CHCPAL003

Deliver care services using a palliative approach

Release 1

Learner Guide

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Learning Resources

CHCPAL003 Deliver care services using a palliative approach, Release 1

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Contents

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Before you begin

This Learner Guide is based on the unit of competency *CHCPAL003 Deliver care services using a palliative approach*, Release 1.

Your trainer or training organisation must give you information about this unit of competency as part of your training program.

How to work through this Learner Guide

This Learner Guide contains a number of features that will assist you in your learning. Your trainer will advise which parts of the Learner Guide you need to read, and which Practice Tasks and Learning Checkpoints you need to complete.

Feature of the Learner Guide	How you can use each feature
Learning content	Read each topic in this Learner Guide. If you come across content that is confusing, make a note and discuss it with your trainer. Your trainer is in the best position to offer assistance. It is very important that you take on some of the responsibility for the learning you will undertake.
Examples	These highlight learning points and provide realistic examples of workplace situations.
Practice Tasks	Practice Tasks give you the opportunity to put your skills and knowledge into action. Your trainer will tell you which Practice Tasks to complete.
Callouts	Callouts reiterate key learning points to help students revise for their assessments.
Weblinks	Weblinks provide learners with additional content to contextualise their learning and develop their understanding.
Videos	Videos provide a visual reference of key concepts to aid comprehension and guide learner exploration. Each video is accessed by a QR code in the Learner Guide (or a button in the eBook version) for ease of access.
Glossary/margin definitions	Key terms are defined where they first appear to help consolidate understanding. A glossary of terms is provided at the end of the Learner Guide to assist learner revision of key concepts.
Summaries	Key learning points are provided at the end of each topic.
Learning Checkpoints	There are Learning Checkpoints at the end of each topic. Your trainer will tell you which activities to complete. These activities give you an opportunity to check your progress and apply the skills and knowledge you have learnt.
Case studies	Case studies are interspersed throughout the learning content to provide a workplace setting that contextualises key concepts.

Foundation skills

As you complete learning using this guide, you will be developing the foundation skills relevant for this unit. Foundation skills are the language, literacy and numeracy (LLN) skills and the employability skills required for participation in modern workplaces and contemporary life. They are an integrated part of a unit of competency and are included as part of the learning content.

These skills are listed below:

Foundation skill area	Foundation skill description
Reading	• Understanding how documents are presented and being able to navigate through documents • Understanding industry and job-specific terminology • Interpreting key information in relevant documents • Understanding routine workplace checklists and documentation
Writing	• Planning, drafting and writing reports and documents • Communicating through written letters, email and online • Recording progress; reporting incidents
Oral communication	• Clarifying instructions • Providing information • Supporting others through encouragement, negotiation and conflict resolution • Using body language to model desired behaviour and responding to others' body language
Numeracy	• Calculating costs, weights, measurements of height and distance • Interpreting measurements
Learning	• Understanding your job role, organisational procedures and legal responsibilities • Managing your work and seeing how well you are going • Making goals for yourself at work • Seeking professional development opportunities for continuous improvement
Problem-solving	• Identifying problems • Working out how to fix a problem using problem-solving processes • Reviewing the outcome
Initiative and enterprise	• Recognising opportunities to develop and apply new ideas • Generating ideas by thinking of new ways to do something • Making suggestions to improve work
Teamwork	• Working well with other people by cooperating, collaborating, encouraging and building rapport

Foundation skill area	Foundation skill description
Planning and organising	• Planning your workload and commitments • Implementing tasks • Completing work on time • Knowing how to deal with hazards and risks
Self-management	• Understanding and applying decision-making processes • Reviewing your behaviour and the impact of your decisions
Technology	• Efficiently using digitally based technologies and systems correctly and safely • Accessing, organising and presenting information • Using equipment correctly and safely

Note: Not every unit of competency will contain all foundation skills.

What do you already know?

Use the following table to identify what you may already know. This may assist you to work out what to focus on in your learning.

