Three self-directed learning packages

1. **Nurse (Introduction)**

   This learning package introduces the palliative approach to registered and enrolled nurses. Case studies are utilised to work through three key processes (advance care planning, palliative care case conferences and end of life care pathways) and five clinical care domains (pain, dyspnoea, nutrition and hydration, oral care and delirium). The package takes approximately two hours to complete (earning professional development points). This package includes two educational DVDs to assist your learning.

2. **Nurse (Advanced)**

   This learning package extends and further develops the palliative care skills introduced in Self-Directed Learning Package 1: Nurse (Introduction). The package takes approximately three hours to complete (earning professional development points). Those taking on the role of palliative care link nurse within their facility (or any nurse with a particular interest in furthering their palliative care skills) will benefit from completing this package.

3. **Careworker (Introduction)**

   This learning package introduces the palliative approach to care workers (or assistants-in-nursing). Case studies are utilised to work through in three key processes (advance care planning, palliative care case conferences and end of life care pathways) and five clinical care domains (pain, dyspnoea, nutrition and hydration, oral care and delirium). The package takes approximately two hours to complete. This package includes two educational DVDs to assist your learning.
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Nurse (Introduction)
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:

**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.

**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

**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.
SDLP-1

Self-directed learning package: Introductory Registered & Enrolled Nurse

Welcome to this Learning Package about providing a palliative approach to residents in residential aged care facilities (RACFs). This package is part of the PA Toolkit. Completion of this package including the Quiz attracts 2+ hours of continuing professional development points. If you require more information to help you work through this package, the three modules of the PA Toolkit provide additional information.

Aims of this learning package
After working through this package you will be able to:
• describe what a palliative approach is, and identify when a resident is palliative
• understand the process of advance care planning, and how it can benefit the resident, their family and the aged care team
• describe how you as a nurse can contribute to the planning, implementation and follow up of a palliative care case conference
• describe why it is important to know a resident’s cultural background and preferences
• identify common clinical problems in the palliative phase, provide relevant care within the scope of your practice and report issues to a GP or senior nurse as required
• understand the benefits of an end of life care pathway and the role of the nurse during the final week/s of a resident’s life.

What do I have to do?
You will be asked at specific times to watch two DVDs:
• “Suiting the needs” (produced by Palliative Care Australia)
• “All on the same page” (developed specifically for this toolkit).

These DVDs highlight important aspects of the information you will be reading about in this package. Each runs for less than 15 minutes. To complete this package you need access to a DVD player so make sure you have that before you commence.
We will ask you to reflect on the case studies of Bob and Alfred and to take note of important points. Throughout the package you will see these symbols:

**Thinking Point**
Thinking Points indicate that you should stop and think about the information, questions or ideas being presented. We encourage you to write down your thoughts but this is not compulsory.

**Key Point**
Key Points highlight information or an activity that is critical to your learning in this package.

**See, say, do, write, review**
The “see, say, do, write and review” model breaks down clinical care into five key actions. You will see these prompts throughout the learning package:

- **See** – Recognise and assess
- **Say** – Report your assessment
- **Do** – Manage the symptom
- **Write** – Document your actions
- **Review** – Evaluate and reassess as necessary

**Assessment**
At the end of this package are a series of questions that will assist you to demonstrate your understanding of the care of a resident who requires a palliative approach. You are encouraged to talk with your supervisor or education facilitator if you are unsure about anything in this package.

**How long will this take?**
We anticipate it will take you 2 hours to complete the SDLP. This estimate includes viewing time for the two DVDs (approximately 26 minutes).

**Key Point**
Please note for the purposes of this toolkit, nurse will refer to registered and enrolled nurses and careworker will refer to personal careworkers, health careworkers and assistants-in-nursing.

**OK… LETS GET STARTED**
In this first section we will help you answer these questions:

- What is palliative care?
- What is a palliative approach and when is a resident palliative?
- What is advance care planning and how can it help a resident, their family and health care staff?
- What can you do to identify, assess, report and manage dyspnoea?

While watching the DVD you were introduced to Bob and his wife June.

### Key Points

Before reading any further, watch the DVD “Suiting the needs”. We will refer back to scenes throughout this first section, so you may want to take some notes of the DVD’s key messages.

While watching the DVD you were introduced to Bob and his wife June.

### Case Study - Bob

Bob is a 75 year-old retired house painter. Imagine that he was admitted to your RACF just over 12 months ago when his breathing deteriorated and he could not cope at home even with home supports.

Bob has emphysema (chronic obstructive pulmonary disease) and on rare occasions requires oxygen. He has no cognitive memory deficits and is competent to make decisions about his care. Careworkers need to assist him with showering.

He recently was admitted to hospital when his breathing became very difficult. This scared him and he worries that it will happen again.

His wife June has some arthritis but is still able to live independently at home. She visits Bob after lunch almost every day. Bob has one son, William who visits every two weeks.
What is palliative care?

The World Health Organisation defines palliative care as:

An approach that improves the quality-of-life of individuals and their families facing the problems associated with life-threatening illness, through the perception and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. 17

Three forms of palliative care 4,5

Key Points

When you think about a palliative approach for residents in RACFs, it is important to distinguish between a palliative approach, specialist palliative care and terminal care.

A palliative approach

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.

Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying.

Key Points

A palliative approach is not restricted to the last days or weeks of life.
Why is a palliative approach important?
A palliative approach can:
• reduce distress for residents and their families
• reduce transfers to hospital because aged care staff develop skills to manage the palliative care needs of residents
• help to involve the resident and their family in decision making about their care
• encourage open and early discussion about death and dying which helps advance care planning
• provide opportunities for improved control of pain and other symptoms
• allow the resident to be cared for by staff that they know and have developed a rapport with.

Thinking Point
In the DVD, Bob’s careworker, Kerrie, mentions a number of these important benefits. Can you relate these points to the care of residents in your own facility?

• When has open and early discussion on death and dying facilitated a good death for a resident?
• Has a dying resident been transferred to hospital unnecessarily?
• How did this transfer affect the resident, family and staff?

Bob has chronic obstructive pulmonary disease (COPD)/emphysema that is worsening. He has already been admitted to hospital once and has said he doesn’t want this to happen again.

A palliative approach aims to reduce his suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.

Bob needs review of his symptoms particularly his shortness of breath. He also has some psychological and social needs that require discussion with his GP, the nursing staff and his wife.

Thinking Point
So it seems that a palliative approach is appropriate for Bob. Would any of your current residents benefit from a palliative approach?

When does a resident need a palliative approach?
Watching the DVD, you would have heard that a palliative approach is not limited to the last weeks or days of life.

It is a philosophy of care that may be appropriate many months before a resident actually dies and aims to improve the quality-of-life for people with an eventually fatal condition and their families.

Thinking Point
Do you agree that Bob needs a palliative approach to his care? He has been in the facility for over 12 months. Why do you think it is only now being discussed?

Specialist palliative care
In the DVD, Peter, the GP suggested getting a specialist palliative care team to help plan for and treat Bob’s severe breathlessness.

A small number of residents may experience severe or complex problems as their condition advances. These may be physical symptoms or complex ethical dilemmas, family issues or psychological distress.

Specialist palliative care teams do not usually take over the care of residents but instead can provide advice on complex issues and support to GPs and the aged care team.

Terminal care
Whereas palliative care may take place over many months, terminal care is the care focused on the final days or weeks of life.

This form of palliative care is appropriate when the 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 the resident’s physical, emotional and spiritual comfort and support for the family, including bereavement care.

Identifying when a resident is moving into the terminal phase is not easy because there are few clear indicators to identify when a person should be considered for end of life care. (You will read about this in more detail later in this package).
Advance care planning

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

Advances in medical technology have allowed people to survive longer despite many chronic illnesses. It is good news that many of us will live to a very old age, but people often survive with lots of problems. We now have the technology to keep people alive artificially, where in the past, they may have died naturally.

**Thinking Point**
The tough question is just how much invasive or aggressive medical attention is a good thing. The best answer is that it is up to everyone as individuals to decide for themselves. Have you thought about:

- What constitutes quality-of-life for you?
- What types of invasive medical procedures do you consider to be undesirable?
- If you had multiple physical problems, at what point, would you want the doctors to stop trying to prolong your life?
- What are your values and beliefs (religious, spiritual or otherwise)?
- When your time eventually comes, what would constitute a ‘good death’ for you?

Most people never speak about these issues. When people are critically ill, they are usually unable to participate in these important decisions.
Planning ahead

Thinking Point
When do you think discussions with residents and their family members about advance care planning should be conducted? Immediately after admission? After several months? When a resident becomes terminally ill?

Key Point
Advance care planning should be routine practice for every resident soon after admission to a residential care facility. We advocate this being integrated into the assessment and care planning process from admission onwards.

It is not compulsory to have a legal form filled in BUT there should be a focus on discussion and ongoing communication with the resident and family.

A nurse-led care conference is recommended to facilitate this process. We suggest that the residents GP be invited to attend (or at least be made aware of any wishes or decisions regarding advance care planning).

It is never too early to consider, and write down, thoughts and wishes regarding end of life care. In fact, it is preferable to consider these issues clearly and calmly when the matter is not urgent or critical.

Most residential aged care facilities provide residents and family with information about advance care planning on admission. A discussion between the resident (if able), family, nursing and medical staff will often take place about this time. The outcomes of this discussion are recorded in the resident’s file.

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

Writing it down

In the DVD, Bob wanted to make sure that everyone knew that he did not want to be ‘kept alive’ with a ventilator if his breathing condition worsened again. We saw Bob talking with his GP, nurse, wife and careworker about his wishes. He was keen to ‘…get it down in writing’.

Key Point
Having a written advance care plan or directive can improve end of life care and reduce unwanted and unneeded medical treatments and hospitalisations.

Advance directives are legal documents that record the resident’s wishes about their care if they are unable to voice these wishes themselves. They can also appoint a substitute decision maker, usually called a guardian or medical power of attorney.

Key Point
Every Australian State and Territory has different legislation, guidelines and documents for advance care planning, and where they exist, advance directives. The CareSearch website is a good place to start to find out more: www.caresearch.com.au

Table 1 displays an example of part of an advance health directive.
Table 1
Example of an advance health directive form\textsuperscript{10}

| The directions you give in this section apply only if, in the opinion of your treating medical practitioner: |  |
| - you have a terminal, incurable, or irreversible illness or condition, |  |
| - or you are in a persistent vegetative state, |  |
| - or you are permanently unconscious, |  |
| - or your are so seriously ill or injured that you are unlikely to recover to the extent that you can survive without the continued use of life-sustaining measures. |  |

I request that:

- everyone responsible for my care initiate only those measures that are considered necessary to maintain my comfort and dignity, with particular emphasis on the relief of pain.
  
  Initial here:

- any treatment that might obstruct my natural dying either not be initiated or be stopped.
  
  Initial here:

- unless required for my dignity and comfort as part of my palliative care, no surgical operation is to be performed on me.

If I am in the terminal phase of an incurable illness:

- I do not want cardiopulmonary resuscitation. Initial here:

- I do want cardiopulmonary resuscitation. Initial here:

- I do not want assisted ventilation. Initial here:

- I do want assisted ventilation. Initial here:

- I do not want artificial hydration. Initial here:

- I do want artificial hydration. Initial here:

- I do not want artificial nutrition. Initial here:

- I do want artificial nutrition. Initial here:

- I do not want antibiotics. Initial here:

- I do want antibiotics. Initial here:
Does advance care planning have to be a legal process?

It is not compulsory to complete a legal form. Not all residents are willing (or able) to complete a legal document such as an advance directive.

The Good Palliative Care Plan, developed in South Australia is an alternative option. It can be used in any state or territory and while not legally binding provides opportunity for documenting the outcomes of a discussion about the resident’s current condition and goals of care. Table 2 provides a segment of this document.

Table 2
Excerpt from the Good Palliative Care Plan 9

<table>
<thead>
<tr>
<th>Circle one of the options:</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have agreed that in the event of further deterioration in the patient’s condition:</td>
</tr>
<tr>
<td>1. Full cardiopulmonary resuscitation with total body support as required will be undertaken.</td>
</tr>
<tr>
<td>2. Intensive medical support will be undertaken, but cardiopulmonary resuscitation will not be initiated, and no long-term support measures, including ventilation or dialysis, will be undertaken.</td>
</tr>
<tr>
<td>3. The emphasis of management will be on Good Palliative Care, highlighting the relief of symptoms and discomforts. No artificial measures designed to supplant or support bodily function will be undertaken.</td>
</tr>
<tr>
<td>4. Other. Please specify:</td>
</tr>
</tbody>
</table>

What if a resident is no longer able to express their wishes?

Thinking Point

Bob was able to make his own decisions and put these in writing. Unfortunately, not everyone wants to do this or is able to.

- If Bob had advanced dementia and could not express his wishes about future care, what should happen?
- Should Bob be sent to hospital even if his family say it was not what he wanted?

Key Point

If a resident is not competent to make decisions for themselves, they cannot complete an advance health directive or legally appoint someone to advocate on their behalf.

This does not mean that they cannot be involved in discussions about their advance care planning. It is also worthwhile considering the family’s views on what the resident would have wished.

What is my role as a nurse?

Residents and family members often become close to nurses and careworkers and may mention issues related to advance care planning with you. Sometimes what seems like a ‘throw away’ comment e.g. ‘I wouldn’t want to live like that’ may be important to follow up.

Encourage the resident and/or family member to discuss their concerns. Be alert for any ongoing concerns a resident may raise.

Thinking Point

Has a resident or family member ever talked to you about the resident’s end of life care wishes? How did you handle this? Is there anything you would do differently next time?
Dyspnoea

Dyspnoea is an awareness of uncomfortable breathing. It can also be called breathlessness or shortness of breath.

Thinking Point
Have you ever had the experience of not being able to breathe well? Perhaps after a strenuous exercise session? Can you imagine living with that sensation constantly? If you have, what thoughts or feelings come to mind?

The Australian author Tim Winton wrote in his 2008 novel ‘Breath’:  

‘It’s funny, but you never really think much about breathing, until it’s all you ever think about.’

Dyspnoea

- is common but under-recognised
- impairs activities of daily living, limits mobility, increases anxiety, fear and social isolation
- is often associated by residents and family with impending death
- triggers panic, and panic exacerbates dyspnoea, so the pattern becomes cyclical
- may be equally or even more distressing for the family.

So… what can you do to help a resident with dyspnoea?

See

Recognise and assess

As a nurse, you should be able to complete and document a comprehensive baseline assessment of any resident who presents with dyspnoea.

Review previous medical history

- pre-existing illnesses e.g. COPD
- exacerbating factors e.g. anaemia or profound anxiety
- additional factors e.g. pulmonary embolism, infection or left ventricular failure.

Associated symptoms

- cough
- sputum
- haemoptysis (blood in sputum)
- wheeze
- stridor
- pleuritic pain
- fatigue
- anxiety or panic.

What makes it better or worse?

Observe or ask the resident:

- physical activity?
- posture?
- environmental factors? (e.g. room sprays, pollen)
- emotional factors? (e.g. anxiety, excitement, fear)
- others?

Key Point

Dyspnoea is not so much about how fast or slow, deep or shallow someone is breathing. Rather it is a subjective feeling that everyone experiences differently.
Because health professionals often under-report dyspnoea the resident should be encouraged to rate the severity themselves (if able to do so).

**Severity**

Use a verbal rating scale.

Ask: “On a scale of zero to 10, with zero meaning no breathlessness and 10 meaning the worst breathlessness possible, how much breathlessness do you have right now?”

**Please note**

While dyspnoea is the term health professionals use, it is better to refer to it as breathlessness when talking to residents or family members.

**Timing**

- chronic or intermittent?
- when does it occur?
- how long does it last (duration) and how often does it occur (frequency)?
- interval between episodes?

**Quality-of-life issues**

Ask about:

- impact on mobility
- impact on social isolation
- coping strategies (behavioural and emotional).

### Say

**Report your assessment**

As a nurse you play a critical role in reporting resident’s clinical issues to medical staff.

Try and provide as much information as possible when reporting to the GP. This will allow them to decide how urgently they need to review the resident.

### Thinking Point

If careworkers reported that Bob was always tachypnoeic when walking to the dining room and unable to sustain a conversation, how would you report this to the GP? Which of the following would be most effective?

**Nurse to GP:**

‘Bob is reporting dyspnoea on exertion for the last three days. He says it is moderate when walking the 20 metres to the dining room, usually 5/10. Given five minutes of rest it resolves slowly. We are taking him down in a wheelchair until he can be reviewed. He is not febrile and has no chest pain, wheezing or other symptoms’.

**OR**

‘Bob has been short of breath lately. Please come and review him’.

### Do

**Manage the symptom**

### Thinking Point

Consider the following scenario:

Bob becomes breathless whenever he has a shower. Usually he has to sit and rest for an hour or more afterwards before he feels well enough to carry on with his daily activities.

How might you help Bob manage his breathlessness?

### Key Point

Residents with dyspnoea benefit from having a preventative plan of care. That is, we use management strategies to prevent the onset, or reduce the impact of, the anxiety and distress of dyspnoea.
Here’s some examples of simple measures:

• Bob might be prescribed a small dose of opioid medication (e.g. morphine) at least ½ hour before showering. Ask the careworkers to let you know when he is showering so you can give the medication at the correct time. (Morphine can be effective for breathlessness as well as pain).
• Try not to rush or hurry Bob and allow rest periods during activities (this decreases his need for oxygen and reduces anxiety).
• Encourage careworkers to leave the exhaust fan on in the bathroom and make sure the shower water is deflected away from his face (prevents claustrophobia).
• When Bob returns to his room, sit him upright in a chair, perhaps leaning with his arms over a table or overway table (opens up his chest/lung space to allow more air in).
• Open a window or use a fan to circulate air (for the feeling of moving air).

Oxygen

Thinking Point
Did you notice that oxygen therapy is not mentioned in the list of management strategies? Does this surprise you?

Key Point
Few residents with dyspnoea actually benefit from oxygen therapy.
Oxygen is often considered to be a non-specific treatment for dyspnoea, however:
• Individuals can become highly dependent on oxygen supplementation to the extent that some people consider it to be their ‘lifeline’.
• Just because Bob is short of breath does not mean that he is hypoxaemic (measured with pulse oximetry) and needs oxygen.
• Oxygen may be indicated if Bob’s oxygen saturation (SaO2) is persistently <90% at rest, or on minimal exertion (e.g. dressing, getting out of bed).
• However starting (or changing flow rates) oxygen therapy may be dangerous for some residents.
• Unless in an emergency situation, commencement of oxygen should only be undertaken under the direction of a medical practitioner.

Targeted therapies

Targeted therapies may be appropriate for Bob depending on his prognosis and cognitive state.

If anxiety and panic is a problem and does not respond to the simple measures already discussed, benzodiazepines may be prescribed as a short term anxiolytic.

Thinking Point
What if Bob’s dyspnoea was not responsive to any simple or pharmacological measures listed here?

Sedation may be the only option in these circumstances. This is a challenging situation and significant consultation would normally take place between the resident, their family, GP and nursing staff.
Write

Document your actions

Document enough information to allow others in the multidisciplinary team a clear picture of the clinical situation.

Avoid general statements

<table>
<thead>
<tr>
<th>POOR COMMUNICATION</th>
<th>GOOD COMMUNICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluation of interventions ‘with effect’ or ‘effective’.</td>
<td>‘Resident states dyspnoea has reduced to 2/10 score (was 5/10)’.</td>
</tr>
</tbody>
</table>

Note to GP

‘Please review Bob ASAP re dyspnoea’.

‘Careworkers report Bob is reporting dyspnoea on exertion for the last three days. He reports severity = moderate (5/10) when walking 20 metres to the dining room. Relieved by resting for 5mins. Careworkers wheeling him down in chair until he is reviewed. Afebrile, no chest pain, wheezing or other symptoms’.

Review

Evaluate and reassess as necessary

Thinking Point

You identified that Bob is breathless and conducted an assessment.

You made sure careworkers implemented the simple measures you had documented on the care plan.

There is appropriate medication ordered if necessary (opioids) and you have spent some time addressing Bob’s anxiety about his breathing. Great job!

Can you tick this off your list? Not quite yet.

There is an important question to answer:

Did your strategies work?

You can check the effectiveness of your management strategies by asking the resident to rate the severity of their dyspnoea again (using a rating scale), observing their breathing rate, or asking if their mood, sleep or function has improved.

Key Point

Remember, assessment of any clinical problem is an ongoing process rather than a single event.

Undertaking a formal, scheduled assessment may be more valuable than frequent, brief impressions.

SUCCESS!

You have completed Section 1 of the learning package.

You may decide to pause now and answer the first six questions of the quiz at the back of this learning package.

Avoid general statements

POOR COMMUNICATION

Evaluation of interventions ‘with effect’ or ‘effective’.

Note to GP

‘Please review Bob ASAP re dyspnoea’.

GOOD COMMUNICATION

‘Resident states dyspnoea has reduced to 2/10 score (was 5/10)’.

