express their wishes about advance care planning (see Module 2 for further information) and have these clearly documented in their clinical notes. We recommend that this involves a discussion between the resident, family and the general practitioner (GP) and may result in the completion of a legal advance health directive.

For new residents it can be undertaken as part of the care-planning process. One option is a nurse-led care-planning conference involving the resident (where possible) and appropriate family members or the legal representative. We suggest that the resident’s GP be invited to attend (or at least be made aware of any wishes or decisions regarding advance care planning).

For existing residents that have not had an advance care planning discussion on admission this should be undertaken at the next scheduled review of care.

Residents on this trajectory of care should be reviewed every six months or sooner if there is a significant change that suggests a prognosis of six months or less.

Nurses should review the five palliative care clinical care domains (see Module 3) and include any aspects that are relevant in the resident’s care plan.

**Trajectory B - Estimated prognosis six months or less**

For all new or existing residents where a prognosis of six months or less is expected we recommend a palliative care case conference (see Module 2) be convened. We recognise estimating a prognosis is difficult and imprecise. However, we provide some key questions or markers that may assist members of the multidisciplinary team:

- **Markers for a prognosis of six months or less**
  
  - A positive response to the question: “Would you be surprised if the resident died within the next six months?”
  - If there has been a significant functional or medical decline.
  - If problems are perceived concerning goals of care around futile treatment (perhaps after an acute event).
  - If the resident is transferred or admitted to the RACF specifically for comfort or palliative care.

The aim of a palliative care case conference is to identify clear goals of care for the resident including a review of advance care plans.

A palliative care case conference provides the opportunity to claim for the palliative care component of the Aged Care Funding Instrument (ACFI) if at this conference it is deemed that a “palliative care program involving end of life care where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential aged care setting is required”.

If the palliative care case conference is attended by either the resident’s GP or a specialist palliative care nurse and all requirements for claiming ACFI are met then either of these health professionals can provide this directive.

The five clinical care domains of palliative care (see Module 3) provide a template for care planning, recognising that all residents have individual needs and not all domains may be appropriate at any one time.

The care plan should be reviewed monthly and adjusted as the resident’s care needs change utilising the domains of care as appropriate. If the resident has signs and symptoms that they may die within the next week (requires terminal care) their care plans can be replaced by an end of life care pathway.
Criteria for commencing a resident on the Residential Aged Care End of Life Care Pathway

The existence of three or more of the following signs and symptoms:

- experiencing rapid day-to-day deterioration that is not reversible
- requiring more frequent interventions
- becoming semi-conscious with lapses into unconsciousness
- increasing loss of ability to swallow
- refusing or unable to take food, fluids or oral medications
- irreversible weight loss
- an acute event has occurred requiring revision of treatment goals
- profound weakness
- changes in breathing patterns.

For residents who have not previously had a palliative care case conference this may be useful (if time permits) to inform and support the family and clarify the goals of care. Where a palliative care case conference is not possible the GP or nursing staff should review the resident’s care needs and goals and explain the pathway to the resident and family.

Commencing a resident on the RAC EoLCP provides another opportunity to claim for the palliative care component of ACFI if your facility has not already done so.
Advance care planning
Section 1

Advance care planning

The use of advance care plans can help people to die in the setting of their choice.1,9

This section provides guidance for advance care planning in residential aged care. Advance care planning is a process of reflection, discussion and communication of treatment preferences for a palliative approach that occurs before, and may lead to, an advance care plan or directive being developed. An advance directive is a legal document that sets out a resident’s wishes or appoints another person as substitute decision maker, usually called a guardian or medical power of attorney.2,9

Key points 2,5,8,15,19

- Advance care planning is not a single event, but rather an interactive process of communication between a competent resident and the aged care team.
- Communication is the fundamental principle of advance care planning.
- Advance care planning does not have to be a legalised formal process but rather should focus on ongoing communication with the resident and/or family.
- Advance care planning can extend a resident’s autonomy, and guide decision-making if the resident is rendered incompetent.

Getting started

Advance care planning should be part of the routine practice for every resident soon after admission to a RACF. We advocate advance care planning be integrated into the assessment and care planning process. A nurse-led care conference is recommended to facilitate this process. We suggest that the resident’s GP be invited to attend (or at least be made aware of any wishes or decisions regarding advance care planning).

Keep in mind that an advance care plan does not have to be completed in one sitting. The best outcomes may come from any number of conversations. Giving a resident the time to think about your questions is very important.