Topic	Key outcome	Rate your confidence in each section
Topic 1 Apply the principles and aims of a palliative approach when supporting people	1A Recognise the holistic needs of people accessing palliative care	☐ Confident ☐ Basic understanding ☐ Not confident
	1B Support the person and their network to express needs and preferences	☐ Confident ☐ Basic understanding ☐ Not confident
	1C Communicate about the person's pain, comfort and quality of life	☐ Confident ☐ Basic understanding ☐ Not confident
	1D Adjust communication techniques to meet the individual needs of the person and their network	☐ Confident ☐ Basic understanding ☐ Not confident
	1E Respect and support the carer, family and others as an integral part of the care team	☐ Confident ☐ Basic understanding ☐ Not confident

Topic	Key outcome	Rate your confidence in each section
Topic 2 Respect people's preferences for quality-of-life choices	2A Create a supportive environment for sharing information	☐ Confident ☐ Basic understanding ☐ Not confident
	2B Respect the person's individuality, values and beliefs in the context of support provision	☐ Confident ☐ Basic understanding ☐ Not confident
	2C Identify and refer needs and issues outside your scope	☐ Confident ☐ Basic understanding ☐ Not confident
	2D Communicate in a way that shows empathy and provides emotional support	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 3 Follow the client's advance care directives in the care plan	3A Interpret and follow advance care directives	☐ Confident ☐ Basic understanding ☐ Not confident
	3B Comply with end-of-life decisions and legal requirements	☐ Confident ☐ Basic understanding ☐ Not confident
	3C Report the person's changing end-of-life needs	☐ Confident ☐ Basic understanding ☐ Not confident
	3D Monitor the impact of end-of-life needs, issues and decisions on families and carers	☐ Confident ☐ Basic understanding ☐ Not confident
	3E Deliver services to support the person's right to choose the location of their end-of-life care	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 4 Respond to signs of pain and other symptoms	4A Observe and document pain and other symptoms	☐ Confident ☐ Basic understanding ☐ Not confident
	4B Implement strategies to manage pain and promote comfort	☐ Confident ☐ Basic understanding ☐ Not confident
	4C Evaluate and document the effectiveness of pain management strategies	☐ Confident ☐ Basic understanding ☐ Not confident
	4D Recognise and report concerns about the use of pain-relieving medication	☐ Confident ☐ Basic understanding ☐ Not confident

Topic	Key outcome	Rate your confidence in each section
Topic 5 Follow end-of-life care strategies	5A Regularly check for changes in the individualised plan	☐ Confident ☐ Basic understanding ☐ Not confident
	5B Provide a supportive environment for the end-of-life	☐ Confident ☐ Basic understanding ☐ Not confident
	5C Respect and support the person's preferences and culture	☐ Confident ☐ Basic understanding ☐ Not confident
	5D Maintain dignity at end-of-life and following death	☐ Confident ☐ Basic understanding ☐ Not confident
	5E Recognise and report deterioration or imminent death and dying	☐ Confident ☐ Basic understanding ☐ Not confident
	5F Provide emotional support to others when a death has occurred	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 6 Manage your own emotional responses and ethical issues	6A Manage emotional responses and ethical issues	☐ Confident ☐ Basic understanding ☐ Not confident
	6B Identify and reflect on your own emotional responses to death and dying	☐ Confident ☐ Basic understanding ☐ Not confident
	6C Discuss ethical issues or concerns	☐ Confident ☐ Basic understanding ☐ Not confident
	6D Determine and implement self-care strategies	☐ Confident ☐ Basic understanding ☐ Not confident
	6E Access bereavement care and support of other team members	☐ Confident ☐ Basic understanding ☐ Not confident

Topic 1: Apply the principles and aims of a palliative approach when supporting people

1A Recognise the holistic needs of people accessing palliative care

1B Support the person and their network to express needs and preferences

1C Communicate about the person's pain, comfort and quality of life

1D Adjust communication techniques to meet the individual needs of the person and their network

1E Respect and support the carer, family and others as an integral part of the care team

1A

Recognise the holistic needs of people accessing palliative care

Death and dying are an inevitable part of our human experience.

It is a privilege to be involved in the final stages of a life. You will help to give comfort and support to a dying person and their family. This is an important and significant role to play in somebody's journey through the final stages of their life.

In Western societies, the aim of health care and medical treatment is usually to reverse a person's illness and thereby prolong their life. This is called a curative approach.

The philosophy of palliative approaches

Palliative care takes a different approach to curative care. When a person nears the end of life, or when they have an illness that significantly affects their quality of life, a palliative approach focusses on giving them peace and comfort.

Rather than helping them to live longer, or trying to cure their disease or illness, it channels all available support into helping the person enjoy what is left of their life. The focus is on giving their life quality, rather than time.

Curative approach	Palliative approach
Treats the disease so that the person can live longer.	Treats symptoms, such as pain, so that the person has a better quality of life.
Considers that short-term side effects from treatments, such as chemotherapy or heart medications, are outweighed by the long-term benefits for the person.	Avoids treatments and medications that cause unpleasant side effects, even if that shortens the person's life.
Attempts to cure the person of the disease if possible.	Focus is on pain management rather than attempting to reduce or cure the illness.
Sees death as the worst possible outcome for the person.	Accepts death as a dignified and normal part of life.
Finds the best medical treatment available.	Finds the best emotional support available.
Wants the person to be physically well again.	Wants the person to be emotionally and spiritually well, and at peace.

