The Palliative Approach Toolkit

Module 1: Integrating a palliative approach
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.

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

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”

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.
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.

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, residents 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

Terminal phase
Palliative 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 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 the 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.
The term “evidence-based practice” means the blending of individual clinical judgement and expertise with the best available external evidence to generate the kind of practice that is most likely to lead to a positive outcome. Evidence comes from a variety of sources which can include:

- the internet
- books
- professional journals
- expert opinion
- the collective experience of residents and aged care workers
- evidence-based guidelines.

Evidence-based guidelines evaluate and summarise the best practice evidence and make key recommendations. The PA Toolkit incorporates the following guidelines:

1. “Guidelines for a Palliative Approach in Residential Aged Care - Enhanced Version” were developed by the Australian Palliative Residential Aged Care (APRAC) Project and funded by the Australian Government Department of Health and Ageing. The document can be downloaded from the Department of Health and Ageing website: www.health.gov.au/palliativecare

2. “Pain in Residential Aged Care Facilities: Management Strategies” were developed by the Australian Pain Society (APS) and can be downloaded from the Australian Pain Society website: www.apsoc.org.au
Mapping Key Processes (Module 2) and Clinical Care (Module 3) to Guidelines

Listed here are the APS and APRAC guidelines most relevant for each of the key processes and clinical care domains.

Please note

Although this toolkit focuses on 24 APRAC and three APS guidelines, residential care managers are encouraged to familiarise themselves with the entire set of guidelines.

Key process-Advance care planning:
• Systematic advance care planning increases resident/family satisfaction (APRAC guideline 7).
• Education for the aged care team, residents and families about end of life care and advance care planning increases resident/family satisfaction (APRAC guideline 8).
• Advance care planning that includes ongoing assessment increases resident/family satisfaction (APRAC guideline 9).

Key process-Palliative care case conference:
• Attention to residents’ transition from active curative care to palliative care (with comfort care and symptom management) requires that aged care team members provide the resident and their families with sufficient information about the transition process to facilitate decision making. This provision of information can reduce residents’ and families’ concerns and increase their satisfaction regarding the appropriateness of a palliative approach (APRAC guideline 2).
• Family conferences can provide emotional support to families and an opportunity to discuss concerns about the resident’s illness. This improves the quality-of-life for the resident (APRAC guideline 59).
• Well planned family conferences, conducted in private and attended by the GP and other members of the aged care team, provide an opportunity for building trust and discussing end of life issues of concern, which improves the family’s satisfaction with the care that is provided (APRAC guideline 75).

Key process-End of life care pathway:
• To be actively ‘doing everything’ for a dying resident, in terms of medication, positioning, and other medical and nursing interventions, together with talking to, and spending time or being present with the resident helps family members cope with the dying process (APRAC guideline 74).

Clinical care-Pain:
• The development of a treatment plan that is based on a comprehensive and ongoing assessment of a resident’s needs and wishes, which includes early identification of the main symptoms, provides effective symptom management in accordance with the resident’s goals for care and their specific treatment preferences (APRAC guideline 15).
• Implementation of a palliative approach that includes adequate relief of pain and effective symptom management increases residents and their families’ satisfaction with the care that is provided (APRAC guideline 16).
• A simple method for regular assessment of symptom distress is to ask residents for their own determination of the intensity of their physical and psychological distress. Regular assessments will improve the effectiveness of symptom management and enhance residents’ quality-of-life (APRAC guideline 17).
• A comprehensive assessment of the resident’s pain and the use of evidence-based analgesic decision-making provide enhanced pain management, thereby improving the resident’s quality-of-life (APRAC guideline 18).
• For residents unable to verbalise their pain, accurate reporting based on observations by a skilled person using behavioural cues is particularly important in determining pain. The use of appropriate assessment tools will increase the frequency with which pain is diagnosed when compared with asking the resident “Do you have pain?” (APRAC guideline 19).
• Regular (around the clock) administration of analgesia is the most effective treatment for persistent pain (APS guideline 12).
• The need for short-acting analgesia for breakthrough pain should be anticipated and prescribed on an as needed (PRN) basis (APS guideline 13).
• Physical therapies, such as superficial heat and Transcutaneous Electrical Nerve Stimulation (TENS), can be helpful in reducing pain intensity in the short term, for residents who are able to provide feedback on their experience (APS guideline 19).