Tips and strategies1,8,14,17

Introduce advance care planning
- Ask if the resident has thought about their choices of medical treatment in the future.
- “How can we help you live well?” may be a less threatening reframe to commence discussions, allowing for a gradual lead-in to more sensitive questions.

Experience of end of life decision making
- Ask the resident if they have had any experience with a family member or friend who was faced with a decision about medical care near the end of life.
- If yes, ask them if the experience was positive or if they wish things could have been different, and how.

Selecting a substitute decision maker
- Ask whom they would like to make decisions for them if they were unable to make their own choices known.
- If they have someone in mind, recommend that they discuss their wishes with their potential representative.
- Provide information on appointing a representative. See Table 1 for information on state-based guidelines and legislation.
- A visit to the resident by a legal representative or counsel may be required. Ensure an appropriate level of privacy and provide assistance when needed.

Making decisions about future care
- Ask how they would like decisions to be made if they could no longer make those decisions.
- Advance care planning discussions can encompass issues like:
  - beliefs and attitudes toward death and dying
  - active versus palliative treatments
  - resuscitation wishes
  - hospital admissions/transfers
  - funeral wishes.

Goals and values
- Discuss with the resident what gives their life meaning. Possible responses might be specific beliefs, possessions, experiences, activities or relationships.
Religious, spiritual and cultural beliefs

• Ask who, or what, sustains them when they face serious challenges in life.
• Check if there is someone they would like to speak with to help them think about these issues.
• Cultural customs may differ with respect to patient autonomy, informed decision making, truth telling and control over the dying process.

Don’t rush it

• Allow the new resident and family to “settle in” before discussing the advance care plan in detail.

Review, review, review

• Decisions about end of life care options need to be revisited regularly and regardless of choices made previously.
• An assessment on admission of the resident’s wishes alone is inadequate, because it does not ensure that the resident’s current requirements are documented.
• It can take a resident several months to develop a comprehensive advance care plan that addresses all relevant issues.

Documenting advance care planning - what are the options?

Option 1 – Advance care directives

Every Australian State and Territory has its own legislation for advance care directives. Advance care directives may appoint a substitute decision maker, may record preferences of the person (direction) or both. As these forms are subject to change with new legislation it is important that you check any forms or information you provide are up to date. CareSearch has comprehensive links for each state and territory (http://www.caresearch.com.au). Table 1 provides information on current legislation.

Option 2 – The good palliative care plan

Not all residents are willing to complete a legal document such as an advance care directive. The Good Palliative Care Plan (see Form 1), developed in South Australia is an alternative, non-legal option. The Good Palliative Care Plan can be used in any state or territory and while not legally binding provides opportunity for documenting wishes.
### Table 1
State-based advance care planning guidelines and legislation

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<td>Powers of Attorney Act 2006</td>
<td>Enduring Power of Attorney</td>
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<td>Medical Treatment (Health Directions) Act 2006</td>
<td>Direction</td>
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<td>NSW</td>
<td>Guardianship Act 1987</td>
<td>Enduring Power of Guardianship</td>
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<td>NT</td>
<td>Natural Death Act 1988</td>
<td>Direction</td>
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<tr>
<td>QLD</td>
<td>Powers of Attorney Act 1998</td>
<td>Enduring Power of Attorney (health) and Enduring Power of Attorney (personal)</td>
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<td></td>
<td>Guardianship and Administration Act 2000</td>
<td>Advance Health Directive (includes a personal attorney)</td>
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<td>SA</td>
<td>Advance Care Directives Act 2013</td>
<td>Advance Care Directive*</td>
</tr>
<tr>
<td>TAS</td>
<td>Guardianship and Administration Act 1995</td>
<td>Enduring Power of Guardianship</td>
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<tr>
<td>VIC</td>
<td>Guardianship and Administration Act 1986</td>
<td>Enduring Power of Guardianship</td>
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<tr>
<td></td>
<td>Medical Treatment Act 1988</td>
<td>Enduring Power of Attorney (Medical Treatment) and Refusal of Treatment Certificate</td>
</tr>
</tbody>
</table>

*Advance Care Directive includes previously completed (prior to 30 June 2014) Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions*
Form 1: Good palliative care plan

Is there an Anticipatory Direction? Y / N

Details:

__________________________________________________________

__________________________________________________________

__________________________________________________________

I have discussed with patient

__________________________________________________________

__________________________________________________________

(Please ensure the medical power of attorney, authorising agent, is sighted.)

or their medical agent

__________________________________________________________

__________________________________________________________

and/or family member or attending persons

__________________________________________________________

__________________________________________________________

__________________________________________________________

and with staff members

__________________________________________________________

__________________________________________________________

__________________________________________________________

The patient’s current condition, which can be described as

__________________________________________________________

__________________________________________________________

__________________________________________________________

□ The patient is competent

□ Incompetent

Circle one of the options:

We have agreed that in the event of further deterioration in the patient’s condition:

1. Full cardiopulmonary resuscitation with total body support as required will be undertaken.

2. Intensive medical support will be undertaken, but cardiopulmonary resuscitation will not be initiated, and no long-term support measures, including ventilation or dialysis, will be undertaken.

