Improving End-of-Life Care for Residential Aged Care Residents initiative: Palliative Approach Link Nurse Project

Example Policy and Procedures: Applying a Palliative Approach in Residential Aged Care Facilities

February 2018
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**Purpose of this document**

To provide an example of a *Policy and Procedure: Applying a Palliative Approach in Residential Aged Care Facilities document* (hereafter referred to as the Policy and Procedure document) for use by residential aged care facilities (RACFs) in the Brisbane South PHN (BSPHN) area.

The example Policy and Procedure document is a component of an implementation strategy developed to support RACFs in the BSPHN area to provide an evidence-based palliative approach to the care of residents.

The other components are:

- An education program for Link Nurses
- Education for General Practitioners
- Resources for residents, their families and substitute decision makers

The resources are freely available at: [www.eolcareracf.com.au](http://www.eolcareracf.com.au)

**How to use the Policy and Procedures Document**

The Policy and Procedure Document is a resource for RACFs to use, develop and/or tailor documentation around a palliative approach to care within the policies and procedures framework of each facility. It is not meant to be prescriptive. An RACF may adapt the content of the Policy and Procedure Document to meet the identified needs of each facility.

**How was the Policy and Procedure Document developed?**

It was developed using best practice guidelines regarding palliative care as identified in the literature. Guidelines included:

- **palliAGED:** The palliAGED evidence base is a consolidation of the updated and revised content of the Palliative Approach in Residential Aged Care (APRAC) and Palliative Approach for Aged Care in the Community (COMPAC) Guidelines, and consists of both 'Evidence' and 'Practice Support' components.


- Palliative Care Australia. *Principles for Palliative and End-of-Life Care in Residential Aged Care*. 2016

- *Residential Aged Care Palliative Approach Toolkit*.
POLICY

Statement

[NAME OF FACILITY] is committed to providing quality of life for residents with a life-limiting illness and their families by reducing suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.1

Purpose

To ensure that [NAME OF THE FACILITY] provides high quality care for their residents until death. 2

Definition of a palliative approach

An approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).1,2

Guiding principles3

- Dying is a normal part of life and a human experience, not just a biological or medical event.
- Residents must be empowered to direct their own care, whenever possible. A resident’s needs, goals and wishes at their end of life may change over time.
- Providing for the cultural, spiritual and psychosocial needs of residents, and their families and carers is as important as meeting their physical needs.
- Recognising when a resident is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care.
- End-of-life decision-making should be shared between the interdisciplinary team and the resident. Substitute decision-makers, families and carers should be involved, in accordance with the patient’s expressed wishes and/or jurisdictional legislation.
- Safe and high-quality end-of-life care is resident-and family-centred. Whenever possible, it should be aligned with the values, needs and wishes of the individual, and their family or carers. Such care should consider the resident’s expressed wishes regarding the circumstances, environment and place in which they wish to die.
- Safe and high-quality end-of-life care can require the availability of appropriately qualified, skilled and experienced staff.

3 Palliative Care Australia, et al. Principles for palliative and End-of-Life Care in Residential Aged Care.
Safe and high-quality end-of-life care requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams, within and between settings, and across multiple episodes of care.

A palliative approach to care can be based upon a palliative framework involving three trajectories (refer to figure 1). This approach can be applied to all new and existing residents based on their needs and prognosis. The framework serves as a trigger for guiding appropriate palliative care.4

The trigger question that can be asked to commence the framework is, 'Would you be surprised if your resident were to die in the next 6–12 months?'. It can be answered using clinical knowledge, personal information about the patient, discussions with the resident, clinical intuition, or a combination of all or some of these. Alternatively a prognostication tool can be used, one such prognostication tool is the Australian-modified Karnofsky Performance Scale (AKPS), [https://www.caresearch.com.au/caresearch/tabid/3390/Default.aspx](https://www.caresearch.com.au/caresearch/tabid/3390/Default.aspx)

An AKPS score of less than 40 correlates to a medium survival of around 3 months for residents with advanced cancer.

It is important to recognise that the framework is not about getting the resident’s prognosis exactly right, but to increase mindfulness of proactively managing clinical needs that typically emerge in the last year of life.

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Figure 1: Palliative approach trajectories

The Framework involves three trajectories listed below, and each is associated with a key clinical process.

**Trajectory A:**

- Answer to the surprise question: 'Yes'
- Key clinical process: Advance care planning

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• Advance care planning is an interactive ongoing process of communication between a competent person and/or their substitute decision maker, family/carers and health care providers focussing on the person’s preferences for their care in the future.

**Trajectory B:**

• Answer to the surprise question: ‘No’
• Key clinical process: Palliative care case conference
  - The aim of palliative care case conferencing is to identify clear goals of management so that all stakeholders are on the same page.
  - Questions to consider -
    - Has there been a significant functional or medical decline?
    - Are there existing problems concerning goals of care?