‘Careworkers report Bob is reporting dyspnoea on exertion for the last three days. He reports severity = moderate (5/10) when walking 20 metres to the dining room. Relieved by resting for 5mins. Careworkers wheeling him down in chair until he is reviewed. Afebrile, no chest pain, wheezing or other symptoms’.
In this section we will help you answer these questions:

- How can nurses contribute to the planning and successful outcomes of a palliative care case conference?
- Why is it important to know a resident’s cultural background and preferences?
- What can you do to identify, report and manage four common clinical issues (pain, nutrition and hydration, oral care, and delirium)?
- What are the benefits of, and how do you initiate an end of life care pathway?
- What is the role of the nurse during the final days/weeks of a resident’s life?

**Case Study - Alfred**

Alfred is 82 years old and a retired school teacher. Alfred has two children: Andrew who lives overseas and Sarah who lives close by and visits twice weekly.

Alfred’s wife Alice was admitted to hospital after a severe stroke and remained there, fed through a gastrostomy tube until she died three weeks later of pneumonia.

After Alice died, Alfred remained at home for nine months with increasing support from home care services. Numerous falls and increasing difficulty with activities of daily living led to admission 18 months ago to a residential aged care facility.

Alfred was a heavy smoker until aged 65 but has not smoked since.

He has osteoporosis, osteoarthritis and fractured his hip three years ago.

He is experiencing short term memory loss but not enough to lose his ability to make decisions. Alfred also has chronic obstructive pulmonary disease (emphysema) and is unable to walk 20 metres before needing to rest. He has been admitted to hospital three times in the last six months for infective exacerbations of this condition requiring steroids and antibiotics. Alfred has not returned to his previous functional level after each episode.
Palliative care case conferences

Thinking Point
In the DVD “All on the same page”, Alfred participated in a palliative care case conference.

- Why has a palliative care case conference been arranged for Alfred?
- What are the main reasons for having a palliative care case conference?
- When is the most appropriate time during Alfred’s stay to have a palliative care case conference?

What is a palliative care case conference?

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

The aims are to:

- identify clear goals of care for the resident including a review of any advance care plans
- provide a safe environment where issues and questions about end of life care can be raised and appropriate strategies agreed upon for future care.

When should a palliative care case conference be held?

There is no right or wrong time for a palliative care case conference. However, we recommend using the following markers to help decide:

- 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 care or palliative care.
What is a palliative care link nurse?

A palliative care link nurse (or champion) agrees to take on a special role, promoting and facilitating a palliative approach within the RACF. A link nurse may:
- promote and model the palliative approach
- coordinate the implementation of the PA Toolkit
- act as the ‘link’ person for external providers (e.g. GPs, specialist palliative care services, allied health, clergy)
- assist with auditing or quality improvement processes
- conduct in-service training for staff.

Who organises a palliative care case conference and who should attend?

Alfred’s daughter Sarah, Alfred’s GP, and a nurse and careworker from the facility attended Alfred’s palliative care case conference. The nurse organised and facilitated the conference.

Attendees may vary depending on what is being discussed and who is available. However the following people should be considered:

- resident (if capable)
- legal decision maker/medical power of attorney
- family members
- residential facility staff including a nurse and careworker
- allied health e.g. speech pathologist, occupational therapist, physiotherapist, social worker, dietician
- clergy or pastoral care worker
- specialist palliative care nurse or GP

A palliative care case conference may take a few weeks to organise. It is usually organised by a nurse from the residential facility, often a palliative care link nurse.
In the DVD “All on the same page” a careworker attended the case conference. She was able to describe important aspects of Alfred’s care of which the nurse may not have been aware.

**Key Point**
Careworkers often notice important changes in a resident’s mood, ability to function, swallow, walk, breathe etc. Residents may say things to careworkers that are important for other care providers to know.

**What is the nurse’s role in a palliative care case conference?**

**Key Point**
As a nurse, you may be asked to:
- assist to organise and/or attend a palliative care case conference
- seek information from family members and/or care staff about any questions or information they would like discussed
- collect or collate information before the case conference such as clinical records, medication charts, advance directives etc.

**Thinking Point**
In the DVD “All on the same page”, Penny, a palliative care link nurse attended the case conference. She not only facilitated the process but also provided an update from the nurse’s perspective.

Think about a resident you have recently cared for that requires a palliative approach. What information would be important to mention from a nurse’s perspective?

If you are asked to organise or facilitate a palliative care case conference, there is a planning checklist and facilitators guide in Key Processes (Module 2) of the PA Toolkit.

**What happens in a palliative care case conference?**

The DVD demonstrated the process clearly:
- introductions
- clarify the goal of the meeting
- determine what the resident/family already knows
- review current clinical status, prognosis and treatment options
- discuss the resident’s wishes about their future care (if known)
- deal with any conflict
- summarise consensus, disagreements, decisions and plan
- schedule follow-up meetings as needed.

**Key Point**
It is particularly important to document the key issues and outcomes of the palliative care case conference.

Equally, it should be clear who is responsible for actions/tasks and when they are expected to be resolved or completed.
Cultural considerations

Thinking Point
What if, instead of being of Australian descent, Alfred was from another country and spoke very little or no English?
How might this affect his care?

Australia has a diverse, multicultural population. Over 22% of Australia’s population was born overseas, representing over 200 different countries. Residents and family members from culturally and linguistically diverse (CALD) populations may have particular needs related to end of life care.

Key Point
Having said this, do not make assumptions about cultural needs based on a resident’s language, religion or country of origin. All residents from a CALD background require careful assessment.

Here’s some useful tips for getting it right:

- Do not hesitate to ask about relevant cultural aspects of caring for a resident.
- Be aware of customs that show respect.
- Respect that people have different reactions towards death e.g. for some Indigenous Australians speaking the name of a deceased person can cause considerable stress.
- Communicate in ways that are appropriate e.g. avoid the use of jargon and translate information into terms the family and resident can understand.
- Just because someone can understand spoken English does not mean they can automatically read it as well.
Pain

Key Point
Pain is a subjective experience, occurring when and where the resident says it does.
The way that residents experience and make sense of pain is strongly influenced by their previous experiences of pain, culture, spiritual beliefs, social relationships and other physical symptoms they may be experiencing.

See

Recognise and assess
As a nurse, you have an important role in identifying and assessing pain.

Thinking Point
Alfred has osteoporosis, osteoarthritis and fractured his hip three years ago. He is often heard asking careworkers and nurses if it is time for his next dose of pain medication. He asks for assistance with most activities of daily living because the pain is “terrible”.

• What is the best way to assess Alfred’s pain?
• How do you normally identify if a resident has pain?
• Do you use an assessment tool? Do you write down what a resident says?
If the resident can communicate

Ask the resident if they have any pain.

**Key Point**
If pain has been identified, use the Modified Resident’s Verbal Brief Pain Inventory (M-RVBPI) for an initial comprehensive overview of the resident’s pain.

It has been developed specifically for use in residential aged care facilities (see Module 3).

**Tips:**
- Older people may deny that they are experiencing ‘pain’. Try using other terms like ‘ache’, ‘soreness’ or ‘discomfort’.
- Most pain in older people is related to activity. Ask about pain when they are active e.g. moving, transferring, being turned in bed, not when they are at rest.
- Allow enough time for the resident to think about the question and reply.
- Ask more than one question: ‘does it hurt anywhere?’, ‘do you have any aching or soreness?’, or ‘do you have any pain or discomfort’?

Severity of pain can be assessed by asking the resident to rate their pain on a zero to ten scale where zero is no pain and ten is the worst imaginable.

If the resident cannot communicate or has a cognitive deficit

One of the most difficult aspects of caring for the resident who cannot communicate or is cognitively impaired is identifying whether they are experiencing pain.

**Thinking Point**
What would happen if Alfred was unable to communicate his pain?

How would you know if he was experiencing pain?

How would you know if a treatment to manage the pain had been effective?

Do you use a pain assessment tool for residents who cannot communicate?

**Key Point**
The most effective method to assess pain in residents who cannot communicate is to observe behaviours and facial expressions.
Say

Report your assessment

Try and provide as much information as possible when passing on clinical information to a GP or senior nurse. This will allow them to decide how urgently they need to review the resident.

Thinking Point

Think of a resident you have cared for with advanced dementia or a communication deficit whom you thought might be experiencing pain. Have you observed any of the following?

- whimpering, groaning or crying
- looking tense, frowning, grimacing, looking frightened
- increased confusion, refusing to eat, alteration in usual behaviour patterns
- perspiring, flushed or pale skin, abnormal temperature, pulse or blood pressure
- skin tears, pressure areas, arthritis, contractures, previous injuries.

These pain behaviours and physical cues are measured in the Abbey Pain Scale. We recommend the use of this scale for people who are unable to communicate (see Module 3).

Thinking Point

Which of the following do you think will get the best response?

Nurse to GP:

‘Alfred is reporting a new pain in his right hip. He says it is severe, usually 5/10 but walking increases this to 8/10. It wakes him at night if he rolls over in bed. We have tried hot packs, massage and regular simple analgesia but it is no better’.

OR

‘Alfred has got pain. You need to see him to sort it out’.
**Do**

**Manage the problem**

**Non-pharmacological therapies**

**Key Point**
Combining pharmacological and non-pharmacological treatment strategies is more effective than a single approach.

**Non-pharmacological**
It may be possible to manage a resident’s pain with some simple yet effective interventions.

**Thinking Point**
When you are developing or reviewing a resident’s pain care plan, consider if it provides enough direction for careworkers on:

- **Positioning:** Is the resident lying or sitting in a comfortable position?
- **Manual handling:** Are position lifters and other equipment positioned to prevent pain? Does the resident have to twist or stretch their joints or muscles abnormally when being transferred?
- **Complementary and alternative medicine:** What therapies or strategies might help manage the pain other than medication?

**Pharmacological therapies**

As a nurse, you are responsible for the medications you administer. It is vital that you understand the general principles and pharmacology of managing pain.

**Key Point**
Consult “Therapeutic Guidelines: Palliative Care” for additional and comprehensive prescribing recommendations.

Version 3 of these guidelines is included in the PA Toolkit.

**Basic principles**

**By mouth**
Prescribe and administer analgesia by the oral route unless the resident has a pre-existing condition that makes this impractical e.g. ongoing nausea, vomiting, bowel obstruction or dysphagia, general functional decline.

**By the clock**

- It is better to administer analgesia regularly (around the clock) for baseline pain than wait for the resident to ask for it or as you consider it necessary.
- Short acting ‘as required’ PRN medications should be reserved for breakthrough doses of analgesia or if the pain is intermittent and predictable (incident pain).
- Administer analgesia 30 minutes before activities thought to provoke or exacerbate pain e.g. pressure area care, wound dressings, physiotherapy, and hygiene procedures.

Consider the use of superficial heat or a TENS unit.

*Please note*

Superficial cold is not indicated for pain in the elderly.²
By the ladder

Proceed from a non-opioid, to a weak opioid, and then to a strong opioid, with adjuvant medications added as needed at any stage.

**Thinking Point**

Imagine Alfred presents with a new pain in his hip that he rates as severe.

Do you think it reasonable to start him on a simple analgesic first then move up to a stronger more potent opioid over time?

**Key Point**

It is not necessary to start at the bottom of the ladder. Consider the presenting pain severity reported by the resident.

**Opioids**

- Start with low doses of short acting opioids and titrate up slowly after evaluating its effect on pain scores until satisfactory relief is achieved.
- Only then should sustained/controlled release preparations be commenced e.g. oxycodone (Oxycontin), morphine (MS Contin, Kapanol), buprenorphine (Norspan) or fentanyl (Durogesic).
- Do not use sustained/controlled release preparations for acute pain or breakthrough dosing.

**Key Point**

The parenteral dose of morphine is approximately one-third of the oral dose.\textsuperscript{12,13}

If a resident was taking 30mg oral morphine/24hrs but now cannot swallow, they would only need approximately 10mg parenteral/24hrs to have an equianalgesic effect.

**Figure 1**

The World Health Organisation (WHO) analgesic ladder for pharmaceutical treatment of pain\textsuperscript{16}
Myths about opioids

Spend time with the resident or family to dispel common myths about opioids. Sometimes residents, family members and even aged care staff may have concerns about these medications.

It is important to know that, when used correctly, opioid medicines:

**Do not lead to addiction or dependence**

Opioid medicines are not addictive when used for pain. Addiction only occurs when people have no pain and they abuse opioid medicines.

**Do not hasten death**

Morphine and other opioid medicines are for improving life — not hastening death. Some people fear that being prescribed opioid medicines means that they’re closer to the end. However, relieving pain changes the quality-of-life — not its length.

**Do not cause terrible side-effects**

All medicines can have side effects. The side effects of opioid medicines (constipation, drowsiness, nausea, dry mouth) are usually manageable.

Side effects of opioids can often be anticipated and treated or avoided

Changing to another opioid or another route of administration may be necessary if still troublesome.

Adjuvant analgesics

Alfred not only takes regular paracetamol and a weak opioid for his pain, he is also prescribed a tricyclic antidepressant for his sciatic pain.

This and other medications such as corticosteroids, anticonvulsants and benzodiazepines can supplement analgesics or control symptoms that can exacerbate the perception of pain (e.g. inflammation, oedema, anxiety etc.)

---

**Review**

**Evaluate and reassess as necessary**

**Thinking Point**

You identified that Alfred has pain and conducted an assessment. You’ve updated his care plan to reinforce appropriate manual handling techniques and some massage at night. This morning you discussed with Alfred’s GP about a regular analgesic order. Great job!

*Can you tick this off your list? Not quite yet. There is an important question to answer: Did your strategies work?*

A formal scheduled review using the Modified Resident’s Verbal Brief Pain Inventory (M-RVBPI) or Abbey Pain Scale may be more valuable than frequent, brief impressions. 

---

**Write**

**Document your actions**

**Avoid general statements**

**POOR COMMUNICATION**

Evaluation of PRN analgesia ‘with effect’ or ‘effective’.

Note to GP ‘Please review Alfred ASAP re pain in hip’.

**GOOD COMMUNICATION**

‘Resident states pain has reduced to 2/10 score (was 5/10).’

‘Alfred has a new pain in R) hip. Says its severe, average 5/10, walking = 8/10. Wakens him at night if he rolls over in bed. Have tried hot packs, massage and regular simple analgesia so far but no better’.

---
One of the big worries that Alfred’s daughter, Sarah, had at the palliative care case conference was that Alfred might starve to death if he is unable to eat and drink. Remember that Sarah’s mother was fed through a gastrostomy tube after she had a stroke. This continued for three weeks before she died of pneumonia.

**See**

**Recognise and assess**

Alfred is drowsy and needs prompting to accept a drink from a cup and straw.

He only eats a few mouthfuls of food and sometimes coughs when he swallows. Alfred is dying and this is causing his eating and drinking problems. This is often a difficult and emotional time for families and can sometimes be hard for staff to manage.

**Key Point**

At the end of life the body is beginning to shut down because of the dying process, not because of the absence of food and fluids.

Family members often find it difficult to distinguish between ‘not eating as part of the dying process’ and ‘not eating as bringing about the dying process’. 
Biochemical tests
Biochemical tests can assist in determining the cause of a potentially reversible dehydration.

Thinking Point
Alfred is in the terminal stage and appears dehydrated. Palliative care is often about rationalising and reducing the number of invasive or burdensome tests and procedures so why consider blood tests now?
Alfred was always clear that he did not want artificial nutrition or hydration at the end of life. Determining that he is clinically dehydrated or has an electrolyte imbalance will not change the focus on quality-of-life measures and symptom management.

Key Point
Only investigate something if the result will change the care being provided.

Key Point
Fluid intake charts alone are not recommended for assessing dehydration. They are not an accurate way of determining dehydration unless they also take into account urine output, perspiration and other fluid losses.

Helping families understand
The PA Toolkit contains a brochure “Understanding the Dying Process” which can be given to family members when the resident is in the palliative or terminal phase.
Table 3 provides a brief segment from the “Understanding the Dying Process” brochure. This brochure is included in the PA Toolkit and we recommend you familiarise yourself with the document.

Table 3
Segment from “Understanding the Dying Process” brochure
Most people lose their appetite in the last few weeks of life. This is a very natural and normal part of the dying process because metabolism is slowing down and the body requires less nutrition.
At this time your instincts may be to try and feed the person in order to keep up their strength. The giving of food is often symbolic of loving and nurturing and to deprive someone of this may feel like neglect. However, as the person becomes increasingly weak and drowsy, swallowing and digesting food and fluids often becomes harder and can place strain upon the body.
Whilst the person may have a reduced oral intake, it is important to maintain good oral care. Regular moistening of the mouth and lips will add to the person’s comfort.

Say
Report your assessment

Thinking Point
Which of the following do you think will get the best response?
Nurse to GP:
‘Alfred reports that he has had trouble swallowing for a few days. Careworkers observed that he was coughing when eating his cereal this morning’.
OR
‘Alfred is having problems eating’.
Do

Manage the problem

Diligent hand feeding and offering drinks frequently is important for all residents. If Alfred becomes unable to swallow, staff should cease offering food and drink, instead focusing on excellent mouth care. When a resident cannot swallow food or fluids by themselves, it is possible to provide these by artificial means such as through a tube (PEG tube) or SC (subcutaneous cannula) ‘drip’.

Decision making

There is no simple answer to whether these interventions are right or wrong. The benefits of artificial nutrition or hydration need to outweigh the potential burden and side effects for the resident. Residents and family members cannot make the best decisions if they do not have enough information. Conversations with the nurse and doctor about the positive and negative aspects of artificially providing food or fluids are very important at this stage.

Artificial nutrition

Key Point

For residents requiring a palliative approach, there is limited evidence that tube feeding prolongs life, improves comfort or quality-of-life, prevents aspiration pneumonia, leads to better nourishment or decreases the risk of pressure sores.

Although artificial hydration can be useful to treat reversible causes of dehydration such as over treatment of diuretics, unintended sedation from medications or recurrent vomiting or diarrhoea, it is not normally used when a resident is expected to die within 48 - 72 hours.

Thinking Point

Think about how you feel when you have to talk in front of people at a function or event? Do you get a dry mouth?

Having a drink makes you feel better because it moistens your mouth

Similarly, moistening the mouth of a resident who can no longer swallow fluids will keep them comfortable as much as or more so than a ‘drip’.

Thinking Point

Alfred is unconscious and you would not be surprised if he dies in the next two to three days. A careworker is upset that Alfred cannot drink. He says ‘How bad must it be for Alfred being so dehydrated, he should have a saline drip’.

Do you agree with his comments?

Key Point

Medication side effects, oxygen therapy and mouth breathing can cause a dry mouth. Artificial hydration does not usually relieve the feeling of dry mouth and can actually worsen respiratory secretions, incontinence, vomiting, swelling (oedema) or breathing difficulties.

You will learn more about the importance of oral care in a later section of this learning package.

Artificial hydration
**Write**

Document your actions

Document enough information to allow others in the multidisciplinary team a clear picture of the clinical situation.

Avoid general statements

<table>
<thead>
<tr>
<th>POOR COMMUNICATION</th>
<th>GOOD COMMUNICATION</th>
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<tbody>
<tr>
<td>'Evaluation of artificial hydration'.</td>
<td>'Resident denies thirst or discomfort, mouth moist and intact, urinary output still moderate'.</td>
</tr>
</tbody>
</table>

**Review**

Evaluate and reassess as necessary

Just because artificial nutrition or hydration has been started does not mean that it should be continued until the resident dies.

- Artificial nutrition or hydration needs to be reviewed regularly to ensure it is still the most appropriate intervention for the resident.
- If artificial hydration is commenced, clear criteria and timelines for evaluation need to be documented.
- At the end of life assessment should occur daily. What may have been appropriate a week ago may not be if they are now likely to die in the next 48-72hrs.
The ageing process, even when uncomplicated by illness, creates changes in the body which may combine to decrease oral health. As a resident approaches the end of their life, especially when they stop eating or drinking, oral care becomes even more important.

**See**

**Recognise and assess**

Nurses need to complete and document a comprehensive baseline assessment of the resident’s oral cavity using the Oral Health Assessment Form (see Module 3).

**Key Point**

Careworkers should be directed to check a resident’s oral cavity at least daily for problems and report them to a nurse. E.g. whenever assisting with feeding, providing fluids, or conducting mouth care.

Potential problems may include:

- bad breath
- sore mouth and gums
- lip blisters/sores/cracks
- difficulty eating
- broken teeth
- bleeding gums
- reports of pain in mouth/lips
- tongue coated or abnormal colour
- excessive food left in mouth
- mouth ulcer
- refusing oral care
- swelling of face/mouth
- dentures broken/lost.\(^{11}\)

Dry mouth (xerostomia) is the most common oral problem at the end of life.\(^ {11}\)
Say

Report your assessment

Residents get the best outcomes when you provide clear information about the resident.

Thinking Point

Which of the following do you think will get the best response?

Nurse to GP:

‘Alfred has a very dry mouth and oral candida. It seems to have become worse since commencing opioid analgesics last week. He has candida on his tongue and in the corners of her lips. Please review him for some anti fungal medication. We will continue with frequent oral care’.