3. The emphasis of management will be on Good Palliative Care, highlighting the relief of symptoms and discomforts. No artificial measures designed to supplant or support bodily function will be undertaken.

4. Other. Please specify:

__________________________________________________________

__________________________________________________________

__________________________________________________________

This form will be in force for:

□ 1 week

□ 1 month

□ 3 months

□ 12 months

□ Indefinitely

□ or until revoked by the patient

Date:

Signed:

Print name of legally qualified medical practitioner

This form can be downloaded from “PA Toolkit: Forms CD”.
Palliative care case conferences
This section provides guidance for conducting palliative care case conferences in residential aged care.

A palliative care case conference is a meeting held between a resident (and/or their family) and the aged care team.

The aim of a palliative care case conference is to identify clear goals of care for the resident including a review of any advance care plans. It also provides a safe environment where issues and questions about end of life care can be raised and appropriate strategies agreed upon.8,11

Having everyone with a stake in a resident’s care ‘on the same page’ is vital to achieve the best outcomes for the resident.

Key points1,6,8,11,14

- Pre-planning for palliative care case conferences is essential (see Form 2), as is comprehensive follow-up post-conference (see Form 3).
- Palliative care case conferences should not be saved for ‘crisis’ situations. A preventative approach is advocated where issues are anticipated before they become major dilemmas.
- Palliative care case conferences should not be used as an opportunity for the aged care team to debate a resident’s medical status. In this situation, a separate meeting should be convened prior to the case conference.
- Suitable resources can be made available to residents and family members who attend the case conference to complement the issues discussed. Two such brochures are included in this toolkit: “Understanding the Dying Process” and “Now What? Understanding Grief”.

Getting started

A palliative care case conference should be convened if a resident has an expected prognosis of less than six months. That is, a resident with a Trajectory B prognosis (see page 5 for key markers). Convening a palliative care case conference at this time is taking a proactive rather than reactive approach to care. A palliative care case conference can alleviate last-minute emergency discussions when resident /family are less able to clearly think through the issues. It can also provide peace of mind to the resident/family as they have a better understanding of what to expect and how facility staff will work to meet their needs at end of life.

The aged care team has a plan in place, agreed upon by all parties, for various end of life contingencies, so they are confident to act immediately as required.

Tips and strategies for planning a palliative care case conference1,13,14,17

A palliative care case conference may take a few weeks to organise. One person, taking responsibility for organisation, may facilitate a smoother process.

Who should facilitate a palliative care case conference?

- A senior nursing staff member can convene and facilitate a palliative care case conference. If your facility has a palliative care link nurse, this person may facilitate these conferences as part of their role.
- The resident’s GP can also elect to convene and facilitate a palliative care case conference.
- Ideally the facilitator should act as the primary contact point for the family.
What is a palliative care link nurse?

A palliative care link nurse (or champion) agrees to take on a special role, promoting and facilitating a palliative approach within the RACF. A link nurse may:

- promote and model the palliative approach
- coordinate the implementation of the PA Toolkit
- act as the ‘link’ person for external providers (e.g. GPs, specialist palliative care services, allied health, clergy)
- assist with auditing or quality improvement processes
- conduct in-service training for staff.

Who should attend?

- resident (if capable/competent)
- legal decision maker/medical power of attorney
- family members
- aged care team.

The aged care team will generally consist of the resident’s GP, the link nurse, and a careworker. However, other team members may be included based on the identified needs of the resident and family, for example: allied health professionals (including speech pathologists, physiotherapists, occupational therapists, dieticians, or social workers), members of the clergy, or specialist palliative care services.

Invitations

- Contact the GP in the first instance. S/he is likely to have the most limited availability. If they visit your facility on a regular day you may be able schedule the palliative care case conference around this commitment. Notify the GP practice manager to book the case conference into the GP’s patient appointment schedule (see Form 2, for a sample fax template).

Please note

The GP can claim reimbursement for case conferences of at least 15 minutes through the Medicare EPC items.