Clinical care-Dyspnoea:
• A comprehensive plan of care including ready access to appropriate medication, plus non-pharmacological interventions to reduce psychological distress, may prevent residents with gradually increasing dyspnoea being unnecessarily transferred to hospital (APRAC guideline 40).
• A physical examination and a complete history that covers factors that are likely to have influenced the severity of the symptom, including pre-existing illnesses and exacerbating factors will provide sufficient information to accurately determine a diagnosis of dyspnoea (APRAC guideline 41).
• Non-pharmacological interventions based on psychosocial support, controlled breathing and learned coping strategies can help residents cope with dyspnoea, which will reduce their physical and emotional distress (APRAC guideline 42).
• The use of sustained-release low-dose oral morphine administered orally or parenterally can benefit individuals with dyspnoea by reducing the severity of their symptoms and improving the quality of their sleep (APRAC guideline 43).

Clinical care-Nutrition and hydration:
• Good nutritional care requires an individualised approach that includes early recognition of weight loss and the identification and management of likely causes (e.g. adverse medication effects, poor oral health or depression). This careful attention to assessment and management of residents’ nutritional requirements improves quality-of-life (APRAC guideline 21).
• Giving residents oral foods and fluid, even in small amounts, is preferable to using more invasive enteral (e.g. nasogastric or PEG) feeding methods. However, a dysphagia assessment is essential to provide direction for oral feeding (APRAC guideline 22).
• The aged care team member assisting with feeding should be seated at eye-level with the resident and take time to establish and maintain a relationship with the resident to create an atmosphere that is conducive to relaxing the resident. This approach to feeding enhances the resident’s nutritional intake and improves his / her social well-being (APRAC guideline 23).
• Recommendations regarding fluid therapy that are based on an ongoing assessment of each resident’s circumstances, including the resident’s and family’s treatment preferences, improve the resident’s and family’s satisfaction with the care that is provided (APRAC guideline 24).
Finding ‘good’ evidence: Try CareSearch

As a manager and/or clinician we recognise your time is limited. Conducting extensive literature reviews and summarising the research evidence is not realistic.

Luckily there are other options. CareSearch (www.caresearch.com.au) is an Australian online resource consolidating evidence-based and quality information for various groups within the palliative care community. The website has been funded by the Australian Government as part of the National Palliative Care Program.

CareSearch provides:
- information portals specifically for residential aged care facilities and nurses
- information and resources for patients, carers, families and friends
- links to organisations, groups and services in Australia that provide palliative care or help those requiring palliative care
- information on clinical issues of importance to palliative care (designed for clinicians and providing overviews of the state of evidence as described by systematic reviews)
- resources to find evidence e.g. PubMed Searches, hard-to-find literature, and reviews
- links to education providers in palliative care, conference details, and web-based learning modules
- research data management systems and a research studies register

While it is very user-friendly, we recommend you initially read the “Using CareSearch” page for tips and hints on how to best access the information you need.

Clinical care-Oral care:

- Good oral hygiene, regular assessment, cleansing of dentures and oral fluids can reduce oral complications (APRAC guideline 31).

Clinical care-Delirium:

- A thorough assessment of the symptoms of delirium is required, which includes consideration of the persistence of symptoms (e.g. inattention, disorientation, and impaired memory) to accurately and quickly detect delirium in older persons, which increases residents’ frequency of treatment and referral (APRAC guideline 53).

- Regular presentation of fluids that include strategies such as a colourful beverage cart, verbal prompting or complying with residents preferences will increase the amount of oral fluid intake for those residents able to have oral hydration (APRAC guideline 25).