OR

‘Alfred has problems with his mouth. You better take a look’.

Do

Manage the problem

The best clinical outcomes will be achieved if care plans are developed after careful assessment of the resident’s oral cavity.

Thinking Point

Alfred’s medications cause a dry mouth, he occasionally uses oxygen and often sleeps with his mouth open. He has a ‘sore’ spot on his gum and his tongue is coated. What could you do to help Alfred with his dry mouth?

Dry mouth (xerostomia)

- moisten oral cavity with frequent rinsing and sipping of water
- apply water-based moisturiser to lips
- discourage strong cordials, juices or sugary drinks
- reduce caffeine intake
- stimulate saliva with tooth friendly lollies
- encourage resident to drink water after meals, medications and other drinks and snacks
- use saliva substitutes such as a water spray or an oral balance gel or liquid. ¹¹

Pain or ulceration

- help the resident to rinse or swab their mouth with warm saline three to four times a day until resolved
- check the fitment of dentures
- avoid spicy or acidic foods or food with sharp edges
- offer cold, soft food
- local or systemic analgesics may be required
- medical review if not resolved within seven days. ¹¹

Coated tongue, mucosa or teeth

- remove debris with a soft toothbrush or mouth swab
- help the resident to rinse or swab their mouth with warm saline three to four times a day until resolved
- brush tongue gently with soft toothbrush. ³
Oral care in the final days of life

In the final scenes of the “All on the same page” DVD, Alfred has only hours or days left to live. He cannot swallow food or fluids, is very drowsy, and breathes through his mouth. His tongue and lips are dry.

Thinking Point
Think about when you have a dry mouth. When you moisten it with water, how long does it take until the dryness returns? Not very long? Perhaps five minutes?
Imagine you are Alfred who relies on you to provide this comfort measure for him.

As a resident approaches death they lose the ability to feed themselves or have a drink. Eventually swallowing becomes difficult and unsafe. Functionally they cannot clean their teeth or oral cavity by themselves. Often this is when a ‘mouth care’ trolley or tray is seen in the resident’s room.

Key Point
Every time you attend to a resident:

Apply dry mouth products: e.g. water spray, oral balance gel or liquid via mouth swabs.

Apply water based lip moisturisers: Do not use petroleum based products (e.g. vaseline) as they can increase the risk of inflammation and aspiration pneumonia; also contraindicated during oxygen therapy.¹¹

Key Point
Some preparations may damage oral tissues or increase the risk of infection.

Do not use mouthwashes and swabs containing:
• lemon and glycerine
• sodium bicarbonate (high strength)
• preparations containing alcohol (Listerine mouthwash) or hydrogen peroxide
• pineapple or other acidic fruit juices.¹¹
**Write**

**Document your actions**

Document enough information to allow others in the multidisciplinary team a clear picture of the clinical situation.

**Avoid general statements**

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Evaluation of interventions ‘with effect’ or ‘effective’.</td>
<td>‘Resident commenced two days ago on antibacterial and topical analgesic therapy for mouth ulcer in upper right side of oral cavity. Ulceration almost healed. Tolerating more solid foods’.</td>
</tr>
</tbody>
</table>

**Review**

**Evaluate and reassess as necessary**

*Thinking Point*

You identified that Alfred cannot swallow anymore and documented a risk assessment. When you enter his room, you always swab his mouth and apply lip balm. Great job! Can you tick this off your list? Not quite yet.

There is an important question to answer: Did your strategies work?

You can check the effectiveness of your management strategies by checking Alfred's mouth (as detailed in the SEE section previous).

Encourage careworkers to report any concerns to nursing staff.
Delirium in older people is often overlooked or misdiagnosed, especially at the end of life. It can be distressing not only for the resident but for family and health workers.

**Thinking Point**

When you started your shift Alfred was his usual self, quite alert with only minor memory impairment. Towards the end of your shift you notice Alfred has become very drowsy. He is mumbling nonsense about “catching chickens” and keeps trying to get out of bed. He cannot tell you where he is and does not recognise his daughter when she comes in to visit. Three days ago he was diagnosed with a urinary tract infection.

- Which of the information above indicates that Alfred may be suffering a delirium?
- What might have caused Alfred to become confused?

Delirium is a condition where:

- the resident’s behaviour and thinking is disorganised
- they struggle to focus, sustain or shift their attention
- sometimes (but not always) hallucinations or delusions are present
- it can develop over a short period of time and generally fluctuates during the course of the day. ¹⁴

Delirium usually only lasts for a few days but may persist for weeks or even months. ¹⁴

Dementia on the other hand is a long term impairment of thought processes (cognition) with clear consciousness.
Use the Confusion Assessment Method (CAM) tool to help determine if a resident’s symptoms are likely to be caused by a delirium. A copy of this tool can be found in Module 3.

Delirium can be caused by a combination of factors including dehydration, medication side effects, uncontrolled pain and infections.

Consider possible causes
Delirium is often caused by a combination of factors including:
- medications
  - e.g. opioids (especially with renal impairment), tricyclic antidepressants, benzodiazepines, corticosteroids
- any drug with anticholinergic activity
- drug withdrawal
  - e.g. opioids, alcohol, nicotine, benzodiazepines
- metabolic
  - e.g. dehydration (diuretics use, hot weather), hypoglycaemia, hypercalcaemia
- urinary retention or constipation
- infections (especially chest infection, urinary infection with indwelling catheter)
- kidney or liver failure
- sensory impairments
- uncontrolled pain.

Say
Report your assessment
Be as clear and detailed as possible.

Thinking Point
Which of the following do you think will get the best response?

Nurse to GP:
‘Albert is confused, agitated and distressed. He can see spiders on the walls, is plucking bed sheets with his hands and is disoriented in time and place.
He has had more opioid breakthrough analgesic doses than usual today and is febrile 37.9 deg.
His urine from IDC is malodorous’.

OR
‘Alfred is confused. You need to see him to sort it out’.
Do

Manage the problem

It may be appropriate to treat the cause of delirium (if it is known). However, at the end of life simple measures aimed at managing the symptoms may be preferable.

Thinking Point
Imagine you are Alfred. It is night-time and you are lying in your bed. It is dark, no one is around and you are confused, frightened and not sure where you are. You hear noises outside your door that sometimes disturb you. Perhaps you want to get out of bed to find somewhere better to be.

Look at the list below. Which of these measures might help you feel less confused and anxious?

Environmental strategies
- appropriate lighting
- minimise noise especially at night
- provide a clock that the resident can see
- avoid room or location changes and keep personal and familiar objects in view
- modify the environment to minimise the risk of injury e.g. low bed in the lowest position with cot sides down, bed against the wall, potential hazards such as beside tables removed.

Clinical strategies
- address anxiety; residents with delirium are often very frightened
- manage discomfort or pain
- minimise sensory deficits by providing and assisting with hearing and visual aids e.g. clean spectacles and remove wax deposits in hearing aids, check batteries are fresh and hearing aid is turned on
- encourage the presence of people known to the resident e.g. family and friends and regular staff members
- reassure and reorientate resident
- explain delirium and reassure the resident and their family
- AVOID use of physical restraints
- use interpreters and communication aids for residents with Culturally and Linguistically Diverse needs (CALD)
- promote relaxation and sufficient sleep e.g. assisted by massage and/or encouraging wakefulness during the day
- minimise use of indwelling catheters
- review medication e.g. cease or reduce all non essential medications, swap to a different opioid analgesic medication.

Medications
The primary aim is to reduce the resident’s distress by targeting any agitation or hallucinations.

Antipsychotic drugs such as haloperidol, risperidone or olanzapine are considered first line therapy.

Benzodiazepines do not improve cognition but may help associated anxiety. Short acting agents such as lorazepam or midazolam are usually indicated.

Key Point
Benzodiazepines may worsen delirium if not used in combination with an antipsychotic drug.

Sometimes agitation and delirium can cause severe distress and does not respond to medical management, especially in the terminal phase. This is a challenging problem and may require sedation as the only appropriate intervention.

Key Point
Consult “Therapeutic Guidelines: Palliative Care” for additional and comprehensive prescribing recommendations.

Version 3 of these guidelines is included in the PA Toolkit.
**Write**

**Document your actions**

Document enough information to allow others in the multidisciplinary team a clear picture of the clinical situation.

**Avoid general statements**

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<td>'Resident has not reported hallucinations in the last two hours and physical plucking at the bed sheets has stopped'.</td>
</tr>
</tbody>
</table>

**Review**

**Evaluate and reassess as necessary**

It is important to evaluate the effectiveness of the care you deliver to residents.

Every time you provide care to a resident, ask yourself:

• Does it seem to be effective?
• Is it doing any harm?

**Key Point**

Delirium can develop quickly, regular assessment is important.

Regular use of the Confusion Assessment Method (CAM) tool may be more beneficial than frequent brief subjective impressions.
End of life care pathway

Terminal care is care focused on the final days or weeks of life.

**Thinking Point**

In the final scenes of the DVD, Alfred is likely to die within days or hours.

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

Residents may experience some or all of the following when approaching death:

- 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.

**What is an end of life care pathway?**

An end of life care pathway is a set of forms and protocols that acts as a ‘road map’ to guide the care provided by doctors, nurses and careworkers in the last week of a resident’s life.

There are several pathways used in RACFs and hospitals. We recommend the ‘Residential Aged Care End of Life Care Pathway (RAC EoLCP)’. This pathway can be downloaded from http://www.health.qld.gov.au/pahospital/services/pal_care.asp
Thinking Point

Alfred looks like he may die in the next day or so. He is not eating and drinks only a few sips of water each shift. He spends most of the time sleeping and needs assistance with all of his ADLs. When he is asked a question he sometimes opens his eyes but does not speak. This has been a significant change for the worse from one week ago.

Do you think he is displaying signs of approaching death?

Key Point

It is the role of the nurse to initiate the use of the RACEoLCP, with GP approval. The resident’s family must also be contacted.

Support for resident and family members

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

- The first part refers to common symptoms experienced in the last few days of life and the maintenance of syringe drivers.
- The second part consists of common comfort care measures for people who are dying.
- The third part consists of psychosocial support measures for people who are dying.

Family members often spend many hours with the resident at this time. They may share with you their sadness and grief. They may ask you questions about what is happening.

Utilising a tool, such as the Bereavement Risk Index can identify if family members are likely to have problems with grief and loss issues. It allows nurses to provide the most appropriate support, information and perhaps referral to other supports depending on the score.

Key Processes (Module 2) has a copy of the Modified Bereavement Risk Index.

The doctor is responsible for completing section 2 of the pathway which covers medical interventions and advance care planning

- Stopping non-essential medications.
- Changing how other medications are administered. Often this is by injection and can include medication for pain, nausea, anxiety or difficult breathing.
- Stopping any non-essential clinical interventions and observations e.g. blood pressure monitoring, weighs, blood sugar monitoring.

What is your role when a resident requires terminal care?

Your role includes working through the care management page of section three which prompts you to review and plan for:

- spiritual/religious/cultural needs
- communication with family members
- comfort planning.

Then you can set up and begin the daily comfort care chart which lists a set of comfort focused observations that are reviewed a minimum of four hourly.
When the resident dies

While all residential aged care facilities have their own policies and procedures related to the time of death, the after death care section of the pathway provides a checklist of tasks that need to be completed and ensures that all the relevant people are informed of the death.

Grief and loss

Reminisce with family and friends of the deceased resident if you feel comfortable to do so. It shows you saw the resident as an individual, not just “another resident”.

Acknowledge the grief of those around you. If family members are visibly upset, you may for example say ‘it must be hard for you; it is a difficult time…’ Showing family members you are upset e.g. crying is all right.

Key Point
No one ever complained that someone cried; but they have complained that no one seemed to care.

Self-care

Close relationships can develop between nurses and residents. It is important to be aware that when a resident dies, you may grieve as well. You are not expected to be a robot, and it is possible that you may feel sad, angry, upset, confused, guilty or even relieved at this time. Feelings of grief are different for everyone and are a normal reaction to a loss.

The following suggestions may assist you with your 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.

SUCCESS!
You have completed Section 2 of the learning package. Please go on with the quiz.
**Self-directed learning package:**
**Introductory nurses quiz**

### Section 1

1. With a palliative approach, the focus is on managing symptoms and increasing quality-of-life rather than curing illness.  
   - **True**  
   - **False**  
   - **Don’t Know**

2. A palliative approach discourages discussion about death and dying as it may upset the resident.  
   - **True**  
   - **False**  
   - **Don’t Know**

3. A resident completes a written Advance Directive. This is considered a legal document.  
   - **True**  
   - **False**  
   - **Don’t Know**

4. Shortness of breath is the same thing as dyspnoea.  
   - **True**  
   - **False**  
   - **Don’t Know**

5. It is a good idea to ask a resident to rate his shortness of breath by asking him to count how many breaths he takes a minute.  
   - **True**  
   - **False**  
   - **Don’t Know**

6. A resident is always short of breath on exertion. You should administer a PRN dose of morphine mixture after she has a shower and is recovering on her bed.  
   - **True**  
   - **False**  
   - **Don’t Know**

### Section 2

7. Family members have the right to determine if a resident should attend a palliative care case conference on the grounds that ‘it will only upset him/her’.  
   - **True**  
   - **False**  
   - **Don’t Know**

8. Regardless of the language a resident speaks or where they were born their care needs are the same when they are dying.  
   - **True**  
   - **False**  
   - **Don’t Know**

9. If a competent resident tells you they have pain, is it good practice to ask how severe it is on a scale of 0 to 10.  
   - **True**  
   - **False**  
   - **Don’t Know**

10. Facial expressions and vocalisations can indicate if a resident is experiencing pain.  
    - **True**  
    - **False**  
    - **Don’t Know**

11. A resident was taking an average of 30mg of oral morphine every 24hrs. Now that he cannot swallow the GP has changed the order to morphine 30mg/24hrs via a subcutaneous infusion pump. This is an appropriate order.  
    - **True**  
    - **False**  
    - **Don’t Know**

12. Every resident who cannot eat or drink should be fed through a tube (e.g. PEG gastrostomy).  
    - **True**  
    - **False**  
    - **Don’t Know**

13. Pineapple juice on a mouth swab is an effective way of treating a dry but otherwise clean mouth for residents who cannot swallow anymore.  
    - **True**  
    - **False**  
    - **Don’t Know**

14. A resident has not responded to environmental or nursing interventions for her delirium. A benzodiazepine would be the most appropriate drug to control hallucinations.  
    - **True**  
    - **False**  
    - **Don’t Know**

15. A combination of changes in breathing patterns, decreased consciousness and irreversible weight loss may be signs of approaching death.  
    - **True**  
    - **False**  
    - **Don’t Know**
Self-directed learning package:
Introductory nurses quiz answers

### Section 1

1. With a palliative approach, the focus is on managing symptoms and increasing quality-of-life rather than curing illness.
   - A palliative approach aims to improve the quality-of-life for people with an eventually fatal condition and their families.
   - It does this by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.
   - A palliative approach is not just for the end stages of an illness.

2. A palliative approach discourages discussion about death and dying as it may upset the resident.
   - A palliative approach encourages open and early discussion about death and dying which helps advance care planning.

3. A resident completes a written Advance Directive. This is considered a legal document.
   - So long as advance directives are filled out correctly including the appropriate witness's signatures then yes, they are legal documents.
   - They set out a resident's end of life care wishes or appoints another person as decision maker, usually called a guardian or medical power of attorney.

4. Shortness of breath is the same thing as dyspnoea.
   - Dyspnoea is an awareness of uncomfortable breathing and can also be called breathlessness or shortness of breath.

5. It is a good idea to ask a resident to rate his shortness of breath by asking him to count how many breaths he takes a minute.
   - Because health professionals tend to under-report a patient's breathlessness the resident should be encouraged to rate the severity themselves (if cognitively able).
   - This should be done using a vertical or horizontal rating scale from 0 (no shortness of breath) to 10 (severe shortness of breath).
6. A resident is always short of breath on exertion. You should administer a PRN dose of morphine mixture after she has a shower and is recovering on her bed. **False**

- Residents with dyspnoea benefit from having a preventative plan of care that decreases the distress and anxiety of dyspnoea before it occurs.
- This resident would benefit from this medication at least ½ hour before showering (just as analgesics are given prior to activities that are known to cause pain).

---

Section 2

7. Family members have the right to determine if a resident should attend a palliative care case conference on the grounds that ‘it will only upset her’. **False**

- As nurses our primary role is to provide resident centred care which includes advocating on the resident’s behalf.
- Perhaps the resident would be upset about what is discussed, but it is up to them (while they are cognitively able to make decisions competently) to decide whether they will attend.
- Most residents choose to attend case conferences and can provide insights into their condition that family and staff may not have known about otherwise.
- If a resident is likely to become distressed or fatigued, consider holding the case conference in their room where they can rest on the bed. Ask their permission to continue the discussion elsewhere with the remainder of those attending.

---

8. Regardless of the language a resident speaks or where they were born their care needs are the same when they are dying. **True**

- All residents require careful assessment to ensure that assumptions are not made about cultural needs based on a resident’s language, religion or country of origin. Similarly, the care needs for members of our indigenous population (Aboriginal and Torres Strait Islanders) requires careful assessment and planning.

---

9. If a resident tells you they have pain, is it good practice to ask how severe it is on a scale of 0 to 10. **True**

- The use of horizontal or vertical pain scale which asks the person to rate 0 (no pain) or 10 (worst pain possible) is a good way to assess pain for residents who do not have severe cognitive impairment.

---

10. Facial expressions and vocalisations can indicate if a resident is experiencing pain. **True**

- The Abbey Pain Scale lists whimpering, groaning, and crying as possible indicators of pain.
11. A resident was taking an average of 30mg of oral morphine every 24hrs. Now that he cannot swallow the GP has changed the order to morphine 30mg/24hrs via a subcutaneous infusion pump. This is an appropriate order.

- The parenteral dose of morphine is approximately one-third of the oral dose.
- The dose ordered by the GP is effectively tripling the previous dose and is likely to result in adverse effects.

12. Every resident who cannot eat or drink should be fed through a tube (e.g. PEG gastrostomy).

- There is no evidence that tube feeding prolongs life, improves comfort or quality-of-life, prevents aspiration pneumonia, leads to better nourishment or decreases the risk of pressure sores.
- Although artificial hydration can be useful to treat reversible causes of dehydration, it is not normally used when a resident is expected to die within 48 - 72 hours.

13. Pineapple juice on a mouth swab is an effective way of treating a dry but otherwise clean mouth for residents who cannot swallow anymore.

- Pineapple contains an enzyme that chemically cleans but is too strong and damaging if used undiluted and for long periods.
- Do not use mouthwashes and swabs containing:
  - lemon and glycerine
  - sodium bicarbonate (high strength)
  - preparations containing alcohol or hydrogen peroxide
  - pineapple or other juices.

14. A resident has not responded to environmental or nursing interventions for her delirium. A benzodiazepine would be the most appropriate drug to control hallucinations.

- Benzodiazepines do not improve cognition but may help associated anxiety.
- Benzodiazepines may in fact worsen delirium if not used in combination with an antipsychotic drug such as haloperidol.

15. A combination of changes in breathing patterns, decreased consciousness and irreversible weight loss may be signs of approaching death.

Three or more of the following indicates an RACEoLCP may be appropriate and that the resident is likely to be approaching death:

- 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.
Bibliography – SDLP – Nurse (Introduction)

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

**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: Suits 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.

**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

**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.
SDLP-2

Self-directed learning package: Advanced Registered & Enrolled Nurse

Welcome to this advanced learning package about providing a palliative approach to residents in residential aged care facilities (RACFs). Completion of this SDLP including the quiz attracts 3+ hours of professional development points. This package is part of the PA Toolkit. If you require more information to help you work through this package, the three modules of the PA Toolkit provide additional information.

Aims of this learning package
The aim of this learning package is to provide nurses with advanced knowledge and skills to provide a palliative approach in residential aged care facilities (RACFs).

Learning objectives:
After working through this package you will be able to:
• Support and assist residents, family members and RACF staff in the advance care planning process.
• Describe how you can contribute to the planning, facilitation and follow-up of a palliative care case conference.
• Identify common clinical problems, provide relevant care within your scope of practice and report them to a GP as needed.
• Understand the benefits of an end of life care pathway and your role as a senior nurse during the final week of a resident’s life.

Pre-requisites
It is a pre-requisite that you have completed the introductory SDLP for nurses.

What do I have to do?
You will be asked at specific times to watch two DVDs:
• “Suiting the needs” (produced by Palliative Care Australia)
• “All on the same page” (developed specifically for this toolkit).
You will have already seen both of these when completing the introductory learning package but we encourage you to review them again. They highlight important aspects of the information you will be reading about in this package. Each runs for less than 15 minutes. To complete this package you need access to a DVD player so make sure you have that before you commence.

We will ask you to reflect on the case studies of Bob and Alfred and to take note of important points. Throughout the package you will see these symbols:

**Thinking Point**
Thinking Points indicate that you should stop and think about the information, questions or ideas being presented. We encourage you to write down your thoughts but this is not compulsory.