- Contact the primary family member/s and outline the purpose of the case conference. Families are often confused and/or distressed by the term “palliative”, so be prepared to support the family and clarify the “palliative approach”. In the PA Toolkit: Forms CD you will find a palliative care case conference family invitation and questionnaire. Complete the date, time and venue for the case conference and send this out to the family. The invitation provides additional information on palliative care and case conferences. It also asks families to think through and write down any concerns or questions they wish to discuss at the case conference. You may wish to ask families to return this segment prior to the case conference so the aged care team can consider their responses.

Location

- Arrange a comfortable room free of interruptions, tissues available, and with seating arrangements conducive to discussion.
- If meeting in the resident’s room, have an alternative location available in case there is a need to meet with the family separately.
- Where pertinent, and if resources allow, offer to conduct the meeting via teleconference. If GP or family members are participating via teleconference, ensure you have a contact number, and an alternate number (mobile).

Collect information

Collecting information prior to a case conference meeting gives time to prepare responses and anticipate any problems. Sources of information that can be helpful include:

- clinical records
- medication charts
- advance care planning documentation (legal or non-legal)
Tips and strategies for conducting a palliative care case conference

Introductions (take the time to orientate the participants)
• Thank everyone for attending and introduce yourself.
• Invite others to introduce themselves and state their role.
• Review meeting goals and clarify if specific decisions need to be made.
• Establish ground rules in a non-patronising way e.g. “We would like to hear from all of you. However, if possible, could one person please speak at a time? Each person will have a chance to ask questions and express views.”
• Identify the legal decision maker.

Determine what the resident/family already knows
• “What is your understanding of (the resident’s) current medical condition?”
• “What is your understanding of palliative care?”; ask everyone in the room to speak.
• Ask about the past 1-6 months—what has changed in terms of functional decline, weight loss, recent hospital admissions, changes to medications etc.

Review current status, prognosis and treatment options
• Allow all health care professionals including careworkers to have their say. Review issues identified in the staff communication sheet (see Form 3).
• Take into account the preferences of the resident and family regarding how much they wish to be told.
• Ask the resident and family in turn if they have any questions about current status, prognosis and treatment options. Review the family questionnaire/s if completed.
• Defer decision-making until the next step.

Decision making (when the resident is competent)
• Ask resident: “What decision(s) are you considering?”
• Ask each family member: “Do you have questions or concerns about the treatment plan?”; “How can you support the resident?”

Decision-making (when the resident is deemed incompetent)
• Ask each family member in turn: “What do you believe the resident would choose if they could speak for themselves?”
• Ask each family member: “What do you think should be done?”
• Ask the family if they would like the aged care team to leave the room to allow a private family discussion.

When there is no consensus
• Use time as ally: schedule a follow-up conference in the near future.
• Try further discussion: “What values is your decision based upon?”; “How will the decision affect you and other family members?”
• Re-state the goal: “What would the resident say if they could speak?”
• Identify other resources to facilitate decision-making: pastoral care, specialist palliative care team.

Wrapping up
• Summarise consensus, disagreements, and decisions.
• Caution against unexpected outcomes.
• Review the family questionnaire if completed.
• Identify family spokesperson for ongoing communication.
• Document key issues and action plans (see Form 5: Palliative Care Case Conference Summary Sheet).
• Offer a copy of the conference summary to the resident and/or family members.
• Continuity: schedule follow-up meetings as needed.

Afterwards
• Amend resident’s care plan to reflect outcomes and action plan from conference.
• Fax the the Palliative Care Case Conference Summary Sheet (Form 5) to the resident’s GP. This allows the GP to claim Medicare payments if relevant.
A Palliative Care Case Conference has been organised for [resident name].

Date: ____________________ Start Time: ____________________ Expected duration: ____________________

Venue: ____________________

As a vital member of the care team we invite you to participate. Medicare EPC items allow reimbursement for case conferences of at least 15 mins.

Please advise if you are able to participate in this case conference by checking one of the options below:

☐ Attending in person  ☐ Attending via teleconference (Telephone: ____________________)

☐ Unable to attend

Please fax this back to ____________________ (insert fax number) by __/__/____

Looking forward to your reply,

Sincerely,

______________________________
(name)

Palliative Care Case Conference Facilitator

This form is a template only and can be downloaded from “PA Toolkit: Forms CD”. Please modify to suit the needs of your facility.
A Palliative Care Case Conference is planned for [resident name] on [date]

As valuable members of the team your contribution to the case conference is important. Please list below any issues, concerns or suggestions, you would like mentioned. Common issues include review of symptoms (pain, dyspnoea), concerns with nutrition or hydration, family issues, emotional concerns of the resident.