The principles of palliative approaches

A palliative approach begins when the person, with their doctor, makes the decision to focus on comfort over treatment.

This usually happens because the person has a terminal illness, or one that makes their life difficult to endure or enjoy. This may be because of severe symptoms such as pain, and for many people with life-limiting illnesses the transition from curative treatment to palliative care is gradual.

A palliative approach will:

- use a team of different professionals
- include the person and their family at the centre of care
- focus on pain relief as an important priority
- care about, and treat, the distress of the person and their family.

Palliative care does not always begin when a person is diagnosed with a terminal disease, and it does not always end when the person has died.

When appropriate, people can be treated using a palliative approach for months, even years, before they die. This continues during and after the person's death as you continue to support the family, and each other in the care team.

The benefits of palliative approaches

Palliative care stops focusing on treatments that prolong the person's life, and instead provides the person with comfort and relief from distress.

- Using pain specialists, and other resources, can mean relief from pain.
- Stopping other treatments and medications also stops their side effects.
- The person is not expected to focus on health, such as exercising or eating certain foods, unless they want to. Instead, they are able to focus solely on being comfortable.
- The person can be helped to discuss and plan for the end of their life. Family members can be encouraged and supported to have difficult conversations that may be important to the person.

Palliative care settings

Wherever possible, palliative care is provided in a place where the person feels at home, with their family, friends and community close by.

In many cases, the person can be given palliative care in their own home, especially in the last weeks and days, allowing them to die with dignity in familiar surroundings.

Settings for providing palliative approaches	
Hospitals	Most hospitals have access to a palliative care team.
Hospices	All patients receive palliative care. Staff are well trained and specialise in palliative approaches.
Aged care services	Older people must be provided with good quality end-of-life care to meet the Aged Care Quality Standards. This setting is not specifically a palliative care setting. However, a palliative approach is incorporated into the aged care setting.
The person's home	A palliative care team linked to a local hospital or medical team visit the person to provide support.

The palliative care team

A palliative care team is made up of professionals with varied skills and knowledge to enable it to address the different needs of the person.

Palliative approaches are holistic and require the skills of multi-disciplinary teams.

A typical palliative care team can include:

- doctors
- nurses
- pastoral workers (chaplains)
- social workers
- support workers and carers.

At the centre of every palliative care team is the person and their family. Everyone works together, contributing their distinct knowledge so that the person gets the best support possible.

The focus of palliative care is to address the physical, emotional, social, spiritual and cultural needs of those suffering from a life-limiting illness, from the time of diagnosis to the end of their life. A palliative care team actively treats the person with the aim of preventing suffering and making death as comfortable as possible when it occurs.

Team members:	This might include:
The person and their family	• the person • their family, whoever they say that is • significant others • friends • neighbours • advocates.

Allied health professionals	• social workers • physiotherapists • occupational therapists • psychologists • pharmacists • dietitians • counsellors.
Nurses	• aged care nurses • palliative care specialist nurses in community, hospital and in-patient palliative care • pain specialist nurses • independent nurse practitioners.
Medical practitioners	• general practitioners (GPs) • cancer specialists (oncologists) • aged care specialists (geriatricians).
Spiritual carers	• bereavement counsellors from a range of pastoral, spiritual and cultural backgrounds.
Specialist workers and volunteers with language skills and cultural knowledge of ethnic and other diverse groups	• Aboriginal and Torres Strait Islander health workers • LGBTI groups.
Support workers	• personal care workers • attendants and diversional therapists.
Alternative therapists	• massage therapists • aromatherapists • music or colour therapists • meditation therapists.

Your role in the palliative care team

As a support worker in an aged care or community service, your role in the palliative care team is a very important one. You will be at the frontline of care, supporting the person's primary needs in a way that is only secondary to the family.

Some of the most important parts of your role will be to:

- follow the individualised plan to provide comfort and support
- report signs and symptoms of grief, pain or discomfort to a nurse or supervisor
- communicate with the rest of the team about the person's needs
- provide emotional support by listening and talking to the person and their family.

Holistic needs in palliative care

Holistic support involves providing care that considers the whole person by addressing their emotional, social and spiritual wellbeing as well as their physical health.

A person in palliative care will commonly exhibit a wide range of holistic needs which need to be attended to. Here are a few examples.