**Key Point**
Key Points highlight information or an activity that is critical to your learning in this package.

**Activity**
Unlike the introductory learning package, we ask you to undertake some activities. That is, you will be asked to apply what you learn to your workplace.

**Assessment**
At the end of this package are a series of questions that will assist you to demonstrate your understanding of the care of a resident who requires a palliative approach. You are encouraged to talk with your supervisor or education facilitator if you are unsure about anything in this package.

**How long will this take?**
We anticipate it will take you 3 hours to complete the SDLP. This estimate includes viewing time for the two DVDs (approximately 26 minutes).

**Key Point**
Please note for the purposes of this toolkit, nurse will refer to registered and enrolled nurses and careworker will refer to personal careworkers, health careworkers and assistants-in-nursing.

OK... LET'S GET STARTED

While watching the DVD you were introduced to Alfred and his daughter Sarah.

**Case Study - Alfred**
Alfred is 82 years old and a retired school teacher. Alfred has two children: Andrew who lives overseas and Sarah who lives close by and visits twice weekly.

Alfred's wife Alice was admitted to hospital after a severe stroke and remained there, fed through a gastrostomy tube until she died three weeks later of pneumonia.

After Alice died, Alfred remained at home for nine months with increasing support from home care services. Numerous falls and increasing difficulty with activities of daily living led to admission 18 months ago to a residential aged care facility.

Alfred was a heavy smoker until aged 65 but has not smoked since.

He has osteoporosis, osteoarthritis and fractured his hip three years ago.

He is experiencing short term memory loss but not enough to lose his ability to make decisions. Alfred also has Chronic Obstructive Pulmonary disease (emphysema) and is unable to walk 20 metres before needing to rest. He has been admitted to hospital three times in the last six months for infective exacerbations of this condition requiring steroids and antibiotics. Alfred has not returned to his previous functional level after each episode.

We will use Alfred and Sarah's story to highlight important points as well as using some other case studies along the way.
Planning ahead

Advance care planning should be part of routine practice for every resident soon after admission to a RACF. It does not have to be a legalised formal process but it should revolve around ongoing communication with the resident and family.

We advocate advance care planning being integrated into the assessment and care planning process you undertake from admission onwards.

A nurse-led care conference is recommended to facilitate this process. We suggest that the resident’s GP be invited to attend (or at least be made aware of any wishes or decisions regarding advance care planning).

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

**Thinking point**
In the DVD, Alfred is clear that he does not want any extraordinary measures if he deteriorates. Certainly not to be resuscitated or sent to hospital. Sometimes it is not quite that simple. Consider the case of Anna...
Case study – Anna
Anna is 82 years old. She was born in Germany but has lived in Australia for over 30 years. She was admitted to the dementia unit shortly after the death of her husband.

Before her diagnosis of dementia, Anna had made it clear to her GP that she would always want to be resuscitated in the event of a respiratory or cardiac arrest. The GP had clearly documented these wishes in her notes.

Anna has one adult child, Helen, who has found it extremely difficult to accept her father’s death and her mother’s declining mental capacity.

Helen holds the legal right to make decisions about her mother’s care and is the immediate ‘next of kin’ for her mother. Helen, however, has been reluctant to become involved in discussions regarding planning for her mother’s care. Contact has been made with Anna’s grandson David who has agreed to assist staff with making a care plan for Anna. Despite her mental confusion and ill health, Anna recognises David and appears to agree with his suggestions.

Over a short period of time, Anna’s physical health has begun to deteriorate. She suffers more frequent angina attacks and has become wheelchair bound as a result of a fall that caused her right hip to fracture. She also has been experiencing low oxygen saturation, tiredness and shortness of breath.

This morning, you are asked to review Anna by the careworker. Anna is clearly unwell and you note a drop in blood pressure, pale skin and obvious shortness of breath.

You contact the doctor and her family to relay this change in condition. When Helen arrives, she tells you that she does not wish to have her mother resuscitated or transferred to hospital.

Thinking Point
What do you think will happen to Anna and why?

This is a common scenario in RACFs. It is a good example of why there has been a move from simply asking about resuscitation to a broader approach of advance care planning.

Key Point
A key advantage of having an advance care plan is that they can extend a resident’s autonomy. However the process is about more than just getting a form filled in or directives documented in the clinical notes. Discussing these with family and other parties is equally important.

Substitute decision making
Discussions about advance care planning ideally should involve the resident when s/he is capable of making decisions about their preferences for living and dying well. But what about those residents who are no longer deemed competent to make these decisions or are unable to express their wishes?

Thinking Point
What if Anna had not communicated her wishes to her GP before she experienced significant cognitive decline? Do decisions about care and treatment automatically defer to the family?

If a resident is not competent to make decisions, they cannot complete an advance health directive or legally appoint someone to advocate on their behalf.
The Good Palliative Care plan, developed in South Australia, is an alternative option. It can be used in any state or territory and while not legally binding, it provides opportunity for some guidance at the end of life for clinicians. We advocate this form be used to document the outcomes of advance care planning decisions that arise from a palliative care case conference.

The Good Palliative Care Plan is best used as a record of a conversation/discussion held between the clinical team and family members.

**Key Point**

At Common Law, substitute decision-making only comes into effect when the individual loses capacity or is mentally or developmentally delayed: whereby unable to understand the nature and effects of any treatment.  

The scope of decisions of the ‘substitute decision maker’ (SDM)

- A SDM can only make decisions that promote a person’s health and wellbeing.
- It is preferable that a resident’s SDM be involved with the resident’s complete care process (from admission, case conferencing, plan of care discussions etc.).
- The SDM needs to be given the same information that the resident would be given with respect to care or treatment. The care team needs to be honest about the benefits or burdens of any care that is offered to the resident.

**Activity**

Locate the relevant State or Territory legislation related to advance care planning and substitute decision making. You can find links to this legislation at the CareSearch website: www.caresearch.com.au

**Thinking Point**

Anna’s daughter and legal SDM, Helen continues to avoid discussions concerning Anna’s advance care plans. Anna’s grandson David agrees to assist staff. Despite her mental confusion and ill health, Anna recognises David and appears to agree with his suggestions. Would advance care planning legislation in your state allow Anna’s son David to make decisions on behalf of his grandmother? Why or why not?
Assigning a substitute decision maker

Let’s assume for a moment that Anna’s dementia is only mild and she still has the capacity to make decisions for herself (as assessed and documented by her GP).

**Activity**

Refer, again, to your relevant State or Territory legislation, regulations or tribunal (hint: guardianship related to advance care planning and substitute decision making).

**Thinking Point**

You may be called upon to guide residents and family members through the maze of advance care planning. Think about how you would respond to these questions:

In your State or Territory:

- What would Anna need to do in order to appoint a family member as a SDM?
- What documents would she need to complete?
- What types of decisions could this person NOT make?
- When would they be able to make decisions for Anna?
- Under what circumstances does the appointment of a SDM end?
- According to your State or Territory legislation, can Anna have more than one SDM?

**Advance Directives**

An advance directive is a document that sets out personal wishes about future medical treatment if a person loses the capacity to make these decisions.

**Key Point**

- An advance directive is only one part of the whole process of advance care planning. The value of planning is in the ongoing discussion and involvement of the resident and their family in regard to making decisions that have an impact on the resident and their rights to dignity and choice.
- An advance directive provides a clear statement of a person’s views about medical intervention and treatment.
- This may assist family members, substitute decision makers, health care providers and others by giving them insight into a person’s views and preferences for treatment.
- The person writing the advance directive needs the opportunity to consider current medical treatments and technologies and to discuss the matter with their GP and other health care providers (including you).

**Activity**

A common question is “So what should I write in this directive?”

Review the example of an advance directive in Self-directed learning package: Introductory Registered & Enrolled Nurse.

**Thinking Point**

Have you thought about what your health care wishes would (or would not) be if you were incapacitated or incompetent and unable to make decisions for yourself?
Assisting families with understanding levels of care

In the DVD “All on the same page”, it states that the foundation of ‘good discussion’ revolves around a mutual understanding of terminology and phrases. Here are some helpful terms that may feature in advance care planning discussions.

### Key Point
Residents and families can only make INFORMED choices if they understand what is being said and all the possible options.

### Advance care plan terminology

<table>
<thead>
<tr>
<th>Term</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terminal</td>
<td>A condition that will result in death - the resident can reasonably be expected to die from the disease.</td>
</tr>
<tr>
<td>Irreversible</td>
<td>A condition that is unable to be turned around - there is no possibility that the resident will recover e.g. motor neurone disease.</td>
</tr>
<tr>
<td>Incurable</td>
<td>A condition which has no cure.</td>
</tr>
<tr>
<td>Permanent unconsciousness (Coma)</td>
<td>A condition whereby brain damage is so severe that there is little or no possibility that the resident will regain consciousness.</td>
</tr>
<tr>
<td>Post coma unresponsiveness (PCU or PSV)</td>
<td>A state or condition in which a person has emerged from coma to the extent that he or she is observed to have sleep/wake cycles over a period of time but no purposeful response to stimuli. Some recovery may be achievable but full recovery is highly improbable.</td>
</tr>
</tbody>
</table>

### Clarifying ‘life-sustaining’ measures

<table>
<thead>
<tr>
<th>Life sustaining measures</th>
<th>What occurs at this level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiopulmonary resuscitation (CPR)</td>
<td>Treatment aimed at providing artificial ventilation (air flow) via mouth, mask to mouth, or tube down the throat to maintain breathing. Cardiac (heart) compression is by pumping compressions to chest or electrical stimulation. (Statistics regarding survival rates may be useful to discuss).</td>
</tr>
<tr>
<td>Assisted ventilation</td>
<td>A machine (ventilator) is used to assist the resident to breathe, if they cannot breathe spontaneously.</td>
</tr>
<tr>
<td>Artificial feeding and hydration</td>
<td>Provision of fluid and or liquidised nutrients by artificial means, if the resident is unable to swallow, eat or drink. Feeding occurs via tubes inserted via the nose, via direct insertion of a tube into the stomach or via a tube inserted into a vein.</td>
</tr>
<tr>
<td>Dialysis</td>
<td>Treatment aimed at replacing the function of kidneys i.e. removal of toxic waste products from the body.</td>
</tr>
</tbody>
</table>
Reviewing the advance care planning process

Advance care plans should be reviewed when the following occurs:

- The resident experiences a change in their health condition
  (such as an acute episode of illness, e.g., chest infection or
  a change to their chronic underlying condition).
- The family requests a case conference to review the resident’s
  plan of care.
- There is a change in personal/ carer situation (such as the death
  or loss of capacity of a spouse or substitute decision maker).
- The resident is transferred either into or from the facility
  (recommended that the plan of care is transferred with the
  resident, as with other documentation).
- As a routine requirement in accordance with facility policy.

Key Point

Reviewing does not simply mean checking if
there is an advance care plan present in the notes.
The actual decisions a resident has made need to
be reviewed on a regular basis.

Checking in with the resident!

As part of your holistic care review (every 3 months?)

Ask:

- Are these still your wishes?
- Has anything changed in your life since our last review?
- Do any of these changes reflect on your documented wishes?
- Are there any changes you would like to make to your
  advance care plan?

Activity

Check out where the advance care plans are kept in
your facility.

- Are they accessible to all staff, especially those that
  work after hours or casually?
- Are all staff aware of the resident’s preferences for
  resuscitation in the event of an emergency, is this well
documented?
Thinking Point
Imagine Alfred is a resident at your facility. As a nurse with a special interest in the palliative approach, you have been asked to organise and facilitate a palliative care case conference to plan care to respond to his recent deterioration.

Planning
A palliative care case conference is a meeting held between a resident (and/or their family) and their health care providers. The aims are to:

• identify clear goals of care for the resident including a review of any advance care plans
• provide a safe environment where issues and questions about end of life care can be raised and appropriate strategies agreed upon for future care.

Sometimes there may be differing views about end of life care. Having everyone with a stake in a resident’s care ‘on the same page’ is vital to achieve the best outcomes for the resident.

Key Point
Palliative care case conferences should not be:

• used as an opportunity for health care professionals to debate a resident’s medical status; in this situation, a separate meeting should be convened prior to the case conference
• saved for ‘crisis’ situations; a preventative approach is advocated where issues are anticipated before they become major dilemmas.

Activity
Working through the planning check list (see Module 2), think carefully how you would specifically undertake each of these tasks in the facility where you work.

Review all forms related to case conferences in Module 2. Determine if there are any changes needed to integrate them into your facility. Add your organisation’s logo - make changes to the templates as desired – i.e. get them ready for use.

Are there any barriers or issues that may get in the way of your planning?
Know the resident’s family and social network

Often at times of crisis and especially at the end of life, family members may visit that you have not met before.

One method of clarifying a resident’s social network is with a genogram.

The genogram usually displays three generations and covers the basic family structure. It may also include information on individual family members (e.g. significant dates or ages) and family relationships.

Genogram symbols: Family relationships

In a genogram, a male is represented by a square and a female by a circle. A cross over the shape indicates an individual is deceased.

Male  Female  Deceased Male  Deceased Female

A marital relationship is represented by:

The married couple has divorced:

The married couple has separated:

One of the spouses died while married (widowed):

A sibling relationship is represented by:

List children in birth order beginning with the oldest:

Biological child  Adopted child  Fraternal twins  Identical twins

Stillbirth  Miscarriage  Abortion  Pregnancy
Interpretation of Alfred’s genogram:

Alfred was married to Alice who died during their marriage leaving Alfred a widower. The genogram indicates that Alice passed away in 2006. Alfred and Alice had two children: Andrew and Sarah. Andrew is married to Julie and has one son, Matthew. Sarah is married to John and has two sons, Cameron and Andrew. Cameron is married to Sandra. Alfred had two older sisters – Jennifer who died in childhood and Moya who is still living. The genogram also tells us the Alfred lost his father at an early age. Note that an effort has been made to add in dates significant to Alfred (birthdays, wedding anniversary and dates people died).
Now it is your turn.

Review the case study of Judy and develop a representative genogram (on the next page).

(Yes it’s complex… but so are many of the families you meet in your professional role every day).

Case study: Judy

Judy has been a resident of your facility for four months.

Judy’s elderly husband Paul is being cared for by their daughter Rhonda and her husband Derek. Paul suffered a stroke a number of years ago and is becoming increasingly confused and distressed because he misses his wife and is showing signs of early dementia.

Judy’s daughter, Rhonda (65 years) is working full time but has taken long service leave to care for her father. Derek and Rhonda have one child Robert (aged 32) who is married to Gail. Gail has recently been diagnosed with breast cancer and is undergoing treatment. Gail’s parents (Steven and Pauline) have moved into the family home to help care for Gail and Robert’s four sons. Pauline’s parents Jenny and Gerald are also residents of your facility and have formed a close friendship with Judy.
It is particularly important to document the key issues and outcomes of a palliative care case conference. Equally, it should be clear who is responsible for actions/tasks and when they are expected to be resolved or completed.

Follow up

Often, in times of stress, residents and family members may not remember all that is discussed. Suitable resources can complement the information you provide in the case conference.

Two useful brochures, “Understanding the Dying Process” and “Now What? Understanding Grief” are included in the toolkit.

**Key Point**

Written information should not be used as a substitute for personal conversations with residents or family members.
Dyspnoea

Dyspnoea is an awareness of uncomfortable breathing. It can also be called breathlessness or shortness of breath.

The evidence suggests that 70% of people receiving a palliative approach experience dyspnoea in the last six weeks of life. In the terminal phase of ageing and/or illness, fear of suffocation may be the most troubling symptom. This may significantly affect the ultimate place of death. The experience of dyspnoea (i.e. breathlessness) may not be directly attributed to a disease, because other factors such as anxiety exacerbate the symptoms.

- Shortness of breath becomes more frequent in residents as their disease progresses. It is associated with a poorer prognosis, and is usually multi-factorial in people with advanced disease.
- Dyspnoea frequently worsens as death approaches.
- Dyspnoea can impair a resident’s activities of daily living, limit mobility, increase anxiety, and can leave them feeling fearful and socially isolated.
- It can also be a sign of a deteriorating condition in residents receiving a palliative approach.
- Shortness of breath (dyspnoea) is frightening for patients. They may fear suffocation, and they often associate dyspnoea with impending death. Dyspnoea can be both longstanding and progressive (related to the disease progression), or it can be an acute problem appearing suddenly.
- Dyspnoea triggers panic, and panic exacerbates dyspnoea, so the pattern becomes cyclical.
- Dyspnoea may also be a distressing and frightening symptom for the family. This can lead to increased anxiety for the resident which may increase their dyspnoea. Family members’ perceptions of a resident’s suffering can influence how the family makes meaning of, and come to terms with, the dying experience of the resident.
Despite dyspnoea being an increasingly common problem for residents who require a palliative approach, it is rare to see a care plan that focuses specifically on management of their dyspnoea. Perhaps this is because many RACFs choose to structure their care plans around the Aged Care Funding Instrument (ACFI) questions, which only mentions oxygen therapy in the complex care section.

**Assessment**

**Activity**

Review the dyspnoea section in Module 3.

**Thinking Point**

Do residents in your facility who report dyspnoea have a comprehensive assessment done as part of routine practice?

- How often is a resident’s dyspnoea assessed?
- Do you assess dyspnoea prior to and following an intervention?

**Key Point**

Because health professionals tend to under-report a resident’s dyspnoea, competent residents should be encouraged to rate the severity themselves.

**Management**

**Case Study – Alfred**

Alfred is nearing the end of his life.

Alfred’s main problems are his airways disease, mild dementia and progressive decline in functional status. He requires continuous oxygen, prescribed at 2 litres/minute via nasal specs.

Today it appears to be more severe and he has what appears to be a wheeze and occasional cough.

**Thinking Point**

What additional information might you need before deciding on a management strategy?

**Activity**

List the strategies that may help Alfred’s shortness of breath. Then separate these interventions into short-term and longer-term strategies, keeping in mind that Alfred is already receiving a palliative approach to his care.

Alfred’s GP has decided to treat the dyspnoea with a low dose of PRN oral morphine. The aim is to changeover to a sustained release preparation once the dose requirements are clear.

His daughter Sarah is concerned about the potential for addiction of morphine.
You notice that there are reports of dyspnoea in Alfred’s case notes but no opioids have been administered. When you question the RN responsible, he scoffs at the idea that morphine can help dyspnoea. “That can’t be true, it depresses respirations. I learnt that when I worked on a surgical ward years ago”.

Unfortunately many health professionals are not aware of the current evidence based interventions for dyspnoea.

Activity

It may be helpful to look on the CareSearch website for the one page summary about dyspnoea. This would be a good starting point for a discussion with this nurse about the potential benefits of opioids for dyspnoea.
Pain

What is pain?

The International Association for the Study of Pain defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. So pain not only impacts on the person’s physical being but also their psychological being.

Common causes of pain in the elderly

The common causes of pain in the elderly include:
- cancer
- cardiovascular disease
- peripheral neuropathy secondary to diabetes
- arthritis.

Cancer pain

In residential aged care facilities in Australia, a common cause of pain is cancer and the leading cause of death is cancer.
- The frequency and type of pain varies depending on the stage and primary site of the cancer.
- Moderate to severe pain occurs in one-third of people (30–40%) at the time of diagnosis and two thirds (60-100%) with advanced disease.
- Most individuals with advanced cancer have more than one pain.
Residents may often have more than one type and location of pain. This is especially common with advanced cancer pain.

The following story illustrates a resident with advanced disease where metastases are causing pain in three different locations.

Case Study: Judy

Judy (87 years) has been a resident of your facility for 4 months and is dying.

She was diagnosed with advanced bowel cancer three months ago and her disease has progressed rapidly. She has developed a fungating rectal mass as well as metastasis in her liver and bones (right hip and ribs). She complains of pain in her ‘bottom’ when she is sitting on a chair, intermittent hip pain when she walks or moves in bed and also a ‘discomfort’ in the right upper quadrant of her abdomen occasionally radiating to her right shoulder.

The areas of pain identified in this case study include her rectal lesion, bone pain (worse on movement), and pain from her liver causing referred pain to her shoulder.

Barriers to effective pain assessment and management

Thinking Point
What factors may interfere with Judy’s pain assessment?

Barriers to identifying pain

- concurrent clinical problems
- cognitive impairment
- multiple pain problems
- lack of objective biological markers for chronic pain that can be used to test if pain is present
- communication deficits
  e.g. language, vision, dysphasia
- cultural norms in the expression of pain
  e.g. Western Anglo-Saxon “stiff upper lip”
- false beliefs
  e.g. “People with dementia don’t feel pain”; “It’s normal to have some pain as you age”; “Opioids hasten death”
- fear of the meaning of pain especially when linked to cancer or a terminal illness
- inexperience of healthcare workers in OBJECTIVE assessment of pain.⁷
Types of pain

Pain can be classified in a number of ways:

**Acute or chronic pain**

<table>
<thead>
<tr>
<th>Acute pain</th>
<th>Chronic pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>• due to acute injury/illness</td>
<td>• results from chronic pathological process</td>
</tr>
<tr>
<td>• may last days/weeks, has a predictable and limited duration</td>
<td>• gradual onset and becomes progressively worse</td>
</tr>
<tr>
<td>• clinical signs are obvious: increased blood pressure and heart rate; sweating, pallor</td>
<td>• usually no sympathetic clinical signs</td>
</tr>
<tr>
<td>• anxiety</td>
<td>• may appear depressed, withdrawn with lethargy</td>
</tr>
<tr>
<td>• inactivity until recovery</td>
<td>• requires treatment of underlying disease and regular use of analgesia.</td>
</tr>
<tr>
<td>• temporary use of analgesics.</td>
<td></td>
</tr>
</tbody>
</table>

**Key Point**

In palliative care, pain is usually chronic and the obvious signs such as pallor, sweating, or changes in blood pressure may not be seen.