If you are available and would like to attend the case conference, please contact the Case Conference Facilitator: [name]

<table>
<thead>
<tr>
<th>Issue, concern or suggestion. Please be as specific as possible.</th>
<th>Designation</th>
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This form is a template only and can be downloaded from “PA Toolkit: Forms CD”. Please modify to suit the needs of your facility.
Form 4: Palliative care case conference:
planning checklist

Name of Resident: ____________________________

Date of case conference: ________________ Time: ________________

Location: ____________________________ Room booked ☐ [tick circle]

Case conference facilitator: ____________________________

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<tr>
<th>Participants:</th>
<th>Invitation sent? (Date)</th>
<th>Accepted (A) or declined (D)</th>
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<tr>
<td>Name and contact details</td>
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Document Required Obtained N/A

Family questionnaire

Staff communication sheet

Clinical record (including most recent medication chart)

Advance care planning documentation (legal or non-legal)

Other (specify)

Goals of case conference:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

This form is a template only and can be downloaded from “PA Toolkit: Forms CD”. Please modify to suit the needs of your facility.
Form 5: Palliative care case conference summary

Name of Resident: ___________________________ Date of Birth: ___________________________

Purpose of Case Conference:

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

Participants:
Resident in attendance?  ○ Yes  ○ No

Health Professional

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Family Members

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## Form 5: Palliative care case conference summary (continued)

### Action Plan

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<tr>
<th>Goal</th>
<th>Actions</th>
<th>Key Person Responsible</th>
<th>Review Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**Facilitator**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Position:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature:</th>
<th>Date:</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Time Commenced**

**Time Completed**

General Practitioner: [name]

Tick appropriate box

- GP organises and coordinates a case conference in a RACF
- GP participates in a case conference in a RACF
- Original placed in the resident's clinical notes.
- Copy sent to GP.
- Copy offered to participating allied health.
- Copy offered to the resident/family members.
- Resident's care plan and assessments reviewed and updated.

**Facilitator**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Position:</th>
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<tbody>
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<table>
<thead>
<tr>
<th>Signature:</th>
<th>Date:</th>
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<tbody>
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</tbody>
</table>

This form is a template only and can be downloaded from "PA Toolkit: Forms CD". Please modify to suit the needs of your facility.
End of life care pathways
The RAC EoLCP is a consensus-based, best practice guide to providing resident-centred care during the last days of life. It has been developed by the Brisbane South Palliative Care Collaborative**.

This form is available from http://www.health.qld.gov.au/pahospital/services/pal_care.asp

Key points

- The RAC EoLCP has five sections which have been designed to provide comprehensive documentation of the care provided to a resident during the last days of life.
- The entire document is to be placed in the resident's notes and forms part of their clinical record.
- Depending on individual RACF policies and procedures it may be possible to replace existing documentation and charting requirements when the RAC EoLCP document is commenced.
- The GP and the RACF nursing staff should be in agreement that the resident is entering the terminal phase.
- If the GP is unavailable then the Specialist Palliative Care Service should be consulted.

Agreement and authorisation can be verbal. However, verbal authorisation should be confirmed with a GP or Palliative Care Medical Officer (PCMO) signature in Section 2 within 48 hours.

The final decision to commence the RAC EoLCP is a clinical one, supported by the views of the multidisciplinary team and/or the resident and their representative.
The resident may be taken off the RAC EoLCP

It is possible, in some cases, that the interventions in the RAC EoLCP may improve the condition of the resident, who may no longer require terminal care. In these cases, the RAC EoLCP should be ceased and the resident returned to a normal care plan.

Figure 2 provides a summary of the process of commencing a resident on the RAC EoLCP.
Section 2 - Medical interventions and advance care planning

This section covers the medical review of essential medications and documents advance care planning.

If a ‘no’ or ‘pending’ response against an intervention or advance care planning item is recorded, reasons for this should be documented on the multidisciplinary communication sheet (see Section 4).

**Interventions**
- Review all existing medications and cease all non-essential medications. If oral administration of medications is no longer possible and/or appropriate then order medications by an alternative route (e.g. subcutaneous).
- Cease non-essential clinical interventions and observations (e.g. blood pressure monitoring, BSLs).
- Order as-needed (PRN) medications for anticipated symptoms. Suggestions are provided in the “Medication guidelines for the RAC EoLCP” section of this module (see page 32).