*These questions are considered to be markers for Trajectory B, when a prognosis of 6 months or less is likely (see figure 1).*

**Trajectory C:**

• Answer to the surprise question: ‘No’
• Key clinical process: Terminal care management plan
• Care of patients in this trajectory is focussed on regular assessment and attention to resident comfort and family distress and comfort.
• Signs and symptoms to consider in identifying whether a resident’s condition places them in trajectory C. The resident is:
  - Requiring more frequent interventions
  - Experiencing rapid day-to-day deterioration that is not reversible
  - Becoming semi-conscious with lapses into unconsciousness
  - Increasing loss of ability to swallow
  - Refusing or unable to take food, fluids or oral medications
  - Experiencing irreversible weight loss
  - Displaying profound weakness
  - Changing their breathing patterns
  Or
  - An acute event has occurred requiring revision of treatment goals

*The existence of three or more signs and symptoms are considered to be criteria for a prognosis of less than a week.*

• Please refer to Procedure – Commencing a Residential Aged Care End of Life (Terminal) Care Pathway (RAC EoLCP).

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Related policies and documents

- [Facility specific]
- Example Policy and Procedure: Implementation of Advance Care Planning in Residential Aged Care Facilities

Procedures

There are 5 key clinical procedures in this document:

1. Advance care planning
2. Palliative Care Case Conference
3. Referring to Metro South Specialist Palliative Care in the Residential Aged Care Facility
4. Commencing a Residential Aged Care End-of-Life Care (Terminal) Pathway (RAC EoLCP)
5. Quality activities associated with a palliative approach

Definition of terms

See Appendix 1.
PROCEDURES

Advance care planning

Use of the Example Policy and Procedure: Implementation of Advance Care Planning in Residential Aged Care Facilities developed by Brisbane South Palliative Care Collaborative in 2017. This document provides an example advance care planning (ACP) policy and procedure that residential aged care facilities (RACFs) in the Brisbane South PHN (BSPHN) area may use to develop and/or review relevant ACP documentation within the policies and procedures framework of an individual facility.
Palliative care case conference

Definition
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 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.7,8

The trajectory of the resident can be used as a guide to determine the appropriate timing and frequency for case conferences.

When to hold a palliative care case conference
On admission all residents should be assessed using the framework of care to decide whether a case conference is required. Case conferencing should then be held when a clinical deterioration has occurred and/or at the request of the resident or substitute decision maker(s).

Preparation for a case conference
Attendees may include:7,9

- Facilitator – can be a nursing staff member or the resident’s GP
- Resident
- GP – a fax template (GP invitation) is available
- Substitute decision maker(s) and family members – an invitation and questionnaire is available
- Relevant members of the aged care team.

Collect information9,10
Collecting information prior to a palliative care case conference allows staff to prepare responses and anticipate challenges that may occur during the case conference. Information that is often useful to source prior to the meeting includes:

- Clinical records
- Medication charts
- Advance care planning documentation
- Staff communication form
- Palliative care case conference: Planning checklist
- Invitation and family questionnaire.

8 Palliative Care Australia, et al. Principles for Palliative and End-of-Life Care in Residential Aged Care.
Implementation$^{11,12,13,14}$

- **Introduction points (Facilitator)**
  - Thank everyone for attending and introduce themselves and their role. Invite others to introduce themselves and state their role or relationship to the resident. Review meeting goals and clarify if specific decisions need to be made. Establish ground rules for the meeting and identify the legal decision-maker.

- **Determine what the resident/family already knows**
  - Asking the resident/family about their current understanding of the resident's medical condition provides the team with an understanding of residents'/family level of knowledge. Asking about the past 1-6 months can inform all attendees as to the resident's condition.

- **Review current status, prognosis and treatment options** –
  - When conducting the conference ensure the preferences of the resident and family regarding how much information they wish to receive are known. Allow the resident, family and staff members to discuss issues and questions, including reviewing the staff communication form and family questionnaire.

- **Resources**
  - Ensure suitable resources are available to the resident and family members as required. Some useful resources can be found on [www.eolcareracf.com.au](http://www.eolcareracf.com.au).

- **Decision-making: questions to consider if 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: questions to consider if the resident is cognitively impaired**
  - Ask each family member: “What do you believe the resident would choose if they could speak for themselves?”, “What do you think should be done?”
  - Give the family time and space to allow for a private family discussion if they require it.

- **When there is no consensus**
  - Use time as an ally by scheduling a follow-up conference in the near future.
  - Try questions such as: “what values are your decisions based upon?”; “How will the decision affect you and other family members?”

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$^{12}$ Palliative Care Australia, et al. Principles for Palliative and End-of-Life Care in Residential Aged Care.


- Identify other resources to facilitate decision-making such as pastoral care and the specialist palliative care team.

- Wrapping up
  - Summarise consensus, disagreements and decisions
  - Review the family questionnaire
  - Identify family spokesperson for ongoing communication
  - Document a summary of key issues and action plans
  - Offer this summary sheet to resident and/or family member(s)
  - Schedule a follow-up meeting as needed.