Remember pain may be due to the resident’s disease, their treatment, or a co-morbid illness.
Incident Pain
- pain results from a specific event e.g. wound dressing, movement
- requires analgesia PRIOR to the event that causes the pain.

Key Point
Remember to allow time for analgesia to work before undertaking the intervention.

Breakthrough Pain
- pain occurs between regular scheduled doses of analgesia
- common in cancer pain
- response should be to give an additional prescribed breakthrough dose of analgesia
- review/ reassess pain and treatment regime if doses are needed repeatedly.

Pathophysiology
Pain can also be classified according to its physiological causes.
- Nociceptive pain occurs because of stimulation of nerves in the skin and deep tissues called 'nociceptors'.
- Neuropathic pain is caused by the damage to the actual nerves themselves.

Classification of pain

<table>
<thead>
<tr>
<th>Type</th>
<th>Characteristics</th>
<th>Descriptors</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nociceptive - Somatic</td>
<td>Well localised</td>
<td>Gnawing, aching, throbbing, sharp</td>
<td>Superficial: pressure sores; Deep: bone fracture</td>
</tr>
<tr>
<td>Nociceptive - Visceral</td>
<td>Poorly localised, sometimes referred</td>
<td>Deep, squeezing, penetrating, pressure</td>
<td>Intestinal or biliary colic</td>
</tr>
<tr>
<td>Neuropathic</td>
<td>Can follow dermatome/nerve distribution</td>
<td>Burning, shooting, radiating, tingling, numbness, pins and needles, deep aching</td>
<td>Post herpetic neuralgia (shingles), spinal cord compression</td>
</tr>
</tbody>
</table>
Factors affecting pain threshold

A person’s pain perception and experience are influenced by their mood, past pain experiences, social and physical situation and the meaning they give to both their illness and their pain.

Factors that affect pain threshold

<table>
<thead>
<tr>
<th>Threshold lowered</th>
<th>Threshold raised</th>
</tr>
</thead>
<tbody>
<tr>
<td>• insomnia</td>
<td>• relief of other symptoms</td>
</tr>
<tr>
<td>• fatigue</td>
<td>• sleep</td>
</tr>
<tr>
<td>• anxiety</td>
<td>• sympathy</td>
</tr>
<tr>
<td>• fear</td>
<td>• understanding</td>
</tr>
<tr>
<td>• anger</td>
<td>• relaxation</td>
</tr>
<tr>
<td>• depression</td>
<td>• reduction in anxiety</td>
</tr>
<tr>
<td>• mental isolation</td>
<td>• analgesics.</td>
</tr>
</tbody>
</table>

Thinking Point

Think about the differences between these two lists. Can you recall a time where you noticed differences in a resident’s mood after you encouraged them to participate in group activities, or someone sat and talked to them about their fears?

Activity

Identify a resident who is experiencing pain.

List two non-pharmacological strategies you can trial in the next fortnight to assist with their pain:

1.  
2.  
Pain assessment

Using an evidence-based assessment tool establishes a shared view of the resident’s pain experience and therapy goals. It can also enhance your ability to tailor individualised interventions to the pain situation.

A pain assessment tool gives you a baseline from which to evaluate treatment interventions. It also gives the resident a more active role in dealing with their pain. Residents feel their pain is being taken seriously which in itself can be beneficial.

For residents who can communicate

- The most accurate and reliable evidence of pain in residents who can communicate (even with mild to moderate dementia) is self-reporting.
- Assessment is often more accurate and useful when undertaken during movement or transfer of the resident (rather than at rest).
- Allow enough time for the assessment and for the resident to formulate a response to the questions.

The following story illustrates the importance of listening to the individual about their pain experience.

Case Study: Alfred

Alfred is 82, with a history of osteoporosis, arthritis and a fractured hip, and has been living in your facility for almost two years.

Some of the nurses describe him as a “complainer” and state that he always “goes on” about his pain. These same nurses feel that because he never “looks” like he has pain then he must just want their attention so they avoid him.

It is not until a new nurse starts at the facility and performs a comprehensive pain assessment that the GP prescribes appropriate analgesia. Alfred’s pain reduces from severe to mild and he becomes more interactive with other residents.

Key Point

It is important to never make your own judgments about the pain the resident is experiencing.

Listen to what the resident describes and incorporate the use of a validated pain assessment tool.

Never presume to know what the resident is experiencing; even two people with exactly the same diagnosis will experience pain differently.
Initial assessment

Modified Resident’s Verbal Brief Pain Inventory (M-RVBPI)

A copy of this tool can be found in Module 3.

- Although this tool is primarily utilised with competent residents, it is also reliable and valid for residents who have mild dementia. You can enlist a careworker or relative to jointly report when there is moderate to severe dementia.
- The M-RVBPI assesses physical and psychosocial factors relevant to pain in appropriate detail. Pain intensity and the effectiveness of current treatments is also evaluated.
- On average, it takes about seven minutes to administer.
- The first question determines the need for further assessment. If the answer to the first question is ‘no’, no further questions are indicated.
- A body map records and defines the site of pain. This is helpful in evaluating the cause of pain.
- The size of the area in which pain is felt, the shape (distribution) and travel path (radiation) also suggest the underlying cause (for example, sciatica).
- Identifying the location of the pain also guides the effective application of local treatments.
- The remainder of the M-RVBPI looks at the impact of pain on activity, mood, mobility, socialisation and sleep.²

Key Point

Completing an assessment is important BUT equally important is doing something with the information that is obtained. Be sure to follow the action guide at the bottom of the M-RVBPI form.

Case Study: Judy

Judy, who we met earlier, has advanced bowel cancer with a fungating rectal mass as well as metastasis in her liver and bones (right hip and ribs).

You sit with her just after she’s been assisted with her shower. She looks like she wants to cry when you ask her if she has any pain.

She describes:

1. Severe pain in her ‘bottom’ when she is sitting on a chair. This stops her from going to the activities room to play bridge with her friends.
2. Moderate hip pain when she walks or moves in bed (drops to mild when lying still but never goes away completely).
3. Mild discomfort in the right upper quadrant of her abdomen radiating to her right shoulder.

Judy tells you that she always has some level of pain, especially in her hip.

Thinking Point

Refer back to the assessment you made of Judy’s pain. How would you classify each pain she describes?

Activity

Read through the M-RVBPI and scoring instructions. Then complete the tool using the information provided about Judy.

Ongoing assessment

Pain rating scales are the best tools for ongoing pain assessment and intervention evaluations.
Key Point
Assessments need to be done:
• at the point of contact with the resident, not at the end of your shift
• by careworkers and nurses
• REGULARLY.

For residents who cannot communicate
Assessing pain with a resident with cognitive impairment or dementia requires different assessment methods.

We recommend the Abbey Pain Scale which is based on direct observation of the resident as well as knowledge of their usual functioning and medical history. You will have read about this in the introductory education package.

Apart from using a tool, it is very important to collect observations from people who are closely involved with the resident such as family members and careworkers.

Thinking Point
Do careworkers undertake pain assessments in your facility?
If not, can you see any benefit in careworker involvement?
What barriers are there and how might you address these?

Pain management
Key Point
Combining pharmacological and non-pharmacological treatment strategies is more effective than a singular approach.

We mentioned earlier that residents experience pain differently and that their perception of pain is influenced by their mood, past pain experiences, social and physical situation and the meaning they give to both their illness and their pain.

Pharmacological approaches
As a nurse, you are responsible for the medications you administer. It is vital that you understand the general principles and pharmacology of managing pain.

Comprehensive details of pharmacological pain management can be found in "Therapeutic Guidelines: Palliative Care (version 3)" - included in the PA Toolkit.
Judy seems to have pain most of the time. She is only prescribed as needed (PRN) analgesics and is rarely comfortable.

Thinking Point
How might you explain the problem to her GP when he next visits to ensure she gets more appropriate analgesia?

Judy has been taking paracetamol intermittently for several weeks. Yesterday, her GP prescribed 20mg of sustained release oral morphine/day in response to reports of severe pain. Night staff report Judy feeling nauseous as well as slightly confused when they spoke to her.

Thinking Point
Why might this have happened?
What would have been a better method of starting Judy on opioids?

Judy’s daughter Rhonda visits the next day. She becomes angry that her mother is taking morphine as “She needs to leave this until later. If she starts on it now, it won’t work later and then what will she do?”

Thinking Point
How might you respond?

You are doing the medication round. You notice that since starting on opioids, no one has been administering paracetamol to Judy. A colleague’s response is “She’s on the strong stuff now. She doesn’t need paracetamol as well.”

Thinking Point
Why it is important to continue with non-opioid analgesics?

Despite ever increasing doses of opioids, Judy’s hip pain does not seem to be getting any better.

Thinking Point
Are there any other pharmacological measures that may help?
What are they and why are they more likely to be effective?

Key Point
Concise answers to all of these questions are in the “Therapeutic Guidelines: Palliative Care (version 3)” - included in the PA Toolkit.
Get into the habit of referring to it in your clinical practice.

Non-pharmacological approaches
You are approached by some careworkers who want to know what they can do to help Judy be more comfortable.

Activity
Write down some key points of what you would tell them.

Make your instructions specific, detailed and concrete. Be sure to stay focused on their scope of practice.

You notice that most evenings over the last week, around 11.00pm, Judy’s pain score seems to increase from 4/10 to 7/10 on a visual analogue scale. Night staff have documented twice that Judy was teary. She couldn’t identify any one pain that was a particular problem. Normally she can tell you the location of her pain.

Thinking Point
Why might Judy’s pain be worse late at night? What strategies would you use to address the situation?
Nutrition and hydration

Key Point
The benefits of artificial nutrition or hydration must outweigh the potential burden and side effects for the resident.

Case Study – Alfred
A careworker reports that Alfred, who normally has a good appetite, is not eating his meals. He seems to have lost interest in his food and is ‘withdrawn’. Alfred’s main problems are his airways disease requiring oxygen, mild dementia, and a general decline in functional status.

Activity
The ‘MEALS ON WHEELS’ tool summarises specific nutrition and hydration issues prevalent in the elderly population.

Circle or mark which issues might be worth pursuing further with Alfred.

<table>
<thead>
<tr>
<th>MEALS ON WHEELS tool</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medication</strong></td>
<td>Side effects, amount</td>
</tr>
<tr>
<td>Emotional problems</td>
<td>Depression, anxiety</td>
</tr>
<tr>
<td>Anorexia (late onset anorexia nervosa)</td>
<td></td>
</tr>
<tr>
<td>Alcoholism</td>
<td></td>
</tr>
<tr>
<td>Late-life paranoia</td>
<td></td>
</tr>
<tr>
<td>Swallowing disorders</td>
<td></td>
</tr>
<tr>
<td>Oral factors</td>
<td></td>
</tr>
<tr>
<td>Not culturally appropriate</td>
<td>Food, presentation or environment</td>
</tr>
<tr>
<td>Wandering and other dementia-related behaviours</td>
<td></td>
</tr>
<tr>
<td>Hyperthyroidism, hyperparathyroidism, hypoadrenalism</td>
<td></td>
</tr>
<tr>
<td>Enteric problems (malabsorption)</td>
<td></td>
</tr>
<tr>
<td>Eating problems</td>
<td>Resident unable to feed themselves</td>
</tr>
<tr>
<td>Low-salt, low-cholesterol diets</td>
<td>Therapeutic diets</td>
</tr>
<tr>
<td>Socially inappropriate</td>
<td>Food; environment; lack of interaction; inappropriate positioning of resident</td>
</tr>
</tbody>
</table>
Alfred continues to deteriorate despite his constipation resolving and the increased attention he receives from careworkers during meal times. He is now bed bound, eating only a few mouthfuls of food when assisted by a careworker, and has starting coughing when he swallows. Thickened fluids also result in coughing. Alfred is increasingly drowsy and needs significant prompting to accept a drink from a cup and straw.

His daughter Sarah visits most days and tells you she thinks Alfred is just “not trying hard enough” to eat. She cajoles him and tries to spoon food into his mouth, even bringing food from home. Sarah contacts Alfred’s GP requesting a feeding tube so he “doesn’t starve to death.”

At the palliative care case conference, Sarah was very concerned that Alfred would starve to death if he was unable to eat and drink. Remember that Sarah’s mother (Alfred’s wife) was fed through a gastrostomy tube after she had a stroke. This continued for three weeks and then she died of pneumonia.

You convene a palliative care case conference with Alfred, Sarah, Alfred’s GP and a careworker who regularly works with Alfred.

Key Point
Providing food for a loved one is often viewed as a way of expressing affection and concern. When family are unable to continue this function they become distressed and may feel they are neglecting the resident.

Family members may find it difficult to distinguish between “not eating” as part of the dying process and “not eating” as bringing about the dying process.

Key Point
Deciding to withhold or withdraw artificial feeding or hydration needs to involve recognition of the emotional impact on family and staff, particularly careworkers.
Thinking Point
Think about how you would respond to Sarah’s insistence that Alfred should go to hospital to have a feeding tube inserted.

Hint: the Tube Feeding Decision Aid below may help.

Alfred is unconscious and you would not be surprised if he dies in the next two to three days.

This time it is a careworker who approaches you, upset that Alfred cannot drink. He says that he feels terrible if he forgets to drink any fluids during a busy eight hour shift so “how bad must it be for Alfred being so dehydrated?”

Tube Feeding Decision Aid

<table>
<thead>
<tr>
<th>Information to be provided to the resident and family should include:</th>
<th>Steps to decision making should include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common causes of eating and swallowing problems in older persons:</td>
<td>Guiding the resident and their family through what they have learned about PEG tubes:</td>
</tr>
<tr>
<td>Technical considerations regarding placement and use of PEG tubes</td>
<td>How to apply this knowledge to the resident’s preferences, personal values, and clinical situation:</td>
</tr>
<tr>
<td>Principles of substitute / proxy decision making (if not already discussed)</td>
<td>What is the resident’s situation?</td>
</tr>
<tr>
<td>The risks and benefits of tube feeding</td>
<td>What would the resident want?</td>
</tr>
<tr>
<td>The option of supportive / comfort care (e.g. hand feeding; responsive to resident’s requests regarding the need for, or the refusal of, food and fluids); and</td>
<td>How is the decision affecting the family?</td>
</tr>
<tr>
<td>Some considerations regarding future discontinuation of PEG tube (e.g. when and how often will the need for the PEG tube be reviewed; who can request a review / discontinuation and is there a process for this.)</td>
<td>What questions need answering before the resident / or their family can make a fully informed decision?</td>
</tr>
<tr>
<td></td>
<td>Who should decide about PEG placement?</td>
</tr>
<tr>
<td></td>
<td>When should the PEG be disbanded; and</td>
</tr>
<tr>
<td></td>
<td>What is the resident’s / or his / her family’s overall thoughts about the decision?</td>
</tr>
</tbody>
</table>

Alfred is still alive the next day and his GP suggests that subcutaneous (s/c) fluids (hypodermoclysis) may be needed.

Activity
List the possible benefits and burdens that need to be taken into account when considering whether to administer s/c fluids.

Thinking Point
How would you respond to the careworker?
We suggest you use the “Understanding the Dying Process” brochure (found in the PA Toolkit) to facilitate discussions with careworkers just as you would with family members.
Oral care

The ageing process, even when uncomplicated by illness, creates changes in the body which may combine to decrease oral health. As a resident approaches the end of their life, especially when not eating or drinking, oral care becomes even more important.

Activity

Locate a copy of the Better Oral Care in Residential Care resource in your facility.

The professional portfolio was written to assist GPs and RNs to undertake oral health assessment and care planning for people in residential aged care. While not targeted specifically at palliative care, the principles are the same.

Case Study – Alfred

Alfred is nearing the end of his life. His main problems are his airways disease, mild dementia and general decline in functional status. He requires continuous oxygen, prescribed at 2 litres/minute via nasal specs.

Four weeks ago he was commenced on amitryptiline 25mg nocte for depressive symptoms. Last week this was increased to 50mg. He is using a fluticasone inhaler after a recent exacerbation of his airways disease.

Careworkers report that Alfred, who normally has a good appetite, is not eating as much as normal. He seems to have lost interest in his food and is ‘withdrawn’.

You note that he has a full bottom denture and a partial top plate.

Activity

List all the risk factors you can think of that may impact on Alfred’s oral health.
Assessment

After the reports of problems from the careworkers you conduct a comprehensive oral assessment on Alfred.

You notice his mouth is coated with food debris and early signs of candidiasis (thrush). His tongue is dry and coated. Alfred becomes distressed when you attempt to look in the upper right corner of his mouth where you notice an ulcer on his gum where the denture has been rubbing.

It would appear that careworkers are not routinely assessing Alfred's mouth or providing the oral care he requires. His care plan covers only routine preventative oral care.

Thinking Point

Why might Alfred’s mouth be in this condition?

Consider the influence of Alfred, careworkers, nurses and the organisation as a whole.

What steps could you take to address this shortfall in care. In particular, what could you do to ensure that this was an isolated incident and would not happen again?

Management

Key Point

Oral care needs to be focused on the specific problems highlighted during a comprehensive assessment, not ‘one care plan fits all’.

Activity

For each of Alfred’s oral care problems, identify suitable management strategies.
Delirium

Key Point

Delirium is distressing not only for the resident but for family and health care workers.

Delirium in older people is often overlooked and misdiagnosed, especially at the end of life.

Health care workers often find it difficult to differentiate between depression, delirium, and dementia.

Assessment

Delirium is a condition where the resident’s behaviour and thinking is disorganised. They struggle to focus, sustain or shift their attention. Sometimes hallucinations or delusions are present. It develops over a short period of time and generally fluctuates during the course of the day.19

It is important to distinguish between delirium, dementia and depression.
Alfred has always been quite alert with only minor memory impairment. Today, however, he is very drowsy. He mumbles that he needs help to “catch the chickens” and keeps trying to get out of bed. He cannot tell you where he is or identify significant family members. Three days ago he was diagnosed with a urinary tract infection.

**Activity**

Use the ‘Confusion Assessment Method’ (CAM) tool to help determine if a resident’s symptoms are likely to be caused by a delirium.
Confusion Assessment Method (CAM) Shortened Version Worksheet

Name of resident:  
Date of Birth:  
Date: / /  
Time:  

<table>
<thead>
<tr>
<th>Box 1</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. ACUTE ONSET AND FLUCTUATING COURSE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Is there evidence of an acute change in mental status from the patient’s baseline?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>b) Did the (abnormal) behaviour fluctuate during the day, that is tend to come and go or increase and decrease in severity?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>II. INATTENTION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did the patient have difficulty focusing attention, for example, being easily distractible or having difficulty keeping track of what was being said?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>III. DISORGANISED THINKING</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was the patient’s thinking disorganised or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>IV. ALTERED LEVEL OF CONSCIOUSNESS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall, how would you rate the patient’s level of consciousness?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alert (normal)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vigilant (hyperalert)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lethargic (drowsy, easily aroused)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stupor (difficult to arouse)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coma (unarousable)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Do any checks appear in box 3?  
If all items in Box 1 are ticked and at least one item in Box 2 is ticked a diagnosis of delirium is suggested.

Activity

For each of the behaviours listed below, classify them according to one of these three categories: 1. Inattention
2. Disorganised thinking
3. Altered level of consciousness

<table>
<thead>
<tr>
<th>Examples of observed behaviours</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The resident dozes off while you are asking questions.</td>
<td></td>
</tr>
<tr>
<td>2. As you ask the resident a question, she keeps repeating the answer to the previous question. You repeat the question clearly, yet she continues to repeat the previous answer; you ask AGAIN – same result.</td>
<td></td>
</tr>
<tr>
<td>3. The resident startles easily at any sound or touch. His eyes are wide open.</td>
<td></td>
</tr>
<tr>
<td>4. You ask the resident to tell you what he had for breakfast. He responds, “I’ve gotta get to the Yellow Brick road”.</td>
<td></td>
</tr>
<tr>
<td>5. As you are talking with the resident, her eyes are roving around the room. You call the resident’s name and touch her arm. She looks at you momentarily, but does not acknowledge your presence. You repeat a question several times without response. Her eyes continue to rove the room.</td>
<td></td>
</tr>
<tr>
<td>6. You ask the resident if she is able to feed herself. She replies, “It depends what kind of party I’m at; I need a taxi.”</td>
<td></td>
</tr>
</tbody>
</table>

Answers:
1. altered level of consciousness (lethargic)
2. inattention
3. altered level of consciousness (vigilant)
4. disorganised thinking
5. inattention
6. disorganised thinking
Consider possible causes of delirium
Delirium is often caused by a combination of factors including:

- medications
e.g. opioids (especially with renal impairment), tricyclic antidepressants, benzodiazepines, corticosteroids any drug with anticholinergic activity
- drug withdrawal
e.g. opioids, alcohol, nicotine, benzodiazepines
- metabolic
e.g. dehydration (diuretics use, hot weather, hypoglycaemia, hypercalcaemia)
- urinary retention or constipation
- infections (especially with indwelling urinary catheter)
- kidney or liver failure
- sensory impairments
- uncontrolled pain.