**Advance care planning**
- Inform the resident (where possible) and their representative of the decision to commence the pathway.
- Discuss future care, including wishes regarding transfer to hospital and other life sustaining measures.
- Discuss and agree upon a ‘not for resuscitation’ (NFR) order with the resident and/or their representative.

**Spiritual/religious/cultural needs:**
- Spiritual/religious/cultural needs are identified and documented. These will include specific death and/or post death related practices and rituals.
- Where appropriate, relevant resources and contacts will be identified and used when required.

**Communication with resident/resident’s representative:**
- The residents nominated representative is identified and informed that the resident is dying.
- The nominated representative contact details and availability are confirmed.
- An opportunity for the nominated representative to express any concerns is provided and key issues are documented and addressed.
- Grief and loss issues are broached with the resident’s nominated representative.
- The Bereavement Risk Index can be used to identify persons at potential risk following the death of the resident.¹²

**Comfort planning:**
- The need for a special pressure relieving mattress and/or other comfort aids is assessed and addressed.

Section 2 should be completed and signed by either the GP or PCMO within 48 hours of gaining verbal authorisation to commence the pathway.

**Completion of this section enables the GP to claim Medicare benefits for a Comprehensive Medical Assessment (CMA), if the resident has not had a CMA completed in the previous 12 months. Further information can be obtained from your local Division of General Practice or Medicare Australia.**

Section 3 - Care staff interventions

This section covers the planning, delivery and documentation of care provided by nurses and careworkers.

**Part A - Care management**

This section is to be completed by a Registered Nurse when the resident is commenced on the RAC EoLCP.

It covers spiritual/religious/cultural needs, communication and comfort planning.

The information may already be documented in the resident’s existing chart. If this is the case, the RN should check that the information is current and document any changes as necessary.

If the RN records a ‘no’ or ‘pending’ response in any section, reasons for this should be documented on the multidisciplinary communication sheet (see Section 4).
Part B - Comfort care chart

The comfort care chart lists a set of comfort focused observations that are reviewed a minimum of four hourly. However, the frequency of observation will be determined by individual RACFs. A new chart is commenced each day.

This chart is completed by nurses and careworkers directly caring for the resident.

The first part refers to common symptoms experienced in the last few days of life and the maintenance of syringe drivers. It includes references to:
- pain
- nausea and vomiting
- respiratory difficulties
- agitation
- subcutaneous cannula and subcutaneous infusion checks.

The second part consists of common comfort care measures for people who are dying. These are:
- comfortable positioning
- mouth care
- eye care
- skin care
- micturition
- bowel care.

The third part consists of psychosocial support measures for people who are dying. These are:
- support for resident and their representative
- spiritual / cultural support.

Each symptom, comfort care and psychosocial support measure has a care goal.

Outcomes for each care goal should be recorded with one of the following options:
- A = assessed and no action required
- F/A = further action required
- R/C = routine care
- N/A = not applicable

If a care goal is not met, the nurse records 'F/A'.

All further actions should be documented on the further action sheet (see Section 3 - Part C).

Part C - Further action sheet
- When a further action (F/A) is recorded by a nurse / careworker on the “further action sheet”, any outcomes of care provided to address the symptom or care measure are documented.
- This documentation provides a record of care given as well as a mechanism for analysing reasons for not achieving desired outcomes of care.
- The nurse records the date, time and why F/A was required and what was done about it.
- The nurse who records the F/A should then reassess the intervention and record the result.
- If the intervention has not resolved the symptom / issue, and further action is again required, then this should be recorded until the care goal is resolved.
- If a facility normally uses medication stickers to record symptom management, they can be applied to this sheet.

Section 4 - Multidisciplinary communication sheet

This section is for members of the multidisciplinary team to record any communication or treatment notes while the resident is on the pathway.

Using your facilities current paper or electronic based progress notes are an alternative.

Section 5 - After death care

Following the death of the resident, the Registered Nurse completes this section.

It provides a checklist of tasks that need to be completed and ensures that all the relevant people are informed of the death.
- Each RACF will have individual policies and procedures regarding the ‘final acts of care’ and these should be observed by nursing staff.
- If the resident’s representative has not received bereavement information, they should be provided with it following the death of the resident.
- If recording a ‘no’ or ‘pending’ response, please document reasons for this on the multidisciplinary communication sheet to facilitate follow up action.

