Introduction to a Palliative Approach: Educational Flipchart
About this Flipchart

This flipchart:

- Is for use in the education and training of careworkers.
- Provides introductory-level information about key concepts and issues relevant to the delivery of high quality palliative care in Australian residential aged care facilities (RACFs).
- Includes four modules:
  1. What is a Palliative Approach?
  2. Implementing a Palliative Approach Using Three Key Processes
  3. Cultural Considerations in Using a Palliative Approach
  4. Self-Care for Residential Aged Care Staff
- Provides notes for facilitators on how to run introductory-level education sessions for careworkers using the four flipchart modules.

Note: This flipchart is not a stand-alone tool. Consult the Residential Aged Care Palliative Approach Toolkit (PA Toolkit) for additional information and resources.
List of PA Toolkit Resources

The PA Toolkit includes:

**Implementation Guides:**
- Workplace Implementation Guide
- Training Support Guide
- Guidelines for a Palliative Approach in Residential Aged Care (Order Form)

**Clinical Practice Guides:**
- Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents
- Therapeutic Guidelines: Palliative Care [Version 3]

**Learning Modules:**
- Module 1: Integrating a Palliative Approach
- Module 2: Key Processes (Advance Care Planning, Palliative Care Case Conferences, Use of an End of Life Care Pathway)
- Module 3: Clinical Care (Pain, Dyspnoea, Nutrition and Hydration, Oral Care, Delirium)

**Self-Directed Learning Guides:**
- Self-Directed Learning Packages (Nurse Introduction, Nurse Advanced, Careworker)

**Educational DVDs:**
- Suiting the Needs: A Palliative Approach in Residential Aged Care
- All on the Same Page: Palliative Care Case Conferences in Residential Aged Care
- How to Use the Residential Aged Care End of Life Care Pathway [RAC EoLCP]

**Educational Flipcharts:**
- Introduction to a Palliative Approach
- Clinical Care Domains

**Family & Staff Support Resources:**
- Brochure: Understanding the Dying Process
- Brochure: Now What? Understanding Grief
- Bereavement Support Booklet for Residential Aged Care Staff
- PA Toolkit Forms CD (included on the Educational DVD: All on the Same Page)

For further information and to download PA Toolkit resources visit: www.caresearch.com.au/PAToolkit
Facilitator’s Notes

List of PA Toolkit Resources

Key Message

- This flipchart is not a stand-alone educational tool. Its effective use in staff education and training requires the facilitator to consult the PA Toolkit for additional information and resources.

Educational Flipchart: Introduction to a Palliative Approach

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- Clinical Education Reference Group for the National Rollout of the Palliative Approach Toolkit for Residential Aged Care Facilities
- Clinical staff from Metro South Palliative Care Services (Queensland Health)

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Flipchart Modules

What is a Palliative Approach?

Implementing a Palliative Approach Using Three Key Processes

Cultural Considerations in Using a Palliative Approach

Self-Care for Residential Aged Care Staff
Flipchart Modules

Key Messages

This flipchart:

- Is for use in the education and training of careworkers.
- Is divided into four modules presented in a recommended order of delivery:
  1. What is a Palliative Approach?
  2. Implementing a Palliative Approach Using Three Key Processes
  3. Cultural Considerations in Using a Palliative Approach
  4. Self-Care for Residential Aged Care Staff

- Focuses on introductory-level information relevant to the delivery of high quality palliative care in Australian residential aged care facilities (RACFs).
- Includes notes to guide facilitators in preparing for and delivering education sessions using the flipchart. These notes:
  - Identify ‘key messages’ for the facilitator to emphasise (get across to participants) in relation to each flipchart page.
  - Suggest a range of ‘optional learning activities’ that the facilitator can use to reinforce and prompt participant reflection/discussion about module content.
  - Provide ‘key content summaries’ to assist the facilitator in preparing for sessions.

Each module requires a minimum of 10 minutes to deliver.
What is a Palliative Approach?
Facilitator’s Notes

What is a Palliative Approach?

Scope
This module is appropriate for careworkers.

Learning Objectives
By the completion of this session, participants will be able to:

• Describe the purpose of palliative care.

• Identify the key differences between a palliative approach, specialised palliative service provision, and end of life (terminal) care.

• Describe some of the goals and benefits of using a palliative approach in residential aged care.

Relevant PA Toolkit Resources

• Learning Module 1: Integrating a Palliative Approach

• Self-Directed Learning Package: Careworker

• Educational DVD: Suiting the Needs: A Palliative Approach in Residential Aged Care (Length: 12 minutes)

Optional Learning Activity: Video

Materials Required:

• Educational DVD: Suiting the Needs: A Palliative Approach in Residential Aged Care [Length: 12 minutes]. A copy of this video is available in the PA Toolkit.

Instructions:
Before commencing this module, the facilitator may wish to show participants the ‘Suiting the Needs: A Palliative Approach in Residential Aged Care’ video.
Palliative Care

- Improves quality of life for individuals and their families facing the problems associated with life-limiting illness.
- Focuses on the prevention and relief of suffering through the early identification, assessment and treatment of pain and other problems – physical, psychosocial and spiritual.