Management

Key Point
When a resident is approaching the terminal phase, it is not always appropriate to actively treat the cause of delirium, even if the cause is known. Decisions need to be informed by the resident’s prognosis and any advance directives about active treatment.

Activity
Identify THREE non-pharmacological management strategies (see over for suggestions) that you would like to implement or further develop in your facility.

Think about how you might do this in easily achievable, concrete steps.

For example, ‘pin up reminder notices in each unit’ is more specific and concrete than ‘keep staff quiet at night’.
Environmental strategies
- lighting appropriate to time of day – windows with a view to outside, curtains and blinds open during the day, and minimal lighting at night
- quiet environment especially at night
- provision of clock and calendar
- avoid room changes
- encourage family and friends to be involved in resident care
- encourage family to bring in resident’s personal and familiar objects
- staff caring for residents with delirium should establish a communication strategy that incorporates elements of both reality orientation and validation techniques
- modify the environment to minimise risk of injury (nurse in a low bed with cot sides down, bed against the wall, potential hazards such as beside tables removed)
- allow family members to stay with resident including overnight
- endeavour to have the same staff members care for the resident during and across shifts
- information regarding the diagnosis, cause and management plan should be communicated to the resident and their family.

Clinical practice strategies
- encourage/assist with eating and drinking to ensure adequate intake
- ensure that residents who usually wear hearing and visual aids are assisted to use them
- regulation of bowel function – avoid constipation
- encourage and assist with regular mobilisation unless the residents condition does not warrant this
- encourage independence in basic ADLs unless the residents condition does not warrant this
- medication review
- promote relaxation and sufficient sleep – can be assisted by regular mobilisation, massage, encouraging wakefulness during the day
- manage discomfort or pain
- provide orienting information including name and role of staff members
- minimise use of indwelling catheters
- AVOID use of physical restraints
- use interpreters and communication aids with CALD patients.

Medications
The primary aim of medications for delirium is to reduce the resident’s distress by targeting any agitation or hallucinations.

Antipsychotic drugs are considered first line therapy e.g. haloperidol, risperidone or olanzapine. Benzodiazepines do not improve cognition but may help associated anxiety e.g. short acting agents such as lorazepam or midazolam are usually indicated.

Key Point
Benzodiazepines may worsen delirium if not used in combination with an antipsychotic drug.

When all else fails
Sometimes agitation and delirium can cause such severe distress and does not respond to medical management, especially in the terminal phase. This is a challenging problem and may require sedation as the only appropriate intervention.

Activity
Please spend some time reading the section on delirium in "Therapeutic Guidelines: Palliative Care (version 3)" - included in the PA Toolkit.
End of life care pathway

Terminal care is focused on the final days or weeks of life.

Thinking Point
In the final scenes of the DVD “All on the same page” Alfred is dying.
Think about a resident you have cared for who was approaching the last weeks of their life.
Did everyone involved (family, nurses, careworkers, GP) agree or understand that the resident was dying?
What was it about the resident that led you to believe they may die soon?

Diagnosing dying

Residents may experience some or all of the following when they are approaching death and requiring terminal care:
1. rapid day to day deterioration that is not reversible
2. requiring more frequent interventions
3. becoming semi-conscious with lapses into unconsciousness
4. increasing loss of ability to swallow
5. refusing or unable to take food, fluids or oral medications
6. irreversible weight loss
7. an acute event has occurred requiring revision of treatment goals
8. profound weakness
9. changes in breathing patterns.¹

The Residential Aged Care End of Life Care Pathway

The Residential Aged Care End of Life Care Pathway (RAC EoLCP) is a document designed to help make consensus based best practice care possible for residents at the end of life. It is intended to support residential aged care facility staff in their efforts to ensure those dying will do so with the best available care in place.

Care pathways are structured multidisciplinary care plans which detail essential steps in the care of patients with a specific clinical problem. In the case of the RAC EoLCP the specific clinical problem is terminal care.

Activity


 Thinking Point
Have you used this pathway in your clinical practice?
If yes, what benefits have you seen in your practice and those you work with?

Benefits of using the RAC EoLCP

- promotes evidence and consensus-based, best practice palliative care
- provides documented evidence of care as it is delivered
- ensures high quality, standardised care for all residents
- supports internal quality assurance and audit processes.
What is your role when a resident requires terminal care?

**Key Point**

It is the nurse’s role to initiate the use of the RACEoLCP. GP agreement must be obtained and the family needs to be contacted.

Your role as a senior nurse also includes working through the care management page of section three which prompts you to review and plan for:

- spiritual/religious/cultural needs
- communication with family members
- comfort planning.

The PA Toolkit and introductory education package outline in detail how to use the End of Life Care Pathway. We will now focus on some other related issues that more senior and experienced nurses are likely to have to deal with at this time.

Cultural considerations

Australia has a rich multicultural population.

Culture refers to a set of beliefs, values, norms and practices that are learned, shared, and dynamic. They influence people’s thoughts, expressions and actions in a patterned way.

Residents and family members from culturally and linguistically diverse populations may have particular needs that members of the aged care team should address in order to provide a compassionate and effective palliative approach to care. These may become increasingly important as the resident enters the terminal phase.

**Thinking Point**

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

**Activity**

Complete a Modified Bereavement Risk Index for Rhonda using the form on the next page. Based on Rhonda’s score what support would you offer?
**Modified Bereavement Risk Index**

Name of Resident:  
Name of family member:  
Relationship to resident:  

**Contact details of family member**  
Address:  
Phone number: (H) (W) (M)

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

**Total Score**

*Will be automatically referred to specialist bereavement support

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

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

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

The resident and/or family must provide the nurse with information concerning their wishes about end of life care at the initial assessment and care planning interview after admission.  

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
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<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
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</table>

There is no way of recording treatment preferences for a resident who has advanced dementia and did not record their wishes on a legal document when they still had mental capacity.  

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don't Know</th>
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<tbody>
<tr>
<td>2</td>
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</table>

Regular reviews of advance care plans mean checking if there is a form in the clinical records from when the resident was admitted.  

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<thead>
<tr>
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<th>True</th>
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<th>Don't Know</th>
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<tbody>
<tr>
<td>3</td>
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</table>

The “Understanding the Dying Process” brochure is appropriate to give to family members at a palliative care case conference.  

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<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don't Know</th>
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<tbody>
<tr>
<td>4</td>
<td></td>
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</table>

It is appropriate to accept a careworker estimation of the severity of a resident’s dyspnoea if they cannot remember what rating score a resident provided them.  

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don't Know</th>
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<tr>
<td>5</td>
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</table>

Attitudes and beliefs of residents, family and health professionals can be barriers to effective pain management.  

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don't Know</th>
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<tbody>
<tr>
<td>6</td>
<td></td>
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</table>

A resident with chronic pain that is moderate to severe intensity will look pale, perhaps be sweating and have changes in their heart rate and/or blood pressure.  

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<th>False</th>
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<tr>
<td>7</td>
<td></td>
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</table>

A tingling, burning pain that runs around one side of the chest wall between two ribs is most likely to be neuropathic in origin.  

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<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don't Know</th>
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<tbody>
<tr>
<td>8</td>
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</table>

It is up to the nurse to assess the condition of a resident’s oral health each day.  

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<th></th>
<th>True</th>
<th>False</th>
<th>Don’t Know</th>
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<tbody>
<tr>
<td>9</td>
<td></td>
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</table>

A resident with dementia exhibits fluctuating confusion and wakefulness. This is best attributed to the dementia itself.  

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<th>True</th>
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<th>Don’t Know</th>
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<tbody>
<tr>
<td>10</td>
<td></td>
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</table>

Alfred has not responded to environmental and nursing interventions for his delirium. You should question the GP’s order of a dose of diazepam to help manage Alfred’s hallucinations.  

<table>
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<tr>
<th></th>
<th>True</th>
<th>False</th>
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<tbody>
<tr>
<td>11</td>
<td></td>
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</table>

Urinary tract infections that are the cause of a delirium should always be treated.  

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<th></th>
<th>True</th>
<th>False</th>
<th>Don’t Know</th>
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<tbody>
<tr>
<td>12</td>
<td></td>
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</table>

The GP is responsible for initiating the use of an End of Life Care Pathway when a resident is expected to die in the next week.  

<table>
<thead>
<tr>
<th></th>
<th>True</th>
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<tbody>
<tr>
<td>13</td>
<td></td>
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</table>

A resident born in India lists their religion as Buddhist. This means that they must not be given strong analgesics or sedatives, especially at the end of life as it is important for the mind to be clear.  

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don’t Know</th>
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</thead>
<tbody>
<tr>
<td>14</td>
<td></td>
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</tbody>
</table>

If Rhonda’s Modified Bereavement Risk Index score is eleven, you only need to give her a copy of the “Now What? Understanding Grief” booklet.  

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don’t Know</th>
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</thead>
<tbody>
<tr>
<td>15</td>
<td></td>
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</tbody>
</table>
## Section 1

1. The resident and/or family must provide the nurse with information concerning their wishes about end of life care at the initial assessment and care planning interview after admission.

- An advance care plan does not have to be completed in one sitting. The best outcomes may come from any number of conversations. Giving a resident the time to think about your questions is very important.
- Advance care planning should be part of the routine processes for every resident soon after admission to a residential care facility.
- A nurse-led care conference is recommended to facilitate this process. We suggest that the residents’ GP be invited to attend (or at least be made aware of any wishes or decisions regarding advance care planning).

2. There is no way of recording treatment preferences for a resident who has advanced dementia and did not record their wishes on a legal document when they still had mental capacity.

- The resident’s wishes can still be obtained from family members if known and recorded in the clinical record as an important but not legally binding guide for members of the health care team to follow.
- A good example is the “good palliative care plan”.

3. Regular reviews of advance care plans mean checking if there is a form in the clinical records from when the resident was admitted.

- Reviewing does not simply mean checking if there is an advance care plan present in the notes. The actual decisions a resident has made need to be reviewed with them on a regular basis.
- As part of your holistic care review (every 3 months?) ask:
  - Are these still your wishes?
  - Has anything changed in your life since our last review?
  - Do any of these changes reflect on your documented wishes?
  - Are there any changes you would like to make to your advanced care plan?

4. The “Understanding the Dying Process” brochure is appropriate to give to family members at a palliative care case conference.

- Often in times of stress, residents and family members may not remember all that is discussed. Suitable resources should be available in order to complement the information you provide them in the case conference.
- However, written information should not be used as a substitute for personal conversations.
5 It is appropriate to accept a careworker estimation of the severity of a resident’s dyspnoea if they cannot remember what rating score a resident provided them.  
- Because health professionals tend to under-report a patient’s breathlessness the resident should be encouraged to rate the severity themselves (if cognitively aware).

6 Attitudes and beliefs of residents, family and health professionals can be barriers to effective pain management.  
- Attitudes and beliefs can cause reluctance to report pain or prescribe/administer appropriate analgesics.  
- Examples of faulty attitudes/beliefs include:  
  - “People with dementia don’t feel pain”  
  - “It’s normal to have some level of pain as you age”  
  - “Opioids hasten death”.  

7 A resident with chronic pain that is moderate to severe intensity will look pale, perhaps be sweating and have changes in their heart rate and/or blood pressure.  
- In palliative care, pain is usually chronic and the obvious signs such as pallor, sweating, or changes in blood pressure may not be seen.

8 A tingling, burning pain that runs around one side of the chest wall between two ribs is most likely to be neuropathic in origin.  
- Neuropathic pain often follows dermatome/nerve distribution paths.  
- It is described as burning, shooting, radiating, tingling, numbness, pins and needles or deep aching.

9 It is up to the nurse to assess the condition of a resident’s oral health each day.  
- Careworkers are in an ideal position to check for problems related to oral health.  
- Encourage them to check and report to a nurse anything out of the ordinary at meal times, when providing mouth care, cleaning dentures etc.

10 A resident with dementia exhibits fluctuating confusion and wakefulness. This is best attributed to the dementia itself.  
- Dementia has no diurnal effects and symptoms are progressive yet relatively stable over time.  
- Delirium however has short, diurnal fluctuations in symptoms; worse at night in the dark and on awakening.

11 Alfred has not responded to environmental and nursing interventions for his delirium. You should question the GP’s order of a dose of diazepam to help manage Alfred’s hallucinations.  
- Benzodiazepines do not improve cognition but may help associated anxiety.  
- Benzodiazepines may in fact worsen delirium if not used in combination with an antipsychotic drug such as haloperidol.
12 Urinary tract infections that are the cause of a delirium should always be treated.

- When a resident is approaching the terminal phase of a terminal illness, it is not always appropriate to actively treat the cause of delirium, even if the cause is known.
- Decisions need to be informed by the resident's prognosis and any advance directives about active treatment.

13 The GP is responsible for initiating the use of an RACEoLCP when a resident is expected to die in the next week.

- It is the role of the nurse to initiate the use of the End of Life Care Pathway, with GP approval obtained within 48 hours.
- The resident's family must also be contacted.

14 A resident born in India lists their religion as Buddhist. This means that they must not be given strong analgesics or sedatives, especially at the end of life as it is important for the mind to be clear.

- Just because someone was born in a particular country or speaks a different language does not mean that we can assume their religious, spiritual or social rituals and preferences are the same as they are described in a reference book.
- ALWAYS seek this information out early to avoid problems.

15 If Rhonda's Modified Bereavement Risk Index score is eleven, you only need to give her a copy of the "Now What? Understanding Grief" booklet.

- For a high risk score of 10 or more: Rhonda should be encouraged to contact a health professional e.g. General practitioners, psychologist, counseling service or bereavement counselor.
- AND give her the booklet – Now What? Understanding Grief.
Bibliography – SDLP - Nurse (Advanced)


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


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


Careworker (Introduction)
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:

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: Suits 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.

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

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.
Welcome to this self-directed learning package (SDLP) about providing a palliative approach to residents in residential aged care facilities (RACFs).

Aims of this learning package

After working through this package you will be able to:
• describe what a palliative approach is, and identify when a resident is palliative
• understand the process of advance care planning, and how it can benefit the resident, their family and the aged care team
• describe how you as a careworker can contribute to a palliative care case conference
• describe why it is important to know a resident’s cultural background and preferences
• identify common clinical problems in the palliative phase, report them to nursing staff, and provide relevant care within your scope of practice
• understand the benefits of an end of life care pathway and the role of the careworker during the final week/s of a resident’s life.

What do I have to do?

You will be asked at specific times to watch two DVDs:
• “Suiting the needs” (produced by Palliative Care Australia)
• “All on the same page” (developed specifically for this toolkit).

These DVDs highlight important aspects of the information you will be reading about in this package. Each runs for less than 15 minutes. To complete this package you need access to a DVD player so make sure you have that before you commence.
We will ask you to reflect on the case studies of Bob and Alfred and to take note of important points. Throughout the package you will see these symbols:

**Thinking Point**
Thinking Points indicate that you should stop and think about the information, questions or ideas being presented. We encourage you to write down your thoughts but this is not compulsory.

**Key Point**
Key Points highlight information or an activity that is critical to your learning in this package.

### ‘See, say, do, write, review’

The “see, say, do, write and review” model breaks down clinical care into five key actions. You will see these prompts throughout the learning package:

- See – Recognise and assess
- Say – Report your assessment
- Do – Manage the symptom
- Write – Document your actions
- Review – Evaluate and reassess as necessary

### Assessment

At the end of this package are a series of questions that will assist you to demonstrate your understanding of the care of a resident who requires a palliative approach. You are encouraged to talk with your supervisor or education facilitator if you are unsure about anything in this package.

### How long will this take?

We anticipate it will take you 2 hours to complete the SDLP. This estimate includes viewing time for the two DVDs (approximately 26 minutes).

**Key Point**

Please note for the purposes of this toolkit, nurse will refer to registered and enrolled nurses and careworker will refer to personal careworkers, health careworkers and assistants-in-nursing.

OK... LET'S GET STARTED
SECTION 1

Bob

In this first section we will help you answer these questions:

- What is palliative care?
- What is a palliative approach and when is a resident palliative?
- What is advance care planning and how can it help a resident, their family and health care staff?
- What can you do to identify, report and manage dyspnoea (shortness of breath)?

**Key Points**
Before reading any further, watch the DVD “Suiting the needs”. We will refer back to scenes throughout this first section, so you may want to take some notes of the DVD’s key messages.

While watching the DVD you were introduced to Bob and his wife June.

**Case study - Bob**
Bob is a 75 year-old retired house painter. Imagine that he was admitted to your RACF just over 12 months ago when his breathing deteriorated and he could not cope at home even with home supports.

Bob has emphysema (chronic obstructive pulmonary disease) and on rare occasions requires oxygen. He has no cognitive memory deficits and is competent to make decisions about his care. Careworkers need to assist him with showering.

He recently was admitted to hospital when his breathing became very difficult. This scared him and he worries that it will happen again.

His wife June has some arthritis but is still able to live independently at home. She visits Bob after lunch almost every day. Bob has one son, William who visits every two weeks.
What is palliative care?

The World Health Organisation defines palliative care as:

An approach that improves the quality-of-life of individuals and their families facing the problems associated with life-threatening illness, through the perception and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. 13

Three forms of palliative care 4,5

<table>
<thead>
<tr>
<th>Key Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>When you think about a palliative approach for residents in RACFs, it is important to distinguish between a palliative approach, specialist palliative care and terminal care.</td>
</tr>
</tbody>
</table>

A palliative approach

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.

Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying.

<table>
<thead>
<tr>
<th>Key Points</th>
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<tbody>
<tr>
<td>A palliative approach is not restricted to the last days or weeks of life.</td>
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</tbody>
</table>
Why is a palliative approach important?

A palliative approach can:

- reduce distress for residents and their families
- reduce transfers to hospital because aged care staff develop skills to manage the palliative care needs of residents
- help to involve the resident and their family in decision making about their care
- encourage open and early discussion about death and dying which helps advance care planning
- provide opportunities for improved control of pain and other symptoms
- allow the resident to be cared for by staff that they know and have developed a rapport with.

Bob has chronic obstructive airways disease (COPD)/emphysema that is worsening. He has already been admitted to hospital once and has said he doesn’t want this to happen again.

A palliative approach aims to reduce his suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.

Bob needs review of his symptoms particularly his shortness of breath. He also has some psychological and social needs that require discussion with his GP, the nursing staff and his wife.

Thinking Point
So it seems that a palliative approach is appropriate for Bob. Would any of your current residents benefit from a palliative approach?

Specialist palliative care

In the DVD, Peter, the GP suggested getting a specialist palliative care team to help plan for and treat Bob’s severe breathlessness.

A small number of residents may experience severe or complex problems as their condition advances. These may be physical symptoms or complex ethical dilemmas, family issues or psychological distress.

Specialist palliative care teams do not usually take over the care of residents but instead can provide advice on complex issues and support to GPs and the aged care team.

Terminal care

Whereas palliative care may take place over many months, terminal care is the care focused on the final days or weeks of life.

This form of palliative care is appropriate when the 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 the resident’s physical, emotional and spiritual comfort and support for the family, including bereavement care.

Identifying when a resident is moving into the terminal phase is not easy because there are few clear indicators to identify when a person should be considered for end of life care. (You will read about this in more detail later in this package).
Advance care planning

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

Advances in medical technology have allowed people to survive longer despite many chronic illnesses. It is good news that many of us will live to a very old age, but people often survive with lots of problems. We now have the technology to keep people alive artificially, where in the past, they may have died naturally.7

Thinking Point
The tough question is just how much invasive or aggressive medical attention is a good thing. The best answer is that it is up to everyone as individuals to decide for themselves. Have you thought about:

• What constitutes quality-of-life for you?
• What types of invasive medical procedures do you consider to be undesirable?
• If you had multiple physical problems, at what point, would you want the doctors to stop trying to prolong your life?
• What are your values and beliefs (religious, spiritual or otherwise)?
• When your time eventually comes, what would constitute a ‘good death’ for you?7

Most people never speak about these issues. When people are critically ill, they are usually unable to participate in these important decisions.7
Planning ahead

**Thinking Point**
When do you think discussions with residents and their family members about advance care planning should be conducted? Immediately after admission? After several months? When a resident becomes terminally ill?

**Key Point**
Advance care planning should be routine practice for every resident soon after admission to a residential care facility.

It is never too early to consider, and write down, thoughts and wishes regarding end of life care. In fact, it is preferable to consider these issues clearly and calmly when the matter is not urgent or critical.