Post case conference

- Update the resident’s care plan to reflect outcomes and the clinical action plan from case conference.
- Fax the palliative care case conference summary sheet to the resident’s GP.

Subsequent case conferences are dependent on the resident’s condition. (refer to the Palliative Approach trajectory flow chart on page 6).

- Relevant documentation
- Fax template (GP invitation)
- Palliative care case conference: Invitation and family questionnaire
- Palliative care case conference: Staff communication sheet
- Palliative care case conference: Planning checklist
- Palliative care case conference: Summary

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Referral to Metro South Specialist Palliative Care in the RACF Team

The Metro South Specialist Palliative Care in the Residential Aged Care Facility team provide consultative support services to residents of RACFs with complex presentations that cannot be managed independently by the GP or facility care team. The Metro South Specialist Palliative Care in the Residential Aged Care Facility team uses a consultative model of care that enables a supportive partnership between specialist palliative care staff and the RACF primary care team.16

Mandatory referral criteria17

- The patient/substitute decision-maker consents to specialist palliative care involvement.
- The resident’s family are experiencing complex issues that cannot be managed by the GP or care team in the RACF. These may include complex physical symptoms and/or psychosocial issues.
- The resident's GP has been informed and consented to palliative care specialist involvement.
- The resident resides within the Metro South Health Service District.
- No other specialist palliative care service / provider is involved, and no other specialist team is involved in the management of same issue, e.g. referral for pain management where the acute pain team is involved.

Referral process17

- Confirm eligibility against the above criteria.
- Referrals must be made using the Consultative Palliative Care Service in the Residential Aged Care Facility form and faxed to:
  - Brisbane South fax: 07 3710 2230
  - Logan / Beaudesert fax: 07 3710 2230
  - Redlands / Bayside fax: 07 3488 3650
  - Provide a medical referral including supporting information i.e. patient details, detailed health summary, recent correspondence, advance care planning documentation, current medication and allergy list and investigation reports to the appropriate Metro South Palliative Care Service (MSPCS) team in your area.
  - Response categories:
    - Urgent - needs to be contacted within 24 hours
    - Priority - needs to be contacted within 3 days
    - Routine - needs to be contacted within 7 days.


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**Please note:** If urgent or priority response is required, please phone the appropriate Team Leader on the contact list to discuss.

- All referrals are reviewed by the Team Leader daily (Monday-Friday).
- Residents will be contacted and seen within business hours, Monday to Friday.

**Relevant documentation**¹⁸

The Consultative Palliative Care Service in the Residential Aged Care Facility

*End-of-life care framework – Last 12 months of Life*


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Commencing a Resident on the Residential Aged Care End-of-Life (Terminal) Care Pathway (RAC EoLCP)

Definition:
The Residential Aged Care End-of-Life Care (Terminal) Pathway (RAC EoLCP) is a consensus-based, best practice guide to providing resident-centred care during the last days of life. Residents with a prognosis of less than one week can be commenced on an end-of-life care pathway.19,20,21

It is usually appropriate to start the pathway if three or more of the following symptoms/signs are displayed by the resident:

- Experiencing day to day deterioration that is not reversible
- Requiring more frequent interventions
- Unable to take oral medications
- Becoming semi-conscious, with lapses into unconsciousness
- Increasing loss of ability to swallow
- Refusing or unable to take food or fluids
- Irreversible weight loss is occurring
- An acute event has occurred, requiring revision of treatment goals
- Profound weakness is apparent
- Changes in breathing patterns.

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, as appropriate (Refer to figure 2. Commencing the RAC EoLCP for residents).

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 may 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 of the RAC EoLCP within 48 hours.

Ensure all health professionals involved in the resident’s care are aware of the plan and any limitations of treatment orders are easily accessible.


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Figure 2: Commencing the resident on the RAC EoLCP for residents

- Assessment criteria completed.
  - Resident meets criteria (3+ signs/symptoms from Section 1).
    - Can GP be contacted?
      - Yes
        - Does GP give verbal authorisation?
          - Yes
            - Resident commences on RAC EoLCP, GP to sign within 48 hours.
          - No
            - Resident does not commence on pathway.
        - No
          - Are 2 RNs available to authorise commencing pathway?
            - Yes
              - Resident commences on RAC EoLCP (GP to be informed asap and signs documentation within 48 hours).
            - No
              - Resident commences on RAC EoLCP.
          - No
            - Contact Specialist Palliative Service.

- No
  - Is agreement reached?
    - Yes
      - Resident commences on RAC EoLCP (GP to be informed asap and signs documentation within 48 hours).
    - No
      - Residence commences on RAC EoLCP.

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How to use the RAC EoLCP:  

- The RAC EoLCP has five sections which have been designed to provide comprehensive documentation of the care provided to a resident during their last days of life.
  - Section 1: Commencing a resident on the RAC EoLCP
  - Section 2: Medical interventions and advance care planning
  - Section 3: Care staff interventions
  - Section 4: Multidisciplinary communication sheet
  - Section 5: After death care

- The entire document is to be placed in the resident’s notes and forms part or all of their clinical record.