Three Forms of Palliative Care

1. A palliative approach
2. Specialised palliative service provision
3. End of life (terminal) care
Palliative Care

Key Messages

- Palliative care focuses on ‘quality of life and comfort care’ rather than on ‘cure’.
- Palliative care addresses the physical, psychosocial and spiritual needs of individuals with advanced life-limiting illnesses and their families.
- Careworkers play a key role in palliative care through the comfort care and support that they provide to residents and families.
- It’s important to distinguish between three forms of palliative care:
  - A palliative approach
  - Specialised palliative service provision
  - End of life (terminal) care

Optional Learning Activity: Group Discussion

Instructions:
To reinforce the purpose of palliative care, ask participants to reflect on and share their ideas about what would constitute a ‘good death’ and a ‘bad death’ for them.
A Palliative Approach

- Improves quality of life for residents with life-limiting illnesses and their families by reducing suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.
- Is not limited to the last days or weeks of a resident’s life.

When should a palliative approach commence?
1. If the resident has one or more advanced life-limiting illnesses.
2. If the resident’s quality of life is at risk.
3. If treatment goals are ‘comfort care focused’ rather than ‘cure focused’.
A Palliative Approach

Key Messages

A palliative approach:

- Improves quality of life for residents with life-limiting illnesses and their families.
- Reduces suffering through early identification, assessment and treatment of pain, physical, psychological, cultural, social and spiritual needs.
- Is not limited to the last days or weeks of a resident’s life.

A palliative approach should commence:

- If the resident has one or more advanced life-limiting illnesses.
- If the resident’s quality of life is at risk.
- If treatment goals are 'comfort care focused' rather than 'cure focused'.

Important: Careworkers aren’t expected to decide whether a resident needs a palliative approach. However, their observations about the resident’s condition will help the GP/nursing staff to determine whether a palliative approach is indicated.

Using a palliative approach does not mean that the resident has only days or weeks to live.

Key Content Summary for Facilitators*

1. A palliative approach:
   - Offers care and support for residents who are experiencing advanced life-limiting illnesses and their families.
   - Improves the resident’s level of comfort and function by addressing physical, psychological, cultural, social and spiritual needs.
   - Is not limited to the last days or weeks of a resident’s life.
   - Requires care staff to have a positive and open attitude towards death and dying.

2. A palliative approach to care should be considered if the following are present:
   - If the resident has one or more life-limiting illnesses – e.g.
     - Heart failure
     - Respiratory diseases [e.g. chronic obstructive pulmonary disease]
     - Neurological diseases [e.g. Parkinson’s disease; Alzheimer’s disease and other forms of dementia]
     - Cancer-related illnesses
   - If the resident’s quality of life is at risk due to physical/psychosocial issues associated with an advanced life-limiting illness – e.g.
     - Physical [e.g. fatigue; weakness; loss of appetite; weight loss; loss of mobility; pain; breathlessness; confusion/memory loss]
     - Psychological [e.g. anxiety; sadness; grief; depression]
   - If treatment goals are ‘comfort care focused’ rather than ‘cure focused’. Identifying and responding to a resident’s goals of care requires ongoing and open communication between the resident, the resident’s family and substitute decision maker, and the RACF care team.

* These notes are for use by the facilitator in preparing for this session.
RACF staff may seek advice and support from a specialist palliative care team to manage complex issues related to a resident’s care. For example:

- Complex physical symptoms
- Complex psychological distress
- Complex ethical dilemmas
- Complex family issues
Specialised Palliative Service Provision

Key Messages

- RACF staff may seek advice and support from a specialist palliative care team to manage complex issues related to a resident’s care – e.g.
  - Complex physical symptoms
  - Complex psychological distress
  - Complex ethical dilemmas
  - Complex family issues

- Specialist palliative care teams do not usually take over the care of the resident – but rather provide expert advice on complex issues and support to GPs and aged care teams.

Key Content Summary for Facilitators*

1. Some residents may experience complex problems as their condition advances – e.g.
   - Complex physical symptoms
   - Complex psychological distress
   - Complex ethical dilemmas
   - Complex family issues

2. Specialised palliative service provision:
   - Involves a team of specialist palliative care doctors, nurses and allied health professionals (not directly employed by the RACF).
   - Provides assistance and support to the RACF care team when a resident is experiencing complex problems.

3. Specialist palliative care teams do not usually take over the care of the resident – but rather provide expert advice on complex issues and support to GPs and aged care teams.

* These notes are for use by the facilitator in preparing for this session.
End of Life (Terminal) Care

- Is appropriate when a resident is in the final days or weeks of life when care decisions need to be reviewed more frequently.
- Focuses on the resident’s immediate physical, emotional and spiritual comfort needs and support for the resident’s family.
End of Life (Terminal) Care

Key Messages

End of life (terminal care):

• Is appropriate when a resident is in the final days or weeks of life when care decisions need to be reviewed more frequently.

• Focuses on a resident’s immediate physical, emotional and spiritual comfort needs and support for the resident’s family.