Most residential aged care facilities provide residents and family with information about advance care planning on admission. A discussion between the resident (if able), family, nursing and medical staff will often take place about this time. The outcomes of this discussion are recorded in the resident’s file.

**Key Point**
Advance care planning should be seen as an ongoing process rather than a single event.

Writing it down

In the DVD, Bob wanted to make sure that everyone knew that he did not want to be ‘kept alive’ with a ventilator if his breathing condition worsened again. We saw Bob talking with his GP, nurse, wife and careworker about his wishes. He was keen to ‘...get it down in writing’.

**Key Point**
Having a written advance care plan or directive can improve end of life care and reduce unwanted and unneeded medical treatments and hospitalisations.

Advance directives are legal documents that record the resident’s wishes about their care if they are unable to voice these wishes themselves. They can also appoint a substitute decision maker, usually called a guardian or medical power of attorney.

**Key Point**
Every Australian State and Territory has different legislation, guidelines and documents for advance care planning, and where they exist, advance directives. The CareSearch website is a good place to start to find out more: www.caresearch.com.au

Table 1 displays an example of part of an advance health directive.

Be mindful that the resident’s end of life care wishes need to be revisited over time. Residents and families may change their minds, or become clearer about their wishes concerning end of life options. Perhaps, like Bob, they have a distressing experience where they are transferred to hospital and are anxious that this not happen again.
Table 1
Example of an advance health directive form

The directions you give in this section apply only if, in the opinion of your treating medical practitioner:
- you have a terminal, incurable, or irreversible illness or condition,
- or you are in a persistent vegetative state,
- or you are permanently unconscious,
- or your are so seriously ill or injured that you are unlikely to recover to the extent that you can survive without the continued use of life-sustaining measures.

I request that:

- everyone responsible for my care initiate only those measures that are considered necessary to maintain my comfort and dignity, with particular emphasis on the relief of pain.

  Initial here:

- any treatment that might obstruct my natural dying either not be initiated or be stopped.

  Initial here:

- unless required for my dignity and comfort as part of my palliative care, no surgical operation is to be performed on me.

If I am in the terminal phase of an incurable illness:

- I do not want cardiopulmonary resuscitation. Initial here:

- I do want cardiopulmonary resuscitation. Initial here:

- I do not want assisted ventilation. Initial here:

- I do want assisted ventilation. Initial here:

- I do not want artificial hydration. Initial here:

- I do want artificial hydration. Initial here:

- I do not want artificial nutrition. Initial here:

- I do want artificial nutrition. Initial here:

- I do not want antibiotics. Initial here:

- I do want antibiotics. Initial here:
Does advance care planning have to be a legal process?

It is not compulsory to complete a legal form. Not all residents are willing (or able) to complete a legal document such as an advance directive.

The Good Palliative Care Plan, developed in South Australia is an alternative option. It can be used in any state or territory and while not legally binding provides opportunity for documenting the outcomes of a discussion about the resident’s current condition and goals of care. Table 2 provides a segment of this document.

Table 2
Excerpt from the Good Palliative Care Plan

<table>
<thead>
<tr>
<th>Circle one of the options:</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have agreed that in the event of further deterioration in the patient’s condition:</td>
</tr>
<tr>
<td>1. Full cardiopulmonary resuscitation with total body support as required will be undertaken.</td>
</tr>
<tr>
<td>2. Intensive medical support will be undertaken, but cardiopulmonary resuscitation will not be initiated, and no long-term support measures, including ventilation or dialysis, will be undertaken.</td>
</tr>
<tr>
<td>3. The emphasis of management will be on Good Palliative Care, highlighting the relief of symptoms and discomforts. No artificial measures designed to supplant or support bodily function will be undertaken.</td>
</tr>
<tr>
<td>4. Other. Please specify:</td>
</tr>
</tbody>
</table>

What if a resident is no longer able to express their wishes?

**Thinking Point**
- Bob was able to make his own decisions and put these in writing. Unfortunately, not everyone wants to do this or is able to.
- If Bob had advanced dementia and could not express his wishes about future care, what should happen?
- Should Bob be sent to hospital even if his family say it was not what he wanted?

**Key Point**
If a resident is not competent to make decisions for themselves, they cannot complete an advance health directive or legally appoint someone to advocate on their behalf.

This does not mean that they cannot be involved in discussions about their advance care planning. It is also worthwhile considering the family’s views on what the resident would have wished.

What is my role as a careworker?

Residents and family members often become close to careworkers and may mention issues related to advance care planning with you. Sometimes what seems like a ‘throw away’ comment e.g. ‘I wouldn’t want to live like that’ may be important to follow up.

Ask the resident and/or family member if they would like to talk to a nurse about their concerns, and report back to the nurse so s/he can arrange a meeting. Be alert for any ongoing concerns a resident may raise.

**Thinking Point**
Has a resident or family member ever talked to you about the resident’s end of life care wishes? How did you handle this? Did you report this information to a nurse? Is there anything you would do differently next time?
Dyspnoea is an awareness of uncomfortable breathing. It can also be called breathlessness or shortness of breath.

**Thinking Point**

Have you ever had the experience of not being able to breathe well? Perhaps after a strenuous exercise session? Can you imagine living with that sensation constantly? If you have, what thoughts or feelings come to mind?

The Australian author Tim Winton wrote in his 2008 novel ‘Breath’:

“It’s funny, but you never really think much about breathing, until it’s all you ever think about.”

Dyspnoea

- is common but under-recognised
- impairs activities of daily living, limits mobility, increases anxiety, fear and social isolation
- is often associated by residents and family with impending death
- triggers panic, and panic exacerbates dyspnoea, so the pattern becomes cyclical
- may be equally or even more distressing for the family.

So... what can you do to help a resident with dyspnoea?
Thinking Point
Consider the following scenario: You are walking with Bob to the dining room and he is breathing quickly and having trouble catching his breath, particularly when he speaks. He says he’s been feeling very breathless for a few days.
How would you report this to the nurse?

Key Point
Sometimes it is an emergency
Call a nurse immediately if the resident has dyspnoea and:
• it is rated as (or appears) severe, or
• it prevents the resident from talking, or
• the resident also has chest pain, or
• their skin is pale or cyanosed (i.e. blue tinge to the fingers, lips or tongue).

Thinking Point
Which of the following would be most effective?
Careworker to nurse:
‘Bob appears to be short of breath. He cannot walk to the dining room without having to stop twice to catch his breath. He says it has been a problem for a few days now’.
OR
‘Bob can’t breathe properly, please come and review him’.

Key Point
Residents with dyspnoea benefit from having a preventative plan of care. That is, we use management strategies to prevent the onset, or reduce the impact of, the anxiety and distress of dyspnoea.

Here are some examples:
• Try not to rush or hurry Bob and allow rest periods during activities. This will decrease his need for oxygen and reduce his anxiety levels.
• To prevent feelings of claustrophobia in the bathroom, leave the exhaust fan switched on and make sure the shower water is deflected away from Bob’s face.
• When Bob returns to his room, sit him upright in a chair, perhaps leaning with his arms over a table or over-way table. This will open up his chest and lung space to allow in more air.
• To create a sensation of moving air, open a window or use a fan to circulate air.

Report your assessment
As a careworker you play a critical role in reporting resident’s symptoms to the nursing staff.

Do
Manage the symptom
What will the nurse do?
Bob might be administered a small dose of opioid medication (e.g. morphine) at least 30 minutes before showering. Let the nurse know when you will be showering Bob so they can give the medication at the correct time.

Please note
Morphine can be effective for dyspnoea as well as pain.

Thinking Point
Did you notice that oxygen therapy is not mentioned in the list of management strategies? Does this surprise you?

Key Point
Few residents with dyspnoea actually benefit from oxygen therapy.
Starting oxygen therapy, or changing flow rates, may be dangerous for some residents.
The commencement of oxygen should only be undertaken under the direction of a doctor.
Always provide care as directed in the resident’s care plan. If unsure about any aspect, speak to the nurse.

Write
Document your actions
Many residential aged care facilities expect careworkers to document information on assessment charts and in the clinical record.

Avoid general statements
POOR COMMUNICATION
Evaluation of interventions ‘with effect’ or ‘effective’.

GOOD COMMUNICATION
‘Resident states their dyspnoea has reduced to 2/10 score (was 5/10)’.
Review

Evaluate and reassess as necessary

Thinking Point
You identified that Bob is breathless. You opened his window, propped him up with pillows, and set up a bed-side fan. Great job! Can you tick this off your list? Not quite yet. There is an important question to answer: Did your strategies work?

You can check the effectiveness of your management strategies by asking the resident to rate the severity of their dyspnoea again (using a rating scale), observing their breathing rate, or asking if their mood, sleep or function has improved.

Key Point
It is very important that you then pass this information on to a nurse (and document them if this is part of your role as a careworker).

SUCCESS!
You have completed Section 1 of the learning package.
You may decide to pause now and answer the first six questions of the quiz at the back of this learning package.
In this section we will help you answer these questions:

- What can you do as a careworker to contribute to the success of a palliative care case conference?
- Why is it important to know a resident's cultural background and preferences?
- What can you do to identify, report and manage four clinical issues (pain, nutrition and hydration, oral care, and delirium)?
- What are the benefits of an end of life care pathway? What is the role of a careworker during the final days/weeks of a resident's life?

While watching the DVD you were introduced to Alfred and his daughter Sarah.

**Case study - Alfred**

Alfred is 82 years old and a retired school teacher. Alfred has two children: Andrew who lives overseas and Sarah who lives close by and visits twice weekly.

Alfred's wife Alice was admitted to hospital after a severe stroke and remained there, fed through a gastrostomy tube until she died three weeks later of pneumonia.

After Alice died, Alfred remained at home for nine months with increasing support from home care services. Numerous falls and increasing difficulty with activities of daily living led to admission 18 months ago to a residential aged care facility.

Alfred was a heavy smoker until aged 65 but has not smoked since.

He has osteoporosis, osteoarthritis and fractured his hip three years ago.

He is experiencing short term memory loss but not enough to lose his ability to make decisions. Alfred also has Chronic Obstructive Pulmonary disease (emphysema) and is unable to walk 20 metres before needing to rest. He has been admitted to hospital three times in the last six months for infective exacerbations of this condition requiring steroids and antibiotics. Alfred has not returned to his previous functional level after each episode.
Palliative care case conferences

Thinking Point
In the DVD “All on the same page”, Alfred participated in a palliative care case conference.

• Why has a palliative care case conference been arranged for Alfred?
• What are the main reasons for having a palliative care case conference?
• When is the most appropriate time during Alfred’s stay to have a palliative care case conference?

What is a palliative care case conference?

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

The aims are to:

• identify clear goals of care for the resident including a review of any advance care plans and
• provide a safe environment where issues and questions about end of life care can be raised and appropriate strategies agreed upon for future care.

When should a palliative care case conference be held?

There is no right or wrong time for a palliative care case conference. However, we recommend using the following markers to help decide:

• 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 care or palliative care.
What is a palliative care link nurse?

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

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

Who organises a palliative care case conference and who should attend?

Alfred’s daughter Sarah, Alfred’s GP, and a nurse and careworker from the facility attended Alfred’s palliative care case conference. The nurse organised and facilitated the conference.

Attendees may vary depending on what is being discussed and who is available. However the following people should be considered:

- resident (if capable)
- legal decision maker/medical power of attorney
- family members
- residential facility staff including a nurse and careworker
- allied health e.g. speech pathologist, occupational therapist, physiotherapist, social worker, dietician
- clergy or pastoral care worker
- specialist palliative care nurse or GP

A palliative care case conference may take a few weeks to organise. It is usually organised by a nurse from the residential facility, often a palliative care link nurse.
What is the careworker’s role in a palliative care case conference?

In the DVD “All on the same page” a careworker attended Alfred’s palliative care case conference. She was able to describe important aspects of Alfred’s day-to-day care needs.

Key Point
Careworkers often notice important changes in a resident’s mood, ability to function, swallow, walk, breathe etc. Residents may say things to you that are important for other care providers to know.

As a careworker, you may be invited to participate in a palliative care case conference. During the conference you may be asked to comment on the resident’s physical and mental functioning over the last few months. You may also be asked to comment on the careworker’s role in the future care plan.

If you are not asked to attend, you may be asked to write down on a form any issues you feel should be talked about. Your input is essential in providing a comprehensive overview of the resident’s care needs.

Thinking Point
Think about a resident who’s health is declining. What information would you be able to provide if a palliative care case conference was scheduled?
Cultural considerations

**Thinking Point**
What if, instead of being of Australian descent, Alfred was from another country and spoke very little or no English? How might this affect his care?

Australia has a diverse, multicultural population. Over 22% of Australia’s population was born overseas, representing over 200 different countries. Residents and family members from culturally and linguistically diverse (CALD) populations may have particular needs related to end of life care.

**Key Point**
Having said this, do not make assumptions about cultural needs based on a resident’s language, religion or country of origin. All residents from a CALD background require careful assessment.

Here’s some useful tips for getting it right:
• Do not hesitate to ask about relevant cultural aspects of caring for a resident
• Be aware of customs that show respect
• Respect that people have different reactions towards death e.g. for some Indigenous Australians speaking the name of a deceased person can cause considerable stress
• Communicate in ways that are appropriate e.g. avoid the use of jargon and translate information into terms the family and resident can understand
• Just because someone can understand spoken English does not mean they can automatically read it as well.
Pain

Key Point
Pain is a subjective experience, occurring when and where the resident says it does.
The way that residents experience and make sense of pain is strongly influenced by their previous experiences of pain, culture, spiritual beliefs, social relationships and other physical symptoms they may be experiencing.

See

Recognise and assess
As a careworker, you have a very important role in identifying resident pain.

Thinking Point
Alfred has osteoporosis, osteoarthritis and fractured his hip three years ago.
He is often heard asking careworkers and nurses if it is time for his next dose of pain medication.
He asks for assistance with most activities of daily living because the pain is “terrible”.

• What is the best way to assess Alfred’s pain?
• How do you normally identify if a resident has pain?
• Do you use an assessment tool? Do you write down what a resident says?
If the resident can communicate

Ask the resident if they have any pain.

Tips:

• Older people may deny that they are experiencing ‘pain’. Try using other terms like ‘ache’, ‘soreness’ or ‘discomfort’.

• Most pain in older people is related to activity. Ask about pain when they are active e.g. moving, transferring, being turned in bed, not when they are at rest.

• Allow enough time for the resident to think about the question and reply.

• Ask more than one question: ‘does it hurt anywhere?’, ‘do you have any aching or soreness?’, or ‘do you have any pain or discomfort’?

Severity of pain can be assessed by asking the resident to rate their pain on a zero to ten scale where zero is no pain and ten is the worst imaginable.\(^2\)

Thinking Point

What would happen if Alfred was unable to communicate his pain?

How would you know if he was experiencing pain?

How would you know if a treatment to manage the pain had been effective?

Do you use a pain assessment tool for residents who cannot communicate?

Key Point

The most effective method to assess pain in residents who cannot communicate is to observe behaviours and facial expressions.

If the resident cannot communicate or has a cognitive deficit

One of the most difficult aspects of caring for the resident who cannot communicate or is cognitively impaired (e.g. advanced dementia) is identifying whether they are experiencing pain.

Key Point

Everyone has their own pain threshold and it is unhelpful and unfair to compare the scores of different residents. Instead, compare a resident’s individual scores across time.

Thinking Point

Think of a resident you have cared for with advanced dementia or a communication deficit whom you thought might be experiencing pain. Have you observed any of the following?

• whimpering, groaning or crying

• looking tense, frowning, grimacing, looking frightened

• increased confusion, refusing to eat, alteration in usual behaviour patterns

• perspiring, flushed or pale skin, abnormal temperature, pulse or blood pressure

• skin tears, pressure areas, arthritis, contractures, previous injuries.

These pain behaviours and physical cues are measured in the Abbey Pain Scale. We recommend the use of this scale for people who are unable to communicate.
Key Point
Sometimes it is an emergency
If a resident rates their pain as severe, or they report chest pains and difficulty breathing: treat it as an emergency and call a nurse immediately.

Say
Report your assessment
Try and provide as much information as possible when reporting to the nurse. This will allow them to decide how urgently they need to review the resident.

Thinking Point
Which of the following do you think will get the best response?
Careworker to nurse:
‘Alfred appears to have pain. He grimaces when we transfer him from sit to stand. This is not his normal behaviour. It has happened three times today so far. He says it is a new pain’.
OR
‘Alfred has got pain. You need to see him to sort it out’.

Do
Manage the problem
Non-pharmacological therapies
Careworkers can assist in managing a resident’s pain with some simple yet effective activities. Therapies such as massage can provide relief for residents.

Pharmacological therapies
Medications have an important role in managing many types of pain.

Key Point
Consider waiting at least 30 minutes after a resident has been given pain (analgesic) medication before providing any care that is known to cause pain or discomfort.
**Myths about opioids**

Opioids (e.g. morphine, oxycodone, nalore or fentanyl) are a type of strong analgesic.

Sometimes residents, family members and even aged care staff may have concerns about these medications.

It is important to know that, when used correctly, opioid medicines:

- Do not lead to addiction or dependence
- Opioid medicines are not addictive when used for pain. Addiction only occurs when people have no pain and they abuse opioid medicines.
- Do not hasten death
  - Morphine and other opioid medicines are for improving life - not hastening death. Some people fear that being prescribed opioid medicines means that they’re closer to the end. However, relieving pain changes the quality of life - not its length.
- Do not cause terrible side-effects
  - All medicines can have side effects. The side effects of opioid medicines (constipation, drowsiness, nausea, dry mouth) are usually manageable.

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**Write**

**Document your actions**

Many residential aged care facilities expect careworkers to document information on assessment charts and in the clinical record.

**Avoid general statements**

<table>
<thead>
<tr>
<th>POOR COMMUNICATION</th>
<th>GOOD COMMUNICATION</th>
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<tr>
<td>Evaluation of interventions for pain 'with effect' or 'effective'.</td>
<td>'Resident states pain has reduced to 2/10 score (was 5/10)'.</td>
</tr>
</tbody>
</table>

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**Review**

**Evaluate and reassess as necessary**

**Thinking Point**

You identified that Alfred has pain. You helped him straighten up in bed, massaged the painful area (as directed in the care plan) and asked the nurse about some analgesic medication. Great job! Can you tick this off your list? Not quite yet. There is an important question to answer: Did your strategies work?

You can check the effectiveness of your management strategies by asking the resident to rate the severity of their pain again (using a rating scale), observing their behaviours or facial expression, or asking if their mood, sleep or function has improved.

**Key Point**

Once you review and reassess a resident it is very important that you pass this information on to a nurse (and document your assessment if this is part of your role as a careworker).
Nutrition and hydration

One of the big worries that Alfred’s daughter, Sarah, had at the palliative care case conference was that Alfred might starve to death if he is unable to eat and drink. Remember that Sarah’s mother was fed through a gastrostomy tube after she had a stroke. This continued for three weeks before she died of pneumonia.

See

Recognise and assess
Alfred is drowsy and needs prompting to accept a drink from a cup and straw.

He only eats a few mouthfuls of food and sometimes coughs when he swallows. Alfred is dying and this is causing his eating and drinking problems. This is often a difficult and emotional time for families and can sometimes be hard for staff to manage.

Key Point
At the end of life the body is beginning to shut down because of the dying process, not because of the absence of food and fluids.

Family members often find it difficult to distinguish between ‘not eating as part of the dying process’ and ‘not eating as bringing about the dying process’.

Helping families understand
The PA toolkit contains a brochure “Understanding the Dying Process” which can be given to family members when the resident is in the palliative or terminal phase.

Table 3 provides a brief segment from the “Understanding the Dying Process” brochure. This brochure is included in the PA Toolkit and we recommend you familiarise yourself with the document.

Table 3
Segment from “Understanding the Dying Process” brochure
Most people lose their appetite in the last few weeks of life. This is a very natural and normal part of the dying process because metabolism is slowing down and the body requires less nutrition.

At this time your instincts may be to try and feed the person in order to keep up their strength. The giving of food is often symbolic of loving and nurturing and to deprive someone of this may feel like neglect. However, as the person becomes increasingly weak and drowsy, swallowing and digesting food and fluids often becomes harder and can place strain upon the body.

Whilst the person may have a reduced oral intake, it is important to maintain good oral care. Regular moistening of the mouth and lips will add to the person’s comfort.

Say

Report your assessment
As a careworker you play a critical role in reporting resident’s symptoms to the nurse.

Thinking Point
Consider the following scenario:
Alfred cannot feed himself now. When you help to feed him, you notice he falls asleep whilst chewing and sometimes coughs.

How would you report this to the nurse?
Try and provide as much information as possible when reporting to the nurse. This will allow them to decide how urgently they need to review the resident.

Thinking point
Which of the following do you think will get the best response?

Careworker to nurse:
‘Alfred appears to be having trouble drinking and eating. He has been getting worse over the last few days and it seems to be related to him becoming drowsier’.

OR
‘Alfred is refusing to eat or drink’.