Physical	• Staying in a comfortable position. • Having enough to eat and drink. • Supporting bowel movements.
Emotional	• Freedom from anxiety and stress. • Being able to talk about, and work through, feelings of grief and fear. • Feeling that they have achieved what they wanted to before they die. • Being in a space that they enjoy, such as having sunlight or a view of the outside, and having things around them that give them peace and joy such as flowers and music. • Being in control of what will happen to them if they can no longer communicate. • Feeling confident that they will have their wishes respected. • Needing to speak to a counsellor or psychologist to work through emotions.
Spiritual	• Feeling that they have lived a life with purpose. • Following religious practices such as the Last Rites sacraments or discussing their funeral. • Praying. • Being able to believe in an eternal life or other existence after death. • Being at peace with their god or gods. • Being able to meditate. • Having visits from a religious leader.
Cultural	• Continuing to be a part of their community. • Taking part in cultural festivities and routines. • Having a language interpreter to help them be understood. • Having cultural preferences such as food, music and dress respected.
Social	• Having the companionship of others. • Being able to talk to family and friends. • Feeling loved and appreciated. • Having visitors on their own terms. • Having the company of pets.

Intellectual	• Being able to use their mind in pursuits that challenge them at the right level. • Being free from being bored. • Having pursuits that continue to spark curiosity, creativity and enjoyment.
Sexual	• Spending time with their spouse or partner. • Experiencing physical touch and intimacy. • Feeling that they look good and identifying with their gender role through grooming and dress.
Financial	• Feeling capable of managing their finances. • Being able to complete their will. • Being able to afford treatments and medications. • Feeling secure in the knowledge that significant others will be provided for.

Example

Deciding on a palliative approach

Bernard lives alone and suffers with a chronic, degenerative condition that causes him a great deal of pain. When he gets to a point where he requires specialist treatment he is transferred to a hospital. The medication he is given for his condition gives Bernard several negative side-effects, such as constant headaches, dizziness and insomnia. After a few weeks in hospital he decides that he wants to stop taking the medication and informs his doctor of this. He says: “I have no quality of life anymore”.

The doctor arranges for him to speak to the hospital’s palliative care team. Afterwards, Bernard’s treatment plan is changed and a palliative care approach is adopted. He is taken off the medication, there are no more resulting side effects and he is able to go home. His pain is well managed with a continuous morphine infusion, and he is visited by the community palliative team every day. He feels able to enjoy the company of his family and pets for the first time in a long time. He writes his life story and achieves a lot of satisfaction from that.

One month later, Bernard dies peacefully at home surrounded by his family.

Consider why it is important to monitor the needs of the person you support when undertaking a palliative approach.

Practice Task 1

Question 1

Match each term on the left to its description.

Holistic needs	Aims to treat the person's illness and prolong their life.
A curative approach	Aims to treat the person's symptoms only.
A multi-disciplinary approach	Considers all the aspects that make up a person.
A palliative approach	Uses professionals and workers with many different skills and knowledge.

Question 2

Which of the following are part of a person's holistic needs? Tick all that apply.

- ☐ Physical needs
- ☐ Palliative needs
- ☐ Financial needs
- ☐ Emotional needs
- ☐ Kindness needs

1B

Support the person and their network to express needs and preferences

Support workers often find themselves in a position where they can help the person to express their end-of-life needs and wishes.

When a person and their family are first told that the person has an illness that will or may cause them to die, it tends to be a very emotional and difficult time. Everyone reacts differently to this news and, as the person is at the centre of the care team, their unique needs and choices must be the priority.

Diagnosis of a life-limiting illness

There is no particular time frame for how long a person will live with a **life-limiting illness**. Some illnesses may quickly lead to death, such as a serious heart disease or certain types of cancer. Other life-limiting conditions might allow the person to live for months or years following diagnosis.

On the other hand, a **life-threatening illness** is one that might, but also might not, lead to death; depending on complications and how successful treatments are. Examples of life-threatening illnesses include stroke, diabetes, and some types of cancer with early detection and successful treatment outcomes.

Life-limiting (terminal) illness
A chronic disease that does not respond to curative treatment and leads to a terminal diagnosis.

Life-threatening illness
A disease that might lead to death, depending on complications and how successful treatments are.

The emotional impact of diagnosis

When a frail older person has been unwell for a long time, or if their quality of life has significantly diminished, being told their death is imminent can mean the end of their suffering and come as a relief.

For some religious people it can be a spiritual event. They might anticipate joining loved ones in heaven or finding happiness in an afterlife.