Important: Careworkers should immediately report any changes that they observe in a resident’s condition to nursing staff for subsequent assessment and review.

End of life (terminal) care is urgent care.

Key Content Summary for Facilitators*

1. End of life [terminal] care is appropriate when a resident is experiencing signs/symptoms indicating that they may be in the last days or week of life (i.e. the terminal phase of life). These signs and symptoms include:
   • 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.

2. End of life (terminal) care may require decisions about a resident’s care to be reviewed more frequently.

3. End of life (terminal) care involves goals more sharply focused on a resident’s physical, emotional and spiritual comfort needs and support for the resident’s family.

* These notes are for use by the facilitator in preparing for this session.
Use of a Palliative Approach in Residential Aged Care

Improves residents’ quality of life by:

- Encouraging advance care planning and open discussion about death and dying.
- Involving residents and families in decision-making and care planning.
- Providing improved control of symptoms (e.g. pain).
- Allowing residents to die in their RACF home with familiar staff.
Facilitator’s Notes

Use of a Palliative Approach in Residential Aged Care

Key Messages
Using a palliative approach improves residents’ quality of life and comfort by:
• Encouraging advance care planning and open discussion about death and dying.
• Involving residents and families in decision-making and care planning.
• Providing improved control of symptoms (e.g. pain).
• Allowing residents to die in their RACF home with familiar staff who care for them.

Key Content Summary for Facilitators*
1. Context:
   In Australia, the proportion of people dying in RACFs has steadily increased over the last two decades. In addition, those entering residential aged care are increasingly frail, often highly dependent and have multiple co-morbidities.1
   The complex needs of residents and their families have prompted recognition of the importance of using a palliative approach in residential aged care.

   2. The major benefit of using a palliative approach in residential aged care is that it improves residents’ quality of life by:
   • Encouraging open and early discussion about advance care planning as well as death and dying which, for example:
     - Assists residents and their families to understand and accept the implications of disease progression.
     - Helps to involve the resident and their family in care planning and decision-making.
   • Facilitating the early identification of changes in a resident’s condition and the prompt management of emerging symptoms. Thereby providing opportunities for improved control of pain and other symptoms.
   • Reducing unnecessary transfers to hospital because aged care staff develop skills to manage the palliative care needs of residents. Thereby:
     - Enabling residents to be cared for by staff that they know and with whom they have a close relationship.
     - Enabling residents to die in their RACF home.

* These notes are for use by the facilitator in preparing for this session.

Optional Learning Activity: Group Discussion
Purpose:
• To assist participants to consolidate and apply the key points covered in this module.

Instructions:
Use these questions to prompt/guide participants’ discussion:
• What role do careworkers play in providing a palliative approach to caring for residents and their families?
• How has/could the use of a palliative approach improve the care of residents at your facility?
• How has/could the use of a palliative approach assist you in your day-to-day work?

Implementing a Palliative Approach Using Three Key Processes
Implementing a Palliative Approach Using Three Key Processes

Scope
- This module is appropriate for careworkers.
- You may wish to deliver this module in one session or over several linked sessions depending on time available for training.

Learning Objectives
By the completion of this session, participants will:
- Have a basic understanding of the purpose and tasks involved in the three key processes for implementing a palliative approach in residential aged care (as described in the PA Toolkit): (1) advance care planning; (2) palliative care case conferences; and (3) use of an end of life care pathway.
- Have a basic understanding of when each of these key processes should be commenced as part of a resident’s care.
- Be able to describe their role in implementing the three key processes.

Relevant PA Toolkit Resources
- Learning Module 2: Key Processes
- Self-Directed Learning Package: Careworker
- Educational DVD: All on the Same Page: Palliative Care Case Conferences in Residential Aged Care [Length: 14 minutes]
- Educational DVD: How to Use the Residential Aged Care End of Life Care Pathway [Length: 26 minutes]

Optional Learning Activity: Group Brainstorming and Key Concept Review
**Purpose:**
- To identify participants’ current understanding of the key features and benefits of using a palliative approach in residential aged care.

**Instructions:**
Ask participants to brainstorm (as a group) the key features and benefits of using a palliative approach in residential aged care. Use these questions to prompt/guide the brainstorming process:
- What are the aims of a palliative approach?
- What areas of a resident’s care are addressed in a palliative approach?
- In what ways does using a palliative approach improve a resident’s care and quality of life?
- In what ways does using a palliative approach assist in your day-to-day work?

Record participants’ ideas from the brainstorming process on a whiteboard or butcher’s paper so that the group can refer back to them during this session.
Three Key Processes

1. Advance care planning
2. Palliative care case conferences
3. Use of an end of life care pathway

The success of each key process is based on good communication between the resident, their family and substitute decision maker, and the RACF care team.
Three Key Processes in Implementing a Palliative Approach

Key Messages

• Three key processes assist in the implementation of a palliative approach in residential aged care:
  1. Advance care planning
  2. Palliative care case conferences
  3. Use of an end of life care pathway

• The success of each key process is based on good communication between the resident, their family and substitute decision maker, and the RACF care team.