Decision making
There is no simple answer to whether these interventions are right or wrong. The benefits of artificial nutrition or hydration need to outweigh the potential burden and side effects for the resident. Residents and family members cannot make the best decisions if they do not have enough information. Conversations with the nurse and doctor about the positive and negative aspects of artificially providing food or fluids are very important at this stage.

Artificial nutrition

Key Point
For residents requiring a palliative approach, there is limited evidence that tube feeding prolongs life, improves comfort or quality-of-life, prevents aspiration pneumonia, leads to better nourishment or decreases the risk of pressure sores.

Artificial hydration

Thinking Point
Alfred is unconscious and you would not be surprised if he dies in the next two to three days. A fellow careworker is upset that Alfred cannot drink. He says ‘How bad must it be for Alfred being so dehydrated, he should have a saline drip’.

Do you agree with his comments?

Do

Manage the problem

Key Point
Diligent hand feeding and offering drinks frequently is important for all residents.

If Alfred becomes unable to swallow, staff should cease offering food and drink, instead focusing on excellent mouth care.

When a resident cannot swallow food or fluids by themselves, it is possible to provide these by artificial means such as through a tube (PEG tube) or SC (subcutaneous cannula) ‘drip’. 
Artificial hydration is usually administered via a small cannula placed under the skin (a subcutaneous (SC) drip). Although artificial hydration can be useful to treat reversible causes of dehydration, it is not normally used when a resident is expected to die within 48 - 72 hours.

Similarly, moistening the mouth of a resident who can no longer swallow fluids will keep them comfortable as much as or more so than a ‘drip’.

**Write**

**Document your actions**

Many residential aged care facilities expect careworkers to document information on assessment charts and in the clinical record. If this is part of your role, try and avoid general statements. Be as specific as possible.

**Avoid general statements**

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<tr>
<td>Evaluation of artificial hydration ‘with effect’ or ‘effective’.</td>
<td>‘Resident denies thirst or discomfort, mouth moist and intact, urinary output still moderate’.</td>
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</table>

**Review**

**Evaluate and reassess as necessary**

Just because artificial nutrition or hydration has been started does not mean that it should be continued until the resident dies.

Artificial hydration needs to be reviewed regularly by the nurse and doctor to ensure it is still the most appropriate intervention for the resident. In the terminal phase, assessment should occur daily.
As a careworker you play an integral role in maintaining good oral hygiene for the resident and managing common oral health problems.

**Key Point**

Check the resident’s oral cavity regularly for problems every time you assist with feeding, providing fluids or mouth care. If you do not know how to do this, ask a nurse who will help you.

You should look for any of the following:

- bad breath
- sore mouth and gums
- lip blisters/sores/cracks
- difficulty eating
- broken teeth
- bleeding gums
- reports of pain in mouth/lips
- tongue coated or abnormal colour
- excessive food left in mouth
- mouth ulcer
- refusing oral care
- swelling of face/mouth
- dentures broken/lost.

Dry mouth (xerostomia) is the most common oral problem at the end of life.\(^\text{10}\)
Say

Report your assessment

Report to the nurse if you see any of the problems listed previously.

Residents get the best outcomes when you provide clear information about the resident.

Thinking Point

Which of the following do you think will get the best response?

Careworker to nurse:
‘Alfred appears to have a very dry mouth. Swallowing anything more than water is difficult. His tongue is dry and has white spots and there are some cracks in the corners of his lips. He says it got much worse when the strong pain medications began’.

OR

‘Alfred has problems with his mouth. You better take a look’.

Do

Manage the problem

The best clinical outcomes will be achieved if care plans are developed after careful assessment of the resident’s oral cavity.

Thinking Point

Alfred’s medications cause a dry mouth, he occasionally uses oxygen and often sleeps with his mouth open. He has a ‘sore’ spot on his gum and his tongue is coated. What could you do to help Alfred with his dry mouth?

Dry mouth (xerostomia)

- moisten oral cavity with frequent rinsing and sipping of water
- apply water-based moisturiser to lips
- discourage strong cordials, juices or sugary drinks
- reduce caffeine intake
- stimulate saliva with tooth friendly lollies
- encourage resident to drink water after meals, medications and other drinks and snacks
- use saliva substitutes such as a water spray or an oral balance gel or liquid.

Pain or ulceration

- help the resident to rinse or swab their mouth with warm saline three to four times a day until resolved
- check the fitment of dentures
- avoid spicy or acidic foods or food with sharp edges
- offer cold, soft food
- local or systemic analgesics may be required
- medical review if not resolved within seven days.

Coated tongue, mucosa or teeth

- remove debris with a soft toothbrush or mouth swab
- help the resident to rinse or swab their mouth with warm saline three to four times a day until resolved
- brush tongue gently with soft toothbrush.
Oral care in the final days of life

In the final scenes of the “All on the same page” DVD, Alfred has only hours or days left to live. He cannot swallow food or fluids, is very drowsy, and breathes through his mouth. His tongue and lips are dry.

Thinking point
Think about when you have a dry mouth. When you moisten it with water, how long does it take until the dryness returns? Not very long? Perhaps five minutes?
Imagine you are Alfred who relies on you to provide this comfort measure for him.

As a resident approaches death they lose the ability to feed themselves or have a drink. Eventually swallowing becomes difficult and unsafe. Functionally they cannot clean their teeth or oral cavity by themselves. Often this is when a ‘mouth care’ trolley or tray is seen in the resident’s room.

Key Point
Every time you attend to a resident:
- Apply dry mouth products: e.g. water spray, oral balance gel or liquid via mouth swabs.
- Apply water based lip moisturisers: Do not use petroleum based products (e.g. vaseline) as they can increase the risk of inflammation and aspiration pneumonia; also contraindicated during oxygen therapy.

Key Point
Some preparations may damage oral tissues or increase the risk of infection.
Do not use mouthwashes and swabs containing:
- lemon and glycerine
- sodium bicarbonate (high strength)
- preparations containing alcohol (Listerine mouthwash) or hydrogen peroxide
- pineapple or other acidic fruit juices.
Write

Document your actions

Many residential aged care facilities expect careworkers to document information on assessment charts and in the clinical record. If this is part of your role, try and avoid general statements. Be as specific as possible.

Avoid general statements

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<td>‘Resident commenced on treatment for mouth ulcers. Sore spot on inside of mouth resolved’.</td>
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Review

Evaluate and reassess as necessary

Thinking Point

You identified that Alfred cannot swallow anymore and you reported this to the nurse. When you enter his room, you always swab his mouth and apply lip balm. Great job! Can you tick this off your list?

Not quite yet.

There is an important question to answer:
Did your strategies work?

Key Point

Once you review and reassess a resident it is very important that you pass this information on to a nurse (and document your assessment if this is part of your role as a careworker).
Delirium in older people is often overlooked and misdiagnosed, especially at the end of life. It can be distressing not only for the resident but for family and health workers.

**See**

**Recognise and assess**

**Thinking Point**
When you started your shift Alfred was his usual self, quite alert with only minor memory impairment. Towards the end of your shift you notice Alfred has become very drowsy. He is mumbling nonsense about “catching chickens” and keeps trying to get out of bed. He cannot tell you where he is and does not recognise his daughter when she comes in to visit. Three days ago he was diagnosed with a urinary tract infection.

- Which of the information above indicates that Alfred may be suffering a delirium?
- What might have caused Alfred to become confused?

**Key Point**
Delirium is characterised by disorganised thinking and behaviour, and reduced ability to focus, sustain or shift attention from one thing to another. Hallucinations or delusions can also occur (but not always). The disturbance develops over a short period of time and generally fluctuates during the course of the day. Delirium usually only lasts for a few days but may persist for weeks or even months. Delirium can be caused by a combination of factors including dehydration, medication side-effects, uncontrolled pain and infections.
Say

Report your assessment

Signs of delirium always need to be reported to a nurse.
Be as clear and detailed as possible.

Thinking Point
Which of the following do you think will get the best response?
Careworker to nurse:
‘Alfred appears to be confused. He wants to go and catch chickens. He seems to have become confused following a urine infection last week’.
OR
‘Alfred is confused. You need to see him to sort it out’.

Do

Manage the problem

It may be appropriate to treat the cause of delirium (if it is known). However, at the end of life simple measures aimed at managing the symptoms may be preferable.

Thinking Point
Imagine you are Alfred. It is night-time and you are lying in your bed. It is dark, no one is around and you are confused, frightened and not sure where you are. You hear noises outside your door that sometimes disturb you. Perhaps you want to get out of bed to find somewhere better to be.
Look at the following lists of strategies. Which of these measures might help you feel less confused and anxious?

Environmental strategies
• appropriate lighting
• minimise noise especially at night
• provide a clock that the resident can see
• avoid room or location changes and keep personal and familiar objects in view
• modify the environment to minimise the risk of injury
  e.g. low bed in the lowest position with cot sides down, bed against the wall, potential hazards such as bedside tables removed.

Clinical strategies
• address anxiety; residents with delirium are often very frightened
• manage discomfort or pain
• minimise sensory deficits by providing and assisting with hearing and visual aids
  e.g. clean spectacles and remove wax deposits in hearing aids, check batteries are fresh and hearing aid is turned on
• encourage the presence of people known to the resident
  e.g. family and friends and regular staff members
• reassure and reorientate the resident
• explain and reassure the resident and/or family regarding the possible causes of the delirium and describe the management plan
• avoid use of physical restraints
• use interpreters and communication aids for residents with culturally and linguistically diverse needs (CaLD)
• promote relaxation and sufficient sleep
  e.g. assisted by massage and/or encouraging wakefulness during the day
• minimise use of indwelling catheters
• medication review
  e.g. cease or reduce all non-essential medications; change to a different opioid medication; utilise medications to target agitation or hallucinations.
Write

Document your actions

Many residential aged care facilities expect careworkers to document information on assessment charts and in the clinical record. If this is part of your role, try and avoid general statements. Be as specific as possible.

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<td>Evaluation of interventions ‘with effect’ or ‘effective’.</td>
<td>‘Resident has not reported hallucinations in the last two hours and physical plucking at the bed sheets has stopped’.</td>
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Review

Evaluate and reassess as necessary

It is important to evaluate the effectiveness of the care you deliver to residents.

Every time you provide care to a resident, ask yourself:

- Does it seem to be effective?
- Is it doing any harm?

Key Point

Delirium can develop quickly, regular assessment is important.

If you have any concerns, report them to the nurse (and document them if this is part of your role as a careworker).
Terminal care is care focused on the final days or weeks of life.

**Thinking Point**

*In the final scenes of the DVD, Alfred is likely to die within days or hours.*

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

Residents may experience some or all of the following when approaching death:

- 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.

**What is an end of life care pathway?**

An end of life care pathway is a set of forms and protocols that acts as a ‘road map’ to guide the care provided by doctors, nurses and careworkers in the last week of a resident’s life.

There are several pathways used in RACFs and hospitals. We recommend the ‘Residential Aged Care End of Life Care Pathway (RAC EoLCP)’. This pathway can be downloaded from [http://www.health.qld.gov.au/pahospital/services/pal_care.asp](http://www.health.qld.gov.au/pahospital/services/pal_care.asp).
When someone is commenced on the RAC EoLCP the following changes to their care may occur:

- Non-essential medications are stopped.
- Changes occur in how other medications are administered. Medication may be administered by injection or under the tongue instead of orally. The medication may target pain, nausea, anxiety or breathing difficulties.
- Non-essential clinical interventions and observations are stopped e.g. blood pressure monitoring, weighs, blood sugar monitoring.
- Special equipment may be organised e.g. a special pressure relieving mattress or other comfort aids.

**What is the careworker’s role when a resident is on the RAC EoLCP?**

Your role includes delivering the care listed on the Pathway’s comfort care chart.

You may be asked to fill this in regularly during your shift.

---

**Thinking Point**

Alfred looks like he may die in the next day or so. He is not eating and drinks only a few sips of water each shift. He spends most of the time sleeping and needs assistance with all of his ADLs. When he is asked a question he sometimes opens his eyes but does not speak. This has been a significant change for the worse from one week ago.

Do you think he is displaying signs of approaching death?

---

**Key Point**

Report to a nurse if the resident appears to have any of the following:

- pain
- nausea and vomiting
- breathing difficulties
- agitation
- any redness or leaking around a subcutaneous cannula (butterfly needle).

The chart also sets out common comfort care measures that are reviewed at least every four hours:

- comfortable positioning
- couth care
- eye care
- skin care
- micturition (urinary elimination)
- bowel care.

---

**Support for resident and family members**

**Thinking Point**

Alfred’s daughter Sarah has met you many times when she visits her father. Today she approaches you and starts crying. She asks you how long you think it will be until Alfred dies. What could you do?
Family members often spend many hours with the resident at this time. They may share with you their sadness and grief. They may ask you questions about what is happening.

**Key Point**

It is OK to respond to these questions so long as they are within your scope of practice as a careworker. If you are unsure of what to say (or the questions are about nursing or medical issues), reassure the family and tell them you will ask the nurse to come and speak with them.

When the resident dies

When death occurs, the resident stops breathing and the heart stops beating. There will be no response to verbal or physical stimulation. The mouth and eyes may be open (the pupils will be large and fixed on one spot). The resident may have also lost control of their bladder and bowel.

If you are the first person to find a resident who has died, immediately notify a nurse. They will contact the doctor who will need to legally certify that the resident has died.

**Grief and loss**

Reminisce with family and friends of the deceased resident if you feel comfortable to do so. It shows you saw the resident as an individual, not just “another resident”.

Acknowledge the grief of those around you. If family members are visibly upset, you may for example say ‘It must be hard for you; it is a difficult time...’ Showing family members you are upset e.g. crying is all right.

**Key Point**

No one ever complained that someone cried; but they have complained that no one seemed to care.

**Self-care**

Close relationships can develop between careworkers and residents. It is important to be aware that when a resident dies, you may grieve as well. You are not expected to be a robot, and it is possible that you may feel sad, angry, upset, confused, guilty or even relieved at this time. Feelings of grief are different for everyone and are a normal reaction to a loss.

The following suggestions may assist you with your 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.

**SUCCESS!**

You have completed Section 2 of the learning package. Please go on with the quiz.
Section 1

1. With a palliative approach, the focus is on managing symptoms and increasing quality-of-life rather than curing illness.

2. A palliative approach discourages discussion about death and dying as it may upset the resident.

3. A resident completes a written Advance Directive. This is considered a legal document.

4. Shortness of breath is the same thing as dyspnoea.

5. It is a good idea to ask a resident to rate his shortness of breath by asking him to count how many breaths he takes a minute.

6. You are asked to help Bob shower this morning. You should rush him and get it over as quick as possible then he can take the rest of the day to recover.

Section 2

7. Family members have the right to determine if a resident should attend a palliative care case conference on the grounds that ‘it will only upset him/her’.

8. Regardless of the language a resident speaks or where they were born their care needs are the same when they are dying.

9. If a competent resident tells you they have pain, is it good practice to ask how severe it is on a scale of 0 to 10.

10. Facial expressions and vocalisations can indicate if a resident is experiencing pain.

11. A resident commenced on opioid medicines such as morphine is likely to become addicted and the medication may not work later on as they become tolerant to its effects.

12. Every resident who cannot eat or drink should be fed through a tube (e.g. PEG gastrostomy).

13. Lemon and glycerine swabs can be used when a resident has a dry mouth.

14. Urinary tract infections can bring on a delirium.

15. A combination of changes in breathing patterns, decreased consciousness and irreversible weight loss may be signs of approaching death.
Self-directed learning package: Introductory careworker quiz answers

<table>
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<tbody>
<tr>
<td>1. With a palliative approach, the focus is on managing symptoms and increasing quality-of-life rather than curing illness.</td>
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<tr>
<td>A palliative approach aims to improve the quality-of-life for people with an eventually fatal condition and their families.</td>
</tr>
<tr>
<td>It does this by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.</td>
</tr>
<tr>
<td>A palliative approach is not just for the end stages of an illness.</td>
</tr>
<tr>
<td>2. A palliative approach discourages discussion about death and dying as it may upset the resident.</td>
</tr>
<tr>
<td>A palliative approach encourages open and early discussion about death and dying which helps advance care planning.</td>
</tr>
<tr>
<td>3. A resident completes a written Advance Directive. This is considered a legal document.</td>
</tr>
<tr>
<td>So long as advance directives are filled out correctly including the appropriate witness's signatures then yes, they are legal documents.</td>
</tr>
<tr>
<td>They set out a resident’s end of life care wishes or appoints another person as decision maker, usually called a guardian or medical power of attorney.</td>
</tr>
<tr>
<td>4. Shortness of breath is the same thing as dyspnoea.</td>
</tr>
<tr>
<td>Dyspnoea is an awareness of uncomfortable breathing and can also be called breathlessness or shortness of breath.</td>
</tr>
<tr>
<td>5. It is a good idea to ask a resident to rate his shortness of breath by asking him to count how many breaths he takes a minute.</td>
</tr>
<tr>
<td>Because health professionals tend to under-report a patient’s breathlessness the resident should be encouraged to rate the severity themselves (if cognitively able).</td>
</tr>
<tr>
<td>This should be done using a vertical or horizontal rating scale from 0 (no shortness of breath) to 10 (severe shortness of breath).</td>
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You are asked to help Bob shower this morning. You should rush him and get it over as quick as possible then he can take the rest of the day to recover.

- Residents with dyspnoea benefit from having a preventative plan of care that decreases the distress and anxiety of dyspnoea before it occurs.
- Bob might take a small dose of opioid medication (e.g. morphine) at least ½ hour before showering (morphine can be effective for breathlessness as well as pain).
- Don't rush or hurry Bob and allow rest periods during activities (decreases his need for oxygen and reduces anxiety).
- In the bathroom, leave the exhaust fan on and make sure the shower water is deflected away from his face (prevents claustrophobia).

Section 2

7. Family members have the right to determine if a resident should attend a palliative care case conference on the grounds that 'it will only upset him/her'.

- As careworkers our primary role is to provide resident centred care which includes advocating on the resident’s behalf.
- Perhaps the resident would be upset about what is discussed, but it is up to them (while they are cognitively able to make decisions competently) to decide whether they will attend.
- Most residents choose to attend case conferences and can provide insights into their condition that family and staff may not have known about otherwise.
- If a resident is likely to become distressed or fatigued, consider holding the case conference in their room where they can rest on the bed. Ask their permission to continue the discussion elsewhere with the remainder of those attending.

8. Regardless of the language a resident speaks or where they were born their care needs are the same when they are dying.

- All residents require careful assessment to ensure that assumptions are not made about cultural needs based on a resident's language, religion or country of origin. Similarly, the care needs for members of our indigenous population (Aboriginal and Torres Strait Islanders) requires careful assessment and planning.

9. If a competent resident tells you they have pain, is it good practice to ask how severe it is on a scale of 0 to 10.

- The use of horizontal or vertical pain scale which asks the person to rate 0 (no pain) or 10 (worst pain possible) is good practice to assess pain for competent residents who do not have severe cognitive impairment e.g. advanced dementia.

10. Facial expressions and vocalisations can indicate if a resident is experiencing pain.

- The Abbey Pain Scale lists whimpering, groaning, and crying as possible indicators of pain.
11. A resident commenced on opioid medicines such as morphine is likely to become addicted and the medication may not work later on as they become tolerant to its effects.

- Some strong analgesics are called opioids e.g. morphine, oxycodone or fentanyl.
- Sometimes residents or their family members may be concerned about these medications. It is important to know that when used correctly they:
  - do not lead to addiction or dependence
  - do not hasten death
  - are not just for when the resident is dying.

12. Every resident who cannot eat or drink should be fed through a tube (e.g. PEG gastrostomy).

- There is no evidence that tube feeding prolongs life, improves comfort or quality-of-life, prevents aspiration pneumonia, leads to better nourishment or decreases the risk of pressure sores.
- Although artificial hydration can be useful to treat reversible causes of dehydration, it is not normally used when a resident is expected to die within 48 - 72 hours.

13. Lemon and glycerine swabs can be used when a resident has a dry mouth.

- Do not use mouthwashes and swabs containing:
  - lemon and glycerine
  - sodium bicarbonate (high strength)
  - preparations containing alcohol or hydrogen peroxide
  - pineapple or other juices.

14. Urinary tract infections can bring on a delirium.

- Urine infections are a common cause of older people becoming confused.

15. A combination of changes in breathing patterns, decreased consciousness and irreversible weight loss may be signs of approaching death.

A combination of changes in breathing patterns, decreased consciousness and irreversible weight loss may be signs of approaching death.

Three or more of the following indicates an RACeLoLCP may be appropriate and that the resident is likely to be approaching death:

- 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.
Bibliography – SDLP - Careworker (Introduction)

3 Brisbane South Palliative Care Collaborative, Queensland Health/ Griffith University (2010a) Residential Aged Care End of Life Care Pathway (RAC EoLCP), Brisbane
5 Commonwealth of Australia (2006b) Guidelines for a Palliative Approach in Residential Aged Care – Navigational Tool, Canberra
8 Palliative Care Council of South Australia Inc. (1996) Good Palliative Care Plan.