- Frequent small sips of fluids can reduce the resident’s sensation of thirst and oral discomfort that is associated with dehydration (APRAC guideline 26).
Introducing a palliative approach is a strategic decision for a RACF in providing continuing care for their residents through to the end of life. This requires the organisation to include a palliative approach in their formal planning and monitoring cycles, and to commit the appropriate resources to its implementation. Among the resources required are aged care team members, management time, training and education costs, appropriate facilities, reporting requirements and access to external supports. 10

It is the responsibility of management to establish and maintain open lines of communication between the aged care team, residents and their representatives. 10

It is also their responsibility to facilitate opportunities for communication and networking with other RACFs who have a palliative approach in operation, specialist palliative care workers and other areas where palliative care is delivered, e.g. hospices. 10

**Tips for developing policies to support a palliative approach** 10

- Situate the policies within the wider context of the organisation’s policies and framework including issues such as occupational health and safety policies.
- Develop criteria that are to be included in any evaluation of policies or practices.
- Decide how the palliative approach in the facility will be managed and reviewed.
- Ensure consistency and safe practice by identifying areas that may require protocols, standard operating procedures and/or guidelines.

**Meeting the standards with a palliative approach**

*Australian standards for aged care* 1

Outcome 2.9 directly relates to a palliative approach. However, there are other outcomes that are relevant to providing a palliative approach (See Table 1).

*Standards for Providing Quality Palliative Care for all Australians* 14

There are 13 voluntary palliative care standards to support and enhance quality of care for patients with life limiting illness. These are outlined in the Palliative Care Australia brochure: “Standards for providing quality palliative care for all Australians” (download from the Palliative Care Australia website: www.palliativecare.org.au). Standards 1, 2, 6 and 8 have been identified as particularly relevant (see Table 1).
Please note

The Australian Palliative Care Standards can be used in conjunction with the Aged Care Accreditation Standards. Although we have identified the most relevant standards for implementing a palliative approach in residential care we encourage you to consult the Aged Care Accreditation and Australian Palliative Care Australia Standards in their entirety.

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| Clinical Care                          |          |                         |                           |
| Pain                                   | 2.4, 2.6, 2.8, 2.9 | 6                        |
| Dyspnoea                                | 2.4, 2.6, 2.9  | 6                        |
| Nutrition and hydration                 | 2.4, 2.6, 2.9, 2.10 | 6                        |
| Oral care (Terminal phase)             | 2.4, 2.6, 2.9, 2.15 | 6                        |
| Delirium (Terminal phase)              | 2.4, 2.6, 2.9  | 6                        |
Funding for a palliative approach

Question 12 part 14 of the Aged Care Funding Instrument (ACFI) allows a facility to claim funding for:

"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 care setting".

Funding requirements include:

1. A "directive by CNC/ CNS in pain or palliative care or medical practitioner". Where CNC (clinical nurse consultant)/CNS (clinical nurse specialist) is a registered nurse who has at least five years full time equivalent registration experience and approved post-registration nursing qualifications in the specialty fields of pain and/or palliative care; AND a

2. Pain assessment

Further information is available at the Department of Health and Ageing website:

Link nurses and a palliative approach

Identifying a link nurse (or "champion") to promote and facilitate a palliative approach in your facility is recommended. A link nurse can:

- 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.

Selection

Although the link nurse is not expected to be a clinical expert in palliative care, s/he does require sound clinical skills. A registered or enrolled nurse is generally most suitable for this role. They should also have sound communication, leadership and facilitation skills and an ability to influence organisational culture and decision-making.

How many?

As a minimum, we recommend one link nurse for every unit or wing of a facility. Having more than this could be considered to provide for link nurse leave and facilitation across shifts.

Preparation

The link nurse should complete both the introductory and advanced self-directed learning packages for nurses that form part of this PA Toolkit.

Supporting the link nurse

Management of the RACF need to actively support nurses who take on this role. Providing non-clinical time for professional development and duties of the role is imperative.

All facility staff should be made aware of the role and responsibilities of the link nurses. These nurses should be clearly identified to other staff (e.g. a badge, staff photograph displayed).

Formation of a Palliative Approach Working Party (see the next section) can also support the link nurse role.
Palliative approach working parties
Creating a palliative approach working party within your facility can support the initiation and sustainability of a palliative approach and provide a focal point for staff interested in palliative care.