Without ongoing and open communication between all parties involved in a resident’s care, the key processes will fail.

Key Content Summary for Facilitators*

1. Three key processes assist in the implementation of a palliative approach in residential aged care:
   • Advance care planning
   • Palliative care case conferences
   • Use of an end of life care pathway

2. Each key process involves a set of activities undertaken by the resident’s multidisciplinary care team in direct consultation with the resident and the resident’s family/substitute decision maker. Without ongoing and open communication between all parties involved in a resident’s care, the key processes will fail.

3. The three key processes are described in detail in ‘Module 2: Key Processes’ of the PA Toolkit. Our focus in this session will be to:
   • Examine how each key process contributes to the goals of a palliative approach.
   • Highlight the role of careworkers in implementing each key process.

* These notes are for use by the facilitator in preparing for this session.
Framework to Guide the Use of Key Processes by RACFs

ALL NEW AND EXISTING RESIDENTS

TRAJECTORY A
Estimated prognosis of greater than 6 months
Advance Care Planning

TRAJECTORY B
Estimated prognosis of less than 6 months
Palliative Care Case Conference

TRAJECTORY C
Estimated prognosis of less than 1 week
End of Life Care Pathway
Facilitator’s Notes

Framework to Guide the Use of Key Processes by RACFs

Key Messages

- The ‘Palliative Approach Trajectories Framework’ uses three ‘trajectories’ to guide the implementation of key processes.
- Each ‘trajectory’ is based on ‘estimated prognosis’ for the resident. ‘Estimated prognosis’ refers to a prediction made by a suitably qualified health professional about how long a resident has to live based on expert knowledge and clinical judgement about the resident’s condition and specific disease process(es).

- Trajectory A: Estimated prognosis = more than six months
  Key process = advance care planning

- Trajectory B: Estimated prognosis = less than six months
  Key process = palliative care case conference

- Trajectory C: Estimated prognosis = less than one week
  Key process = use of an end of life care pathway

A resident’s estimated prognosis can be used to guide when a key process is implemented.

Optional Learning Activity: Video

Materials Required:

- Educational DVD: All on the Same Page: Palliative Care Case Conferences in Residential Aged Care [Length: 14 minutes]. A copy of this video is available in the PA Toolkit.

Instructions:

Before moving to the next flipchart page, the facilitator may wish to show participants the ‘All on the Same Page: Palliative Care Case Conferences in Residential Aged Care’ video.

Key Content Summary for Facilitators*

1. Based on the ‘Palliative Approach Trajectories Framework’ set out in the PA Toolkit, three trajectories can be applied to all new and existing residents based on their estimated prognosis.

2. Each trajectory [A, B and C] is associated with a particular key process:
   - Trajectory A applies to residents who may have a life-limiting illness [e.g. dementia] but have an estimated prognosis of more than six months. The key process [or action] that is recommended in the PA Toolkit for all residents assigned to Trajectory A is advance care planning.
   - Trajectory B applies to residents who have an estimated prognosis of less than six months. The key process [or action] recommended in the PA Toolkit for residents assigned to Trajectory B is a palliative care case conference.
   - Trajectory C applies to residents with an estimated prognosis of less than one week. The key process [or action] recommended in the PA Toolkit for residents assigned to Trajectory C is use of an end of life care pathway.

3. Important: Prognostication is often imprecise. For this reason residents should be reviewed frequently by the GP/nursing staff for changes in their clinical condition. Whenever a resident experiences an acute event or illness they must be re-reviewed. In the absence of any acute changes in the resident’s condition:
   - Residents assigned to Trajectory A should be reviewed every six months.
   - Residents assigned to Trajectory B should be reviewed monthly.
   - Residents assigned to Trajectory C should be reviewed daily.

4. All members of the RACF care team [including careworkers] should be aware of a resident’s estimated prognosis.

* These notes are for use by the facilitator in preparing for this session.
Advance Care Planning

What is Advance Care Planning?
- Involves thinking about, communicating and documenting wishes for future care and medical treatment.
- Is not a single event – it involves an ongoing process of discussion.
- Is about planning ahead and clearly documenting this plan.

When should Advance Care Planning take place?
- Should be a routine practice by RACFs that commences for each resident soon after admission.
Facilitator’s Notes

Advance Care Planning

Key Messages

• Everyone should have the opportunity to express their wishes about the care and treatment that they receive.

• Advance care planning:
  - Involves a person thinking about, communicating and documenting their wishes for future care and medical treatment.
  - Involves an ongoing process of discussion.
  - Is about planning ahead and clearly documenting this plan.
  - Should be a routine practice by RACFs that commences for each resident soon after admission.

• Residents often mention their concerns about hospitalisation and future treatment to careworkers. It’s important to listen for these comments and to report back to nursing staff for further assessment.

Residents’ preferences for care cannot be respected and followed if they are not known.

Optional Learning Activity: Group Discussion

Instructions:
Ask participants to reflect on and discuss the things that they would include in their own advance care plan. Use these questions to prompt/guide participants’ discussion:

• Do you have an advance care plan? Why/why not?
• What things related to your future care and medical treatment have you included (or will you include) in your advance care plan and why?