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**Education and support for staff when commencing a resident on the RAC EoLCP:**

When commencing a resident on the RAC EoLCP the education package can be utilised to inform staff on how it is to be used. The package consists of a comprehensive learning guide and training video for RACF staff.


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Quality activities for a palliative approach

To develop successful and sustainable systems for delivering safe and high quality end-of-life care, and to effect improvements in the experiences of patients, families and carers, a systematic approach to quality improvement is essential.\textsuperscript{25,26,27} Ongoing monitoring and evaluation of activities, processes and systems for delivering a palliative approach are essential, to establish their efficacy and to track performance over time to determine priorities for improvement.\textsuperscript{28} Quality activities can include:\textsuperscript{29}

- Creation of a palliative approach working party
- Development or review of a palliative approach policy and procedure document
- Audits for quality improvement
- Creation of a framework that supports education and training in a palliative approach.

Many of these activities can be achieved with assistance from a palliative care link nurse. A palliative care link nurse is a registered nurse who has expressed an interest in palliative care and is nominated by the facility to:

- Promote and model the palliative approach to resident care
- Act as a resource for other staff
- Convene or co-convene the Palliative Approach Working Party
- Coordinate the implementation of the PA Toolkit
- Act as the 'link' person between external stakeholders (e.g. general practitioners, specialist palliative care services, allied health professionals, clergy)
- Assist with auditing and quality improvement processes
- Conduct in-service education and training for staff


\textsuperscript{29} Palliative Care Australia, et al. \textit{Principles for Palliative and End-of-Life Care in Residential Aged Care}.
A. Creating a palliative approach working party

A palliative approach working party can guide evaluation and continuous improvement activities within the facility relevant to delivering a palliative approach to care.

**Purpose:**
- Provide ongoing monitoring of best practice in palliative care
- Identify specific palliative care education, and training needs of RACF staff
- Support and collaborate with the RACF’s Palliative Approach Link Nurse(s)

**Identifying likely members:**
- An expression of interest may be the most appropriate recruitment method
- A diverse membership offering a broad range of knowledge and skills in developing solutions/strategies should be encouraged

**Likely members:**
- RACF’s Palliative Approach Link Nurse
- Management representative
- Care worker representative
- Allied health representative
- Lifestyle or diversional therapist representative
- Hospitality staff representative
- Pastoral care representative
- A consumer representative (resident and/or relative)

**External stakeholders:**
- General practitioners and specialist palliative care services can be invited to attend particular meetings (e.g. to inform the implementation process as an engagement strategy)

**Meeting Schedule:**
- Weekly for the first 2 months in the initial implementation phase
- Less frequent after the first 2 months

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B. Develop or review palliative approach policy and procedures

Policies and procedures are designed to influence and determine all major decisions and actions, and to ensure all activities take place within the boundaries set by them. Together, policies and procedures ensure that the organisational governance of an organisation’s point of view is translated into steps that result in an outcome compatible with that view.\(^{31}\)

Points to consider: \(^{32}\)

- Does the RACF have a palliative care policy?
- Does the policy require amending or updating?
- Is there an established timeframe for policy review and details of who will undertake this review?
- Does the RACF require specific policy/procedure documents (e.g. advance care planning)?

Palliative care policy: \(^{32}\)

This document should include:

1. Documentation of the RACF’s vision for palliative care in a clear and concise policy
2. Important definitions
3. A record of sources of evidence used in the policy
4. A list of key procedures associated with the day-to-day actioning of the policy.


C. Conducting audits for quality improvement

Audits need to be directly relevant to the service areas that the facility considers important to review. Evaluation and monitoring should be simple, inexpensive and feasible. The processes should use routinely collected data and data linkage, where possible.33,34

Two such audit tools that may be used are:

1. After-Death Audit Tool – involves auditing individual resident outcomes (see Appendix 2)https://www.caresearch.com.au/Caresearch/Portals/0/PA-Toolkit/After%20Death%20Audit%20Tool%20%28PA%20Toolkit%29.pdf


Ideally clinicians should lead evaluation activities and audits, and feedback aggregate, de-identified data to their peers and colleagues.

Auditing cycles35,33

Developing an annual auditing schedule that is linked to the timing of internal or external reporting requirements is advantageous (e.g. accreditation cycles). Utilising pre- and post-audit data is an important factor in recognising quality improvements. Data about the effectiveness of processes and systems for delivering end-of-life care should be collected, reviewed and reported locally (including over time).

After-Death Audit considerations33

- Who will collect the audit data?
- How will the results be used to inform continuous improvement activity?