Needing to provide further action (F/A)s should not be viewed as failure to deliver good care. Recording further actions is a quality control measure and when analysed, can provide evidence to obtain new resources and identify training needs.
The following medication guidelines are recommended for residents commencing on the RAC EoLCP. The guidelines suggest a minimum medication set designed to manage pain, nausea and vomiting, agitation and restlessness and noisy secretions, which are commonly encountered symptoms in the last days of life.

It is advised that the following guidelines be used when prescribing PRN medications for residents commencing on the RAC EoLCP. The GP and nursing staff need to monitor for known side effects or adverse reactions for each medication. The effectiveness of all symptom-related medications should be assessed following each administration.

*Please contact your local Specialist Palliative Care Service if you need any further information or have any queries regarding these guidelines.*

### Table 2

**Medication guidelines for resident’s commencing on the RAC EoLCP**

<table>
<thead>
<tr>
<th><strong>Pain</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Opioid naive residents</td>
<td>2.5mg – 5mg morphine subcutaneously, prn to 2 hourly. If more than 2 – 3 doses required within 24 hours, consider commencing a 24-hour continuous subcutaneous infusion (CSCI). Starting dose should be equivalent to total dose required in previous 24 hours.</td>
</tr>
<tr>
<td>Residents already requiring morphine</td>
<td>Prescribe total daily dose as a CSCI. Subcutaneous dose is equivalent to 1/3 of the total oral morphine equivalent. For residents requiring more than 60mg oral morphine equivalent consider converting to hydromorphone via CSCI.</td>
</tr>
<tr>
<td>Residents with known renal impairment</td>
<td>Fentanyl via CSCI should be prescribed for these residents. Contact Specialist Palliative Care Services for advice regarding dose. Use hydromorphone as breakthrough medication due to short half-life of Fentanyl.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Nausea and vomiting</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Metoclopramide (Maxolon)</td>
<td>10mg subcutaneous injection prn, 6 hourly 10 – 30mg per 24 hours via CSCI.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Agitation and restlessness</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Midazolam</td>
<td>2.5mg – 5mg via subcutaneous injection prn, 2 hourly If more than 2 – 3 doses required within a 24 hour period convert to CSCI using total dose in last 24 hours as the starting dose (usual dose 10 – 30mg in 24 hours)</td>
</tr>
<tr>
<td>Clonazepam</td>
<td>0.25 - 0.5ml 12 hourly prn for anxiety via sublingual drops. For severe anxiety and panic can be given 6 hourly. Review after 3 doses if symptoms are not relieved.</td>
</tr>
<tr>
<td>Haloperidol (for Delirium)</td>
<td>0.5 – 1mg via subcutaneous injection prn, BD. If 2 doses within a 24 hour period is not effective convert to CSCI with 3mg as total starting dose for 24 hours.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Noisy respirations</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyoscine Butylbromide (Buscopan)</td>
<td>20mg via subcutaneous injection prn, 4 hourly. If more than 2 doses required within a 24 hour period convert to CSCI using 40mg as total starting dose.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Seizures</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clonazepam</td>
<td>0.25 – 0.5ml via sublingual drops prn OR</td>
</tr>
<tr>
<td>Midazolam</td>
<td>5mg via subcutaneous injection prn.</td>
</tr>
</tbody>
</table>
Further information on common medications is provided in Table 3.

### Table 3
#### Medication information

<table>
<thead>
<tr>
<th>Name</th>
<th>Route</th>
<th>Onset of action</th>
<th>Plasma half-life</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine sulphate</td>
<td>Subcutaneous</td>
<td>20 minutes</td>
<td>2 – 3 hours</td>
<td>Morphine is the principal alkaloid of opium. It acts as an agonist, binding to mu receptors in the brain, spinal cord and other tissues (See Therapeutic Guidelines, pg 107).</td>
</tr>
<tr>
<td>Hydromorphone</td>
<td>Subcutaneous</td>
<td>20 minutes</td>
<td>2 – 4 hours</td>
<td>Hydromorphone is a semi synthetic mu receptor agonist. It is a hydrogenated ketone of morphine and is 5 – 10 times more potent than morphine (See Therapeutic Guidelines, pg 110).</td>
</tr>
<tr>
<td>Fentanyl</td>
<td>Subcutaneous</td>
<td>3 – 4 minutes</td>
<td>30 mins – 2 hours</td>
<td>Fentanyl is metabolised in the liver, therefore it is good for residents with renal failure requiring pain management (See Therapeutic Guidelines, pg 110).</td>
</tr>
<tr>
<td>Midazolam</td>
<td>Subcutaneous</td>
<td>5 – 10 minutes</td>
<td>2 – 5 hours</td>
<td>Midazolam is the only water-soluble benzodiazepine with GABA – potentiating actions in the CNS. Midazolam reduces neuronal activity (See Therapeutic Guidelines, pg 128).</td>
</tr>
<tr>
<td>Clonazepam</td>
<td>Sublingual</td>
<td>15 - 30 mins</td>
<td>18 - 45 hours</td>
<td>Clonazepam is a long-acting benzodiazepine with no active metabolites. Anxiolytic and anti convulsant properties (See Therapeutic Guidelines, pg 127).</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>Subcutaneous</td>
<td>10 – 15 minutes</td>
<td>13 – 35 hours (average 16 hours)</td>
<td>Haloperidol is a psychotropic agent. It is a D2 receptor antagonist and has an inhibitory effect on the chemoreceptor trigger zone (See Therapeutic Guidelines, pg 133).</td>
</tr>
</tbody>
</table>
Assessing and managing bereavement risk