Advance Care Planning

What is Advance Care Planning?
- Involves thinking about, communicating and documenting wishes for future care and medical treatment.
- Involves an ongoing process of discussion.
- Is about planning ahead and clearly documenting this plan.

When should Advance Care Planning take place?
- Should be a routine practice by RACFs that commences for each resident soon after admission.

Key Content Summary for Facilitators*

1. Advance care planning involves a person thinking about, communicating and documenting their wishes for future care and medical treatment. Issues considered as part of advance care planning may include:
   • Beliefs, values and attitudes about quality of life, death and dying.
   • Preferences in regards to ‘active’ versus ‘palliative’ treatments.
   • Resuscitation wishes and preferences for hospitalisation at end of life.
   • Appointment of a substitute decision maker.
   • Funeral wishes.

2. Advance care planning is not a single event – it involves an ongoing process of communication between a competent resident and the RACF care team. Remember, a resident’s end of life care wishes need to be revisited over time (e.g. residents may change their wishes and/or their specific wishes may become clearer over time).

3. Advance care planning is about planning ahead and clearly documenting this plan. When people are critically ill they may be unable to participate in decisions about their treatment and care. The process of advance care planning ensures that a person has the opportunity to discuss and document their goals of care and treatment preferences while they still have capacity.

4. Advance care planning should be a routine practice by RACFs that commences for each resident soon after admission.

5. A legal document is not an essential outcome of the advance care planning process – but residents’ preferences for end of life care should be clearly documented in their charts. Each Australian State and Territory has different legislation, regulations, guidelines and documentation for advance care planning.

* These notes are for use by the facilitator in preparing for this session.
What is a Palliative Care Case Conference?

A meeting held between a resident, their family and/or substitute decision maker, and the RACF care team to:

1. Provide a safe environment where issues and questions about the resident’s condition and future care can be discussed.
2. Identify clear goals of care for the resident.
Palliative Care Case Conferences

Key Messages

• A palliative care case conference is a meeting held between a resident, their family and/or substitute decision maker, and the RACF care team to:
  - Provide a safe environment where issues and questions about the resident’s condition and future care can be discussed.
  - Identify clear goals of care for the resident.

• Important: Careworkers play a key role in palliative care case conferences because, in providing day-to-day care for residents, they often notice changes in a resident’s mood, symptoms [e.g. pain, breathing] and/or ability to function [e.g. walking, eating, drinking]. Also, a resident may mention issues to a careworker that are important for other members of the RACF care team to know.

Optional Learning Activity: Staff Communication Sheet

Materials Required:
• Palliative Care Case Conference: Staff Communication Sheet [i.e. Form 3 on the PA Toolkit Forms CD]

Instructions:
Hand out copies of the ‘Palliative Care Case Conference: Staff Communication Sheet’. Ask participants to briefly discuss as a group:
• How could use of this form improve the care provided to residents and their families?
• What might be some of the concerns raised by a resident, their substitute decision maker and/or their family during a palliative care case conference?

Key Content Summary for Facilitators*

1. A palliative care case conference is a meeting held between a resident, their family and/or substitute decision maker, and the RACF care team. Attendees at the case conference may vary depending on what is being discussed and who is available. However, the following people should be considered as potential attendees:
   • The resident (if capable)
   • Substitute decision maker/medical power of attorney
   • Family members
   • RACF staff [including a nurse and a careworker]
   • Allied health staff [e.g. occupational therapist, speech pathologist]
   • Clergy or pastoral care staff
   • GP and/or specialist palliative care nurse

2. The aims of a palliative care case conference are to:
   • Provide a safe environment where issues and questions about a resident’s condition and future care can be discussed.
   • Identify clear goals of care for the resident including a review of the resident’s advance care plan – so that everyone is ‘on the same page’.

3. Using the ‘Palliative Approach Trajectories Framework’ in the PA Toolkit, a palliative care case conference is particularly relevant for residents with an estimated prognosis of six months or less. Markers for an estimated prognosis of six months or less include:
   • Answering “no” to the question: “Would you be surprised if the resident died within the next six months?”
   • If there has been significant functional or medical decline.
   • If there is emerging conflict concerning whether goals of care should be curative or palliative in intent [e.g. after an acute event].
   • If the resident is transferred or admitted to the RACF specifically for comfort or palliative care.

* These notes are for use by the facilitator in preparing for this session.
What is an End of Life Care Pathway?
- A clinical document that guides the delivery of high quality care by staff for residents in the terminal phase of life.

When should an End of Life Care Pathway be used?
- When the resident is experiencing signs/symptoms suggesting that they may be in the last week or days of life.
- If the resident’s condition improves they will be taken off the end of life care pathway and routine care will be resumed.
Facilitator’s Notes

Use of an End of Life Care Pathway

Key Messages

• An end of life care pathway:
  - Is a clinical document that guides the delivery of high quality care by staff for residents in the terminal phase of life.
  - Should be commenced when the resident is experiencing signs/symptoms suggesting that they may be in the last week or days of life.