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D. Create a framework that supports education and training in a palliative approach

An educated and suitably skilled and qualified workforce is essential in providing a palliative approach to care. Education should commence early in training programs and continue as part of all clinicians’ professional development.33

Essential elements of staff education and training include:

1. Foster a learning culture36
   The value placed on education and training by a RACF sends a strong message to staff about how seriously it views education and training initiatives. To communicate the importance of ongoing education and training with regard to a palliative approach, it is critical to establish and continually reinforce a facility-wide ‘learning culture’.
   This may involve:
   a. Forming a Working Group that will be responsible for planning, implementing and continually reviewing the facility’s Palliative Approach Staff Education and Training Strategy (PA-SETS) and related activities. (see https://www.caresearch.com.au/caresearch/tabid/3580/Default.aspx# for PA-SETS Working Group membership)
   b. Aligning the PA-SETS with the facility’s strategic and operational plans. Identifying barriers and enablers that may impact on the PA-SETS.
   c. Using a ‘whole-of-facility approach’ to staff education and training related to implementing a palliative approach. Education, training and professional development in a palliative approach should not be restricted to clinical and direct care staff.
   d. Promoting greater use of mentoring as a learning strategy.
   e. The Program of Experience in the Palliative Approach (PEPA) offers clinical placements in Specialist Palliative Care Services (community and inpatient) and tailored workshops to health professionals from a range of disciplines. PEPA placements are offered free of charge and are funded by the Australian Government Department of Health. www.pepaeducation.com
   f. Build local partnerships to support education and training.36

2. Building collaborative partnerships with local health professionals/organisations will help to implement and sustain the PA-SETS.
   Consider for example:
   a. Establishing formal links with other RACFs in the local area and pooling resources so that palliative care education and training activities for staff across the partner facilities can be delivered at a central site.
   b. Identifying and recruiting local health professionals to provide regular staff education sessions. Advertise these sessions to other local RACFs to make up a viable group of participants.
   c. Inviting local specialist palliative care service (SPCS) to deliver staff education and training sessions.


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d. Developing partnerships with local higher education institutions as a means of establishing an ongoing research and training relationship and to expand career pathways for staff.

3. Access current best practice information.\textsuperscript{37,38}

a. To facilitate optimal clinical and organisational outcomes, it is important that the PA-SETS are informed by, and reinforce, current best practice in addressing the palliative care and related needs of residents. Methods for accessing best practice information include:

b. Current consensus-based and evidence-based practice guidelines


d. Articles and other resources available from the Palliative Care Australia website: www.palliativecare.org.au

e. Awareness-raising, education and training activities provided by Palliative Care Australia and its State/Territory-based member organisations

f. Awareness-raising, education and training activities provided by aged care industry associations and peak bodies

h. Research, education and training partnerships with higher education institutions

h. Local ‘knowledge translation’ activities (e.g. a monthly journal club for staff convened by the facility’s Palliative Approach Link Nurse; practice updates in the facility’s staff newsletter)

4. Identify and prioritise education and training content.\textsuperscript{39,37}

a. Ensuring that the facility’s staff education and training strategy addresses the skills, knowledge and behaviours required to implement a palliative approach in day-to-day practice is essential.\textsuperscript{40}

b. Features of a palliative approach model of care and implications for the planning and day-to-day delivery of care.

c. Legal and other regulations in regards to advance care planning/advance directives.

d. Evidence-based assessment and management of clinical symptoms (e.g. pain, dyspnoea, delirium) for residents requiring a palliative approach.

e. Issues related to oral care, nutrition and hydration for residents requiring a palliative approach.

f. Recognising and responding to the psychosocial, cultural, spiritual and religious needs of residents requiring a palliative approach and their families.

g. Communication skills for supporting dying residents and their families.

h. Understanding, facilitating, documenting and reviewing advance care planning for residents.

\textsuperscript{37} Rosenberg, J. The link nurse role in end of life care in aged care. \textit{Aust Nurs Midwifery J.} 2016;24(2):38.

\textsuperscript{38} palliAGED Palliative Care Aged Care Evidence. \textit{palliAGED}. Available at: https://www.palliaged.com.au/ [Accessed 30 November 2017].


\textsuperscript{40} Australian Commission on Safety and Quality in Health Care. \textit{National Consensus Statement: essential elements for safe and high-quality end-of-life care}. Sydney: ACSQHC, 2015.
i. Understanding, facilitating, documenting and reviewing palliative care case conferences for residents.

j. Use of an end-of-life care pathway in the care of dying residents.

k. Legislative and related requirements in regards to the management and use of end-of-life medications in residential aged care settings.

5. Conducting Training Needs Analysis (TNA):

a. Training Needs Analysis (TNA) involves the systematic review of learning and development needs within an organisation. In particular, TNA identifies the skills, knowledge and behaviours that staff require to effectively undertake their respective roles and how best to develop these competencies.