The modified Bereavement Risk Index (BRI)\textsuperscript{12} should be completed by the nurse who is most involved with the resident’s family member/s as death approaches.

There are four key risk factors and each is allocated a score from 1-5. Following the assessment: information, support and/or referral can be provided, depending on the BRI score.

Memorial services

It is becoming more common for RACFs to hold memorial services, providing closure for both RACF staff and family of deceased residents.

• Memorial services may be held annually or as often as every 3 months for larger facilities.
• Volunteers may be able to assist with organising memorial services.
• Services do not have to be overtly religious but if your facility is part of a religious organisation, support from the local church may be available.
Form 6: Modified bereavement risk index

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Anger</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Mild Irritation</td>
<td>2</td>
</tr>
<tr>
<td>Moderate (occasional outbursts)</td>
<td>3</td>
</tr>
<tr>
<td>Severe (spoiling relationships)</td>
<td>4</td>
</tr>
<tr>
<td>Extreme (always bitter)</td>
<td>5</td>
</tr>
<tr>
<td>2 Self Reproach</td>
<td></td>
</tr>
<tr>
<td>(Self blame/guilt, feeling bad and/or responsible for something)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Mild (vague and general)</td>
<td>2</td>
</tr>
<tr>
<td>Moderate (some clear self-reproach)</td>
<td>3</td>
</tr>
<tr>
<td>Severe (preoccupied with self-blame)</td>
<td>4</td>
</tr>
<tr>
<td>Extreme (major problem)</td>
<td>5</td>
</tr>
<tr>
<td>3 Current Relationships</td>
<td></td>
</tr>
<tr>
<td>Close intimate relationship with another</td>
<td>1</td>
</tr>
<tr>
<td>Warm supportive family</td>
<td>2</td>
</tr>
<tr>
<td>Family supportive but lives at a distance</td>
<td>3</td>
</tr>
<tr>
<td>Doubtful (patient unsure whether family members are supportive or not)</td>
<td>4</td>
</tr>
<tr>
<td>Unsupportive</td>
<td>5</td>
</tr>
<tr>
<td>4 How will key person cope?</td>
<td></td>
</tr>
<tr>
<td>Well (normal grief and recovery without help)</td>
<td>1</td>
</tr>
<tr>
<td>Fair (probably get by without specialist help)</td>
<td>2</td>
</tr>
<tr>
<td>Doubtful (may need specialist help)</td>
<td>3</td>
</tr>
<tr>
<td>Badly (requires specialist help)*</td>
<td>4</td>
</tr>
<tr>
<td>Very badly (requires urgent help)*</td>
<td>5</td>
</tr>
</tbody>
</table>

Total Score

*Will be automatically referred to specialist bereavement support

Low risk score (less than 7)
- Give a copy of the booklet – “Now What? Understanding Grief” (a copy is included in the PA Toolkit)

Moderate risk score (7-10)
- Give a copy of the booklet – “Now What? Understanding Grief”
- Suggest they may like to contact one of the support agencies listed in the booklet

High risk score (10 or more)
- Encourage the person to contact a health professional e.g. GP, psychologist, counselling service, or bereavement counsellor
- Give a copy of the booklet – “Now What? Understanding Grief”
Bibliography


3. Brisbane South Palliative Care Collaborative, Queensland Health/ Griffith University (2010a) Residential Aged Care End of Life Care Pathway (RAC EoLCP), Brisbane

4. Brisbane South Palliative Care Collaborative, Queensland Health/ Griffith University (2010b) Link Nurse Resource Folder, Brisbane


17. Palliative Care Council of South Australia Inc. (1996) Good Palliative Care Plan.