• It’s important for nursing staff and careworkers to be familiar with the signs and symptoms indicating that a resident may be dying.

• If the resident’s condition improves they will be taken off the end of life care pathway and routine care will be resumed.

An end of life care pathway is a clinical care plan that guides and supports high quality care in the last week or days of a resident’s life.

Optional Learning Activity: Group Discussion

Use these questions to prompt/guide a brief discussion between participants:

• Have you experienced the death of a resident?
• Were you aware that the resident was dying?
• What signs of approaching death did you notice in the resident?

Key Content Summary for Facilitators*

1. An end of life care pathway is a set of forms and protocols that guide the care provided by doctors, nurses and careworkers in the terminal phase of a resident’s life.

2. Several end of life care pathways are available for use by RACFs/hospitals. The PA Toolkit recommends the ‘Residential Aged Care End of Life Care Pathway (RAC EoLCP)’. The RAC EoLCP is an evidence-based clinical care plan developed by the Brisbane South Palliative Care Collaborative specifically for use by Australian RACFs.

3. Use of an end of life care pathway is appropriate when a resident is experiencing signs/symptoms indicating that they may be in the last week or days of life (i.e. the terminal phase of life) - e.g.
  • 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.

4. A resident will be taken off the end of life care pathway if their condition improves and routine care resumed.

5. The final decision to commence an end of life care pathway is a clinical one, supported by the views of the GP and multidisciplinary care team in consultation with the resident and/or the resident’s substitute decision maker.

* These notes are for use by the facilitator in preparing for this session.
Cultural Considerations in Using a Palliative Approach
Facilitator’s Notes

Cultural Considerations in Using a Palliative Approach

Scope
This module is appropriate for careworkers.

Learning Objectives
By the completion of this session, participants will be able to:

• Explain why identifying and responding to the cultural needs of residents and their families is important in delivering a palliative approach to care.

• Describe some day-to-day methods for identifying and responding to the cultural needs of residents and their families.

Optional Learning Activity: Group Discussion
Use these questions to prompt/guide individual reflection by participants and then a brief group discussion:

• What cultural groups are represented in the residents and staff at your facility?

• What are some beliefs, values and practices related to end of life care that are important to you? Are these beliefs, values and practices influenced by your culture?

Key Content Summary for Facilitators*

1. Australia has a diverse, multicultural population. Over 22% of Australia’s population was born overseas (representing over 200 different countries).2

2. It is important for RACF staff to be aware of how their own cultural beliefs, values and practices influence the care that they provide to residents and families.

* These notes are for use by the facilitator in preparing for this session.

Culture

- A set of beliefs, values, norms and practices that are learned, shared and dynamic.
- May affect a person’s thoughts, expressions and actions in a patterned way.

Culture and a Palliative Approach

Residents and family members from culturally and linguistically diverse backgrounds may have specific needs regarding end of life care.

But - do not make assumptions about a person’s cultural needs based on their language, religion or country of origin.
Culture

Key Messages

- Culture refers to a set of beliefs, values, norms and practices that:
  - Are learned, shared and dynamic.
  - May influence a person’s thoughts, expressions and actions in a patterned way.
- It’s important for careworkers to be mindful of the specific cultural needs of residents and family members.
- Never stereotype or make assumptions about a resident’s cultural beliefs, values and practices. Instead, actively seek information about the individual cultural needs of each resident and how to respond to these needs appropriately when delivering care.

Key Content Summary for Facilitators*

1. Culture refers to a set of beliefs, values, norms and practices that are learned, shared and dynamic. These may influence a person’s thoughts, expressions and actions in a patterned way.
2. Residents and family members from culturally and linguistically diverse (CALD) backgrounds may have specific needs regarding end of life care. Instead, actively seek information about the individual cultural needs of each resident and how to respond to these needs appropriately when delivering care.
3. It’s important to never stereotype or make assumptions about a resident’s cultural beliefs, values and practices. Instead, actively seek information about the individual cultural needs of each resident and how to respond to these needs appropriately when delivering care.
4. Quality end of life care requires identifying and responding to the person’s specific individual needs - including (but not limited to) their cultural beliefs and practices.

* These notes are for use by the facilitator in preparing for this session.
Some Useful Tips

- Ask about relevant cultural aspects of caring for a resident.
- Be aware of customs that show respect.
- Understand that people have different reactions towards death and dying.
- Remember - someone who can understand spoken English may not be able to read it as well.
- Avoid using jargon.
- Be aware of your own cultural beliefs, values and practices.
Facilitator’s Notes

Some Useful Tips

Key Messages
The facilitator should discuss the six ‘tips’ listed on this flipchart page and provide examples where relevant to assist participants to apply the ‘tips’ to their day-to-day work [see ‘Key Content Summary for Facilitators’ on this page for additional information].

Important: Residents will vary in the level of importance and priority that they give to cultural beliefs, values and practices.

A palliative approach identifies and responds to the individual needs of residents and their families.

Optional Learning Activity: Group Discussion

Instructions:
Ask participants to share and discuss their ideas/experiences about how to identify and respond to the specific cultural needs of residents and their family members. Challenge participants to add new ‘tips’ to those already listed on this flipchart page.