6. Use appropriate education and training methods

There are a variety of opportunities within RACFs for staff to engage in learning activities that are meaningful and directly relevant to their work.

a. Informal Learning: Contemporary views about informal learning suggest that individuals acquire attitudes, values, skills and knowledge via daily experiences occurring outside of formal education and training situations, for example, through exposure to the opinions and practices of others in the workplace.

b. Formal Learning: In contrast, formal learning refers to learning that occurs in structured programs (e.g. seminars and workshops; formal staff mentoring programs). Using a combination of informal and formal learning methods as part of your PA-SETS is optimal.

c. Self-Directed Learning: Self-directed learning involves a process by which the learner takes the initiative and responsibility for the learning process. It requires no formal teaching input and can be facilitated by a range of methods and resources (e.g. online multimedia learning modules). Self-directed learning is most effective when the learner is interested and motivated to further develop knowledge and skills in the subject matter.

d. Facilitated Learning: Facilitated learning describes a teaching process in which the facilitator aims to create a teaching environment which is conducive to learning and empowers the learner.
7. Undertake evaluation and continuous improvement.42

Establishing PA-SETS should improve staff knowledge, skills and behaviours as well as change organisational processes that support the implementation of a palliative approach. These changes, in turn, should contribute to improved outcomes for residents and their families. Consistent with this logic, evaluation and continuous improvement of your PA-SETS requires a consideration of:

a. Processes
b. Impacts
c. Outcomes

For further information summarising the purpose and key issues associated with each of these forms of evaluation please review https://www.caresearch.com.au/Caresearch/Portals/0/PA-Toolkit/Training_Support_Guide_1.pdf

APPENDIX 1: Definition of Terms

- **Palliative Approach**: An approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and quality assessment and treatment of pain and other problems (physical, psychosocial and spiritual).43

- **Advance Health Directive (AHD)**: In Queensland, an AHD is a legally binding advance care planning document stating a formal set of instructions for future health care. It is used to inform doctors about a person’s choices for health care when they become unable to make health care decisions. This document allows a person to record their wishes relating to specific medical circumstances if they eventually lose the capacity to make decisions. It can only be completed by a person with capacity. It must be completed with a doctor and witnessed by a Justice of the Peace, Commissioner for Declarations, a lawyer or notary public.44

- **Enduring Power of Attorney (EPOA)**: An EPOA is a legally binding document that enables a person to appoint another individual to make personal, health and/or financial decisions on their behalf, if they lose capacity. More than one individual can be appointed. The EPOA can only be completed by a person with capacity.44

- **Statutory Health Attorney**: A Statutory Health Attorney is someone with automatic authority to make health care decisions on behalf of a person who is unable to make them because of illness or incapacity. This attorney is not formally appointed; they act in this role only when the need arises. The statutory health attorney is the first available, culturally appropriate adult from the following list, in order: a spouse or de facto partner in a close and continuing relationship; an adult who cares for the person but is not employed to be their carer; or close friend or relative who is not the persons employed carer. The Public Guardian may, under certain circumstances, become the statutory health attorney of last resort.44

- **Advance Care Planning (ACP)**: Advance care planning means thinking about what health care would be wanted in the future and communicating those wishes. Advance care planning may provide the opportunity for a person to discuss their beliefs and values, and helps give peace of mind that the person may receive the right care, at the right time, in the right place.44

- **Statement of Choices (SoC)**: The SoC is a document designed to help a person (or their substitute decision maker if the person does not have decision-making capacity) record their wishes, values and beliefs to guide those close to them to make health care decisions on their behalf if they are unable to make those decisions.44

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• **Substitute Decision Maker (SDM):** A SDM is a general term used to describe a person who has legal power to make decisions on behalf of an adult when that adult is no longer able to make their own decisions. A person can appoint an individual, while they still have legal capacity to do so, using the EPOA or AHD form. If a person has not previously appointed anyone and if they are no longer able to make decisions or complete legal documents then the law provides for a Statutory Health Attorney to speak on their behalf.45

• **Capacity:** Capacity refers to a person’s ability to make a specific decision in a particular area of their life. A person has capacity when they have the ability to understand the information provided by a doctor about their health and treatment options and are able to make a decision regarding their care. The person also needs to be able to communicate their decision in some way and the decision must also be made of the person’s own free will.45

• **Palliative Care Case Conference:** 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 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.46,47

• **Residential Aged Care End-of-Life Care Pathway (RAC EoLCP):** The RAC EoLCP is a consensus-based, best practice guide to providing resident-centred care during the last days of life. All new residents or existing residents with a prognosis of less than one week can be commenced on an end-of-life care pathway.48

• **End of life:** The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.49

• **End-of-life care:** Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient’s body after their death. People are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:
  - advanced, progressive, incurable conditions
  - general frailty and co-existing conditions that mean that they are expected to die within 12 months
  - existing conditions, if they are at risk of dying from a sudden acute crisis in their condition

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47 Palliative Care Australia, et al. *Principles for Palliative and End-of-Life Care in Residential Aged Care*.