**Role**
- Providing a multidisciplinary forum for the development and promotion of a palliative approach within the facility.
- Coordinating the implementation of key processes within the facility.
- Acting as a support mechanism for link nurses to avoid overburdening one or two staff.
- Assisting with continuous improvement processes relating to the palliative approach.
- Assisting with the education of facility staff.

**Getting started**
Likely members of a palliative approach working party:
- link nurses
- director of care
- careworker representative
- allied health
- clergy
- volunteer coordinator
- consumer representative (resident and/or relative).

The palliative approach working party may wish to utilise the skills and resources of external providers, where necessary, such as specialist palliative care services, GPs, education providers, or aged care nurse practitioners.

**Referral to a Specialist Palliative Care Service**
Referral to a specialist palliative care team should be considered when assessing and treating complex symptoms or dealing with complex issues (e.g. ethical dilemmas). Specialist palliative care services provide care for people who have an eventually fatal condition in settings including community, home, RACFs, hospices and palliative care units. 9,15

**Promoting education within your facility**
Staff education is critical for introducing and maintaining a palliative approach in your facility. Information gained in the analysis of regular audit or continuous improvement data 10 (see page 18) can provide a starting point for developing an education and training program.

This toolkit provides a number of useful resources to facilitate education in your facility. Self-directed learning packages are provided for nursing staff (introduction and advanced versions) and careworkers (introduction).

Competency tests conclude each package and the nurse’s self-directed learning packages have been assigned continuing professional development (CPD) points.

Answers for the competency tests are included in the packages. The self-directed learning resources are utilised in combination with two educational DVDs: “Suiting the needs” and “All on the same page”. Brief (10-minute) flipchart presentations targeting careworkers have been provided with facilitator support materials. These presentations correspond to Clinical Care (Module 3) content.

Facility management needs to collaborate with palliative care link nurses to develop and implement a feasible education strategy for your facility.

We recommend you ask staff to complete the introductory self-directed learning packages within three months of orientation. Link nurses can provide presentations using the flipcharts on a regular basis (e.g. monthly) to target as many careworkers as possible.
Continuous improvement

Specific audit tools have not been provided in the PA Toolkit. We recommend consulting the Aged Care Standards and Accreditation Agency resources to assist you in tailoring audits for your facility. Three resources that are useful and available on the Aged Care Standards and Accreditation Agency website (http://www.accreditation.org.au/) are:

1. Audit handbook (2009)
2. Assessment modules (2009)
3. Results and processes (2009)

Section 4 of the Audit handbook discusses Continuous improvement and the Plan-Do-Check-Act cycle. This is illustrated with the following figure:

Plan and do

The PA Toolkit provides you with the resources to plan and implement the improvement (a palliative approach). The PA Toolkit identifies three key processes and five clinical care domains that are essential in providing a palliative approach. In the Standards section in this module each of these has been mapped to the relevant Aged Care Standards. You may choose to implement all of these or select one or two processes or symptoms initially.

Check

Evaluating what you have done is where audits are useful. They provide information on what has been achieved and what still requires action. The “Assessment module handbook” has 14 assessment modules that can assist in identifying what information to include in audits. Most relevant to providing a palliative approach is Module 7 which focuses on nutrition, hydration, oral and dental care and module 12 which focuses on pain management and palliative care. This will give you information on what indicators to use in your audits. Other information that may assist you is the “Results and processes guide”. This has information on the processes to consider in meeting each outcome.

Act

This part of the cycle is about reflecting on how a palliative approach was implemented in your facility. Was it a success? Are changes required? Use the PA Toolkit to assist you with planning the next steps and completing the cycle again.
Bibliography


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

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10 Commonwealth of Australia (2006b) Guidelines for a Palliative Approach in Residential Aged Care – A Navigational Tool, Canberra


14 Palliative Care Australia (2005) Standards for Providing Quality Palliative Care for all Australians, Canberra


17 Parker D (2010) Palliative care in residential aged care facilities. Progress in Palliative Care, 18 (6), 352-357