Key Content Summary for Facilitators*

Some useful tips:

1. Do not hesitate to ask about relevant cultural aspects of caring for a resident. Ask the resident and their family to let you know any customs, traditions and beliefs that are important to them and how they would like you to address these when caring for the resident.

2. Be aware of customs that show respect for the resident and their family members.

3. Understand and respect that people have different reactions towards death and dying. For example, some Indigenous Australians find it distressing to speak the name of a deceased person.

4. Remember - just because someone can understand spoken English does not mean that they can automatically read it as well.

5. Communicate in ways that are clear and appropriate. For example, avoid using jargon and translate information into terms that the resident and/or their family can understand. Good communication is at the heart of a palliative approach.

6. In working with people from other cultures, we inevitably bring with us our own attitudes and beliefs. It’s important to be aware of how your own cultural beliefs, values and practices may influence your interactions with others – including the way in which you deliver care.

Important: Residents will vary in the level of importance and priority they give to cultural beliefs, values and practices. A palliative approach identifies and responds to the individual needs of residents and their families.

* These notes are for use by the facilitator in preparing for this session.
Self-Care for Residential Aged Care Staff
Facilitator's Notes

Self-Care for Residential Aged Care Staff

Scope
This module is appropriate for careworkers.

Learning Objectives
By the completion of this session, participants will be able to:

• Recognise and describe some of the risk factors and reactions associated with loss and grief experienced by staff working in residential aged care.
• Describe some self-care and workplace strategies to reduce the risks associated with loss and grief experienced by staff working in residential aged care.

Relevant PA Toolkit Resources
Bereavement Support Booklet for Residential Aged Care Staff
Working in Residential Aged Care

“Working as part of a care team in residential aged care has enormous rewards – in caring for residents, adding to the quality of their lives, sharing their pasts, and being a valuable part of their present.”

[SafeWork South Australia, 2004]
Facilitator’s Notes

Working in Residential Aged Care

Key Messages

The opportunity to form long-term and close relationships with residents and their families can be a deeply satisfying aspect of working in residential aged care. Therefore, it’s not surprising that staff may feel a deep sense of loss when a resident dies.

Optional Learning Activity: Brief Group Discussion

Instructions:
Ask participants to individually reflect on and then discuss as a group the following question:

• What are some of the rewards of working in residential aged care?

Key Content Summary for Facilitators*

The following resource will assist the facilitator in preparing for this session:

SafeWork South Australia (2004) Managing Loss and Grief in the Aged Care Industry: Guidelines to Assist in the Management of Loss and Grief in Residential Aged Care Facilities and Community Care. Viewed online 28/10/2013:

This document uses a risk management model to provide detailed information about whole of organisation, work team and personal strategies for responding to work-related stress experienced by residential aged care staff (including loss and grief associated with the death of residents).

* These notes are for use by the facilitator in preparing for this session.
Loss, Grief and Bereavement

Loss is the severing or breaking of an attachment to someone or something, resulting in a changed relationship.

Grief is a normal reaction to loss. It includes a range of responses: physical, mental, emotional and spiritual.

Bereavement is the total reaction to a loss and includes the process of healing or ‘recovery’ from the loss.

Close relationships can develop between staff and residents.

When a resident dies, you may experience loss and grief.
Facilitator’s Notes

Loss, Grief and Bereavement

Key Messages

- It’s important to be aware that when a resident dies, staff may experience loss and grief.
- In learning to recognise risk factors and reactions associated with grief in yourself and others, it can be helpful to distinguish between loss, grief and bereavement.

Optional Learning Activity: Group Discussion

Instructions:
Before showing the next flipchart page, read the following case study to participants.

Case Study: Pat’s Story

Pat is a single mum with three children aged ten to sixteen who all live at home with her. Pat was also the main carer for her dad before he died six months ago. She misses her dad very much – his sense of humour and advice always helped to keep things in perspective. Pat has been a careworker for many years and has always enjoyed her job. However, in the last few months Pat has started to feel stressed about her work. Her close friend and co-worker Jenny retired a month ago. For Pat it seems like every day the workload increases – and caring for dying residents and their families has become particularly hard. Before Jenny retired, Pat would often chat with her about how best to look after residents and families in their care. Pat feels tired all of the time so doesn’t play netball on Wednesday nights anymore, and her kids have started to mention that she has ‘a short fuse’ at home. Pat feels that skipping her usual tea break with co-workers is the only way to get on top of her workload. Pat’s co-workers have noticed that she hasn’t been her usual ‘positive and patient self’ for the last few months and worry that she is pushing herself too much.

Question: Use this question to guide group discussion about the case study. Record key points from the discussion on a whiteboard or butcher’s paper.

- What things in Pat’s personal and work life might be contributing to how she is currently feeling, thinking and behaving?

Grief is the normal response to loss. But we all grieve and ‘recover’ in our own way.