Life-threatening acute conditions caused by sudden catastrophic events.\(^{50}\)

- **Goals of Care:** The aims for a patient’s medical treatment, as agreed between the patient, family, carers and healthcare team. Goals of care will change over time, particularly as the patient enters the terminal phase. Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient. The patient’s goals of care may also include non-medical goals – for example, returning home or reaching a particular milestone, such as participating in a family event.\(^{51}\)

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### APPENDIX 2: After Death Audit Tool

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Facility assigned resident ID*</td>
<td></td>
<td>[*Please enter the resident's unique identifier assigned by your facility.]</td>
</tr>
<tr>
<td>2. Date of death (dd/mm/yyyy)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Was this a sudden, unexpected death?</td>
<td>Yes, No</td>
<td></td>
</tr>
<tr>
<td>4. Place of death</td>
<td>Residential aged care facility, Hospital, Other</td>
<td></td>
</tr>
<tr>
<td>5. Was the resident transferred to hospital in the last week of their life?</td>
<td>Yes, No (if no, skip to question 6)</td>
<td></td>
</tr>
<tr>
<td>6. Principal reason for hospitalisation</td>
<td>Symptom management, Sudden, unexpected deterioration or event, Following a fall, Request of resident and/or family, Request of the general practitioner, Other, Specify</td>
<td></td>
</tr>
<tr>
<td>7. Length of hospital stay</td>
<td>Not admission, 1 to 3 days, Greater than 3 days</td>
<td></td>
</tr>
<tr>
<td>8. Were the resident's preferences for end of life care documented?</td>
<td>N.B. Documentation of a funeral provider is not sufficient to check &quot;yes&quot; for this item</td>
<td></td>
</tr>
<tr>
<td>9. Was a palliative care case conference** conducted within the last six months of the resident's life?</td>
<td>Yes, No (if no, skip to question 7)</td>
<td>**A palliative care case conference focuses on end of life issues. The resident and/or family should be in attendance.</td>
</tr>
<tr>
<td>10. Date of palliative care case conference (dd/mm/yyyy)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Was the resident commenced on an end of life care pathway?</td>
<td>Yes, No (if no, skip to Question 13)</td>
<td></td>
</tr>
<tr>
<td>12. Date commenced end of life care pathway? (dd/mm/yyyy)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Did the facility claim Complex Health Care Palliative Care through ACFI for this resident?</td>
<td>Yes, No</td>
<td></td>
</tr>
</tbody>
</table>

*Disclaimer: This Example Palliative Approach Policy and Procedure is intended to assist RACFs develop and/or review their own documentation within their policies and procedures framework. Neither Metro South Health nor Brisbane South PHN, nor any person associated with developing this document, accepts liability for an injury, loss or damage incurred as a result of anyone using or relying on the Example Palliative Approach Policy and Procedures.*
## APPENDIX 3: Organisational Policies and Structures Audit Tool

### Organisational Policies and Structures Audit Tool

**IMPORTANT**
1. For each question in this audit, please circle either “YES” [1] or “NO” [0]. If the answer is “YES” most of the time, circle 1, otherwise circle 0.
2. Please read and keep the following definitions in mind when completing this audit.

A palliative approach aims to improve quality of life for residents with life-limiting illnesses and their families by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs. Importantly, this form of palliative care is not restricted to the last days or weeks of a resident’s life.

Terminal care is appropriate when a resident is in the final days or weeks of life and care decisions may need to be reviewed more frequently. Goals are more sharply focused on a resident’s physical, emotional and spiritual comfort and support for the resident’s family.

### 1) Workforce development

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Do you have a staff member(s) (e.g. palliative approach link nurse) responsible for promoting and facilitating a palliative approach in your facility?</td>
<td>1</td>
</tr>
<tr>
<td>b. Do you have a palliative approach working party responsible for promoting and facilitating a palliative approach in your facility?</td>
<td>1</td>
</tr>
<tr>
<td>c. Does ongoing in-service education for your nursing and care staff (RN/EN/AIN/carereworker) include:</td>
<td></td>
</tr>
<tr>
<td>1. Basic knowledge of legal and other regulations pertaining to advance care planning/advance directives?</td>
<td>1</td>
</tr>
<tr>
<td>2. Communication skills for understanding and supporting dying residents and their families (e.g. conducting a palliative care case conference)?</td>
<td>1</td>
</tr>
<tr>
<td>3. Pain assessment and management for residents requiring a palliative approach?</td>
<td>1</td>
</tr>
<tr>
<td>4. Assessment of non-pain symptoms and complications for residents requiring a palliative approach (e.g. shortness of breath, delirium)?</td>
<td>1</td>
</tr>
<tr>
<td>5. Issues related to nutrition and hydration for residents requiring a palliative approach (e.g. dysphagia, the benefits and risks of feeding tubes)?</td>
<td>1</td>
</tr>
<tr>
<td>6. Issues related to oral care for residents requiring a palliative approach?</td>
<td>1</td>
</tr>
<tr>
<td>7. Use of end of life care pathway (e.g. the Residential Aged Care End of Life Care Pathway)?</td>
<td>1</td>
</tr>
<tr>
<td>8. Cultural, religious and spiritual beliefs and preferences related to palliative and end of life care?</td>
<td>1</td>
</tr>
<tr>
<td>9. Bereavement care for staff and families?</td>
<td>1</td>
</tr>
</tbody>
</table>

### 2) Engaging stakeholders

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Are the following stakeholders engaged in planning and providing a palliative approach:</td>
<td></td>
</tr>
<tr>
<td>1. Specialist palliative care services?</td>
<td>1</td>
</tr>
<tr>
<td>2. General practitioners?</td>
<td>1</td>
</tr>
<tr>
<td>3. Residents and families?</td>
<td>1</td>
</tr>
<tr>
<td>4. Pastoral care?</td>
<td>1</td>
</tr>
<tr>
<td>b. Are there educational materials available for residents/families on decision-making and care for those requiring a palliative approach and/or terminal care?</td>
<td>1</td>
</tr>
</tbody>
</table>

### 3) Policies and procedures

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>Do you have a written statement of the facility's principles or policy regarding care of residents requiring a palliative approach?</td>
<td>1</td>
</tr>
<tr>
<td>b.</td>
<td>Is this written statement of the facility's policy/principles provided to:</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Staff?</td>
<td>1</td>
</tr>
<tr>
<td>2.</td>
<td>Residents?</td>
<td>1</td>
</tr>
<tr>
<td>3.</td>
<td>Families/substitute decision makers?</td>
<td>1</td>
</tr>
<tr>
<td>4.</td>
<td>General practitioners?</td>
<td>1</td>
</tr>
<tr>
<td>c.</td>
<td>Does your care planning process include:</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Establishing and documenting the goals of care for each resident, consistent with resident's personal preferences or values?</td>
<td>1</td>
</tr>
<tr>
<td>2.</td>
<td>Reviewing the residents' preferences with regard to future hospitalisation?</td>
<td>1</td>
</tr>
<tr>
<td>3.</td>
<td>Reviewing the residents' preferences with regard to life sustaining or prolonging treatments (e.g. Do Not Resuscitate order, artificial nutrition)?</td>
<td>1</td>
</tr>
<tr>
<td>d.</td>
<td>Do you have specific policies/guidelines or protocols for:</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Identifying whom a resident requires a palliative approach?</td>
<td>1</td>
</tr>
<tr>
<td>2.</td>
<td>Assessing and managing pain?</td>
<td>1</td>
</tr>
<tr>
<td>3.</td>
<td>Assessing and managing shortness of breath or dyspnoea?</td>
<td>1</td>
</tr>
<tr>
<td>4.</td>
<td>Assessing and managing dysphagia?</td>
<td>1</td>
</tr>
<tr>
<td>5.</td>
<td>Assessing and managing nutrition and hydration issues (e.g. dysphagia)?</td>
<td>1</td>
</tr>
<tr>
<td>6.</td>
<td>Assessing and managing oral health?</td>
<td>1</td>
</tr>
<tr>
<td>7.</td>
<td>Arranging for specialist palliative care when appropriate?</td>
<td>1</td>
</tr>
<tr>
<td>8.</td>
<td>Palliative care case conferences (a meeting held between a resident, their family and aged care team to identify clear goals of care including a review of advance care plans)?</td>
<td>1</td>
</tr>
<tr>
<td>9.</td>
<td>Terminal care (last weeks or days of life)?</td>
<td>1</td>
</tr>
<tr>
<td>10.</td>
<td>When to commence an end of life care pathway (e.g. the Residential Aged Care End of Life Care Pathway)?</td>
<td>1</td>
</tr>
<tr>
<td>11.</td>
<td>Assessing and managing the emotional, spiritual and cultural needs of residents?</td>
<td>1</td>
</tr>
</tbody>
</table>

### 4) Evaluation and continuous improvement

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>Have quality improvement mechanisms been established for:</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Documenting completion and compliance with advance care plans and/or relevant advance directives?</td>
<td>1</td>
</tr>
<tr>
<td>2.</td>
<td>Monitoring delivery of palliative care, such as pain control, management of distressing symptoms (e.g. shortness of breath, anxiety)?</td>
<td>1</td>
</tr>
<tr>
<td>3.</td>
<td>Monitoring outcomes for palliative care case conferences?</td>
<td>1</td>
</tr>
<tr>
<td>4.</td>
<td>Monitoring outcomes related to the use of end of life care pathways?</td>
<td>1</td>
</tr>
<tr>
<td>5.</td>
<td>Transferring residents' advance care plan (e.g. Do Not Resuscitate order, enduring power of attorney) across settings from residential aged care facility to hospital?</td>
<td>1</td>
</tr>
<tr>
<td>b.</td>
<td>When residents are transferred to acute care, is there a routine review to assess the appropriateness of transfer?</td>
<td>1</td>
</tr>
<tr>
<td>c.</td>
<td>Are residents' deaths reviewed to assess quality of care at the end of life?</td>
<td>1</td>
</tr>
</tbody>
</table>

**Note:** Based on material by Tomlin-Cresswell et al. [2009]²