Key Content Summary for Facilitators*

1. It’s important to be aware that when a resident dies, you may experience loss and grief.

2. Distinguishing between loss, grief and bereavement can be useful in learning to recognise risk factors and reactions associated with your own and others’ experiences of grief:
   - Loss is the severing or breaking of an attachment to someone or something, resulting in a changed relationship.
   - Grief is a normal reaction to loss. It includes a range of responses: physical, mental, emotional and spiritual.
   - Bereavement is the total reaction to a loss and includes the process of healing or ‘recovery’ from the loss.

3. Working in a ‘high loss setting’ does not mean that you automatically become accustomed to death and dying. The reality is that familiarity with death does not necessarily make it easier to accept loss and manage grief.

4. It’s important for RACF staff to become aware of the risk factors and reactions associated with grief and to proactively engage in self-care and workplace strategies to manage these risks and reactions.

* These notes are for use by the facilitator in preparing for this session.
Some Risk Factors and Reactions Related to Loss and Grief

**Potential Risk Factors**

- Level of closeness in your relationship with the person who died.
- Nature of how the person died.
- Lack of knowledge and/or confidence about:
  - How to deliver high quality end of life care.
  - How to discuss death and dying.
- Lack of a supportive work environment.
- Other work-related factors (e.g. workload and time pressures).
- Previous bereavement experiences and cumulative grief.
- Stress and other challenges in your personal life.

**Common Reactions**

- Feelings of helplessness, anger, anxiety, apathy (lack of motivation) and/or stress.
- Difficulty concentrating.
- Withdrawing from relationships at work and/or at home.
- Avoiding social activities.
- Not eating or sleeping properly.
- Physical and/or mental exhaustion.
- A sense of not having ‘control’ over thoughts and/or feelings.
- Loss of confidence in ability to function at work and/or at home.
- Physical illness.
- Challenges to religious or spiritual beliefs.
Some Risk Factors and Reactions Related to Loss and Grief

Key Messages

- The facilitator should discuss and, where relevant, provide examples related to the risk factors and reactions associated with loss and grief listed on this flipchart page.
- A particular risk factor will not have the same impact on everyone and a person’s reaction to a particular risk factor may vary across situations/time.
- Grief is experienced in different ways by different people. It doesn’t always ‘look’ and ‘feel’ the same way for everyone.

Key Content Summary for Facilitators*

1. Risk factors:
   - Level of closeness in your relationship with the person who died.
   - Nature of how the person died. A ‘bad death’ may leave staff members feeling that they have ‘failed’ the resident and/or the resident’s family.
   - Lack of knowledge and/or confidence about how to deliver high quality end of life care.
   - Lack of knowledge and/or confidence about how to discuss death and dying.
   - Lack of a supportive work environment.
   - Other work-related factors [e.g. workload and time pressures].
   - Previous bereavement experiences and cumulative grief.
   - Stress and other challenges in your personal life.

Remember – a particular risk factor will not have the same impact on everyone and a person’s reaction to a particular risk factor may vary across situations/time.

2. Reactions:
   - Feelings of helplessness, anger, anxiety, apathy (lack of motivation) and/or stress.
   - Difficulty concentrating.
   - Withdrawing from relationships at work and/or at home.
   - Avoiding social activities.
   - Not eating or sleeping properly.
   - Physical and/or mental exhaustion.
   - A sense of not having ‘control’ over thoughts and/or feelings.
   - Loss of confidence in ability to function at work and/or at home.
   - Physical illness.
   - Challenges to religious or spiritual beliefs.

Remember – unresolved grief is experienced in different ways by different people. It doesn’t always ‘look’ and ‘feel’ the same way for everyone.

* These notes are for use by the facilitator in preparing for this session.
Self-Care and Workplace Activities to Manage Loss and Grief

- Ask the family’s permission to attend the funeral.
- Talk to your supervisor or colleagues about how you are feeling.
- Seek support from a professional counsellor.

In addition, it can be helpful to:
- Develop self-care strategies that promote physical and emotional well-being.
- Participate in creating a workplace that supports staff who are experiencing grief.
Facilitator’s Notes

Self-Care and Workplace Strategies to Manage Loss and Grief

Key Messages

- The facilitator should discuss and, where appropriate, provide examples for each of the ‘strategies’ listed on this flipchart page.
  - Ask the family’s permission to attend the resident’s funeral.
  - Talk to your supervisor or colleagues about how you are feeling.
  - Seek support from a professional counsellor.
  - Develop self-care strategies that promote physical and emotional well-being (e.g. healthy diet, regular exercise, find activities that help you to relax and make time to do them).
  - Participate in creating a workplace environment that recognises and supports staff who are experiencing grief. Workplace strategies include providing opportunities for staff to formally and informally ‘debrief’ following the death of a resident.

- The facilitator should discuss with participants any policies/procedures related to staff bereavement that are in operation at the specific facility.

Optional Learning Activity: Group Discussion

Instructions:

Ask participants to share and discuss self-care and workplace strategies that they have found useful in addressing loss and grief following the death of a resident. Challenge participants to add new ‘tips’ to those already listed on this flipchart page.

* These notes are for use by the facilitator in preparing for this session.