However, for the majority, the early stages after diagnosis of a terminal illness are a distressing and frightening time. While this is especially true for younger people, or those who did not expect to be at the end of their life, it can be true of anyone, at any age and stage of life and regardless of how long they have been told they will live.

Some people might find peace with their diagnosis in time, but others might not. For some, from diagnosis to end-of-life might be quick. They might not feel they have sufficient time to do the things they want to do, or to say goodbye properly.

It is common that they will feel:

- frightened that their death will be painful or lonely

- anxious about those they will leave behind, and how these people will manage without them
- angry that they are being taken too soon
- worried that there will not be enough time to do the things they want to do
- depressed about their situation
- concerned that they need a second opinion, or that their doctor is wrong
- worried that they did something to contribute to their diagnosis
- frightened about what will happen to them after they die.

The stages of grief

People who have been told that they are going to die often experience very powerful and difficult emotions before, hopefully, finding acceptance and peace with their diagnosis.

In 1969, Dr Elizabeth Kübler-Ross published what became a widely acknowledged model of the process of grieving. Academic research now recognises the limitations of the Five Stages of Grief, mainly due to the lack of consideration of individuality within the grieving process. However, it can still be used as a useful tool to try and understand the emotions the person might possibly be experiencing.

Denial	Denial is thought to be a defence mechanism. If we say to ourselves or to others "the doctor was wrong" or "this can't be true", we help to give our brain time to take in the difficult news without going into shock or despair. Some people will express denial as if they did not hear the news at all, or by reacting in a way that seems to be at odds with having been told they have a terminal diagnosis.
Anger	Anger sometimes helps the person to divert feelings of anxiety, fear, blame or guilt outwards. This can help us to avoid or prolong experiencing these challenging emotions. The person might be angry at you, at their doctor, at their family, or at their god or gods. Understanding the functions of anger can help you not to take it personally.
Bargaining	The person might try to bargain with whatever god or gods they believe in. They might try and make deals with the universe, or with their past. This can be expressed in ways such as "if I pray harder", or "if I could go back and change that situation and do it differently".
Depression	Depression is painful and difficult, but it can mean that the person has begun to accept that they will die. In some ways it is important to allow the person to go through these strong feelings of sadness. When the person understands and confronts their emotional pain, they are thought to be a step closer to the more positive emotions of acceptance.

Acceptance	Acceptance does not mean that the person has moved on from their fear or sadness, but that they are able to accept it, and try to enjoy what is left of their life, or to make the most of what they are still able to do. Some people never reach this stage, and others can reach it quite quickly.

The needs of people who are dealing with a life-limiting illness

To know or understand what the person needs, support workers must ask questions, make observations, and encourage the person and their family to communicate everything that can be done to make their life easier and more comfortable.

The needs of people dealing with a life-limiting illness can include:

- being able to work through their emotions to reach a place of spiritual and emotional peace
- having control over what they do and how they do it
- being free of pain and discomfort
- being given dignity and privacy
- having family and friends visit and be with them at times that suit the person, no matter the time of day or the visiting hours of the service
- being able to practise cultural and religious beliefs
- being able to write down their wishes for their death.

Supporting the person and their family to express needs and preferences

Not everyone wants to talk about how they feel, or about what they want for their death. However, you can let the person and their significant others know that it can be helpful for them to talk, and that you are willing to listen. Talking can:

- help the person to let others know their needs and preferences for their care and support, as well as their preferences for their death
- help the person to work through the stages of grief, in whatever form that happens for them, until they are able to reach a level of peace or acceptance
- facilitate conversations about death and dying that might be uncomfortable, but are necessary for the person and their family
- reduce unhelpful feelings of fear, guilt or anxiety
- give you important information that can be passed on to your supervisor and the palliative care team
- provide an opportunity to reassure the person that their needs and preferences for end-of-life care are understood and will be met.

Reporting to your supervisor

Support workers have an important role here as they can inform their supervisor if the person communicates needs related to their death or dying that the care team was not aware of. This can help the team to document the persons wishes.

Information the care team needs to know
• How the person feels about their life-limiting illness and death
• How much the person understands about palliative care
• The type of care they want, including pain relief
• Whether they want their life to be prolonged
• The type of social life they want, including the need for company
• The person's cultural and spiritual needs
• Who the person wants to manage their affairs when they are unable to do so
• Aspects of care the person would like in the dying stage
• Whether the person wants to access voluntary assisted dying
• The type of funeral they want

Example

Support networks

Nell lives in an aged care facility and has been receiving strong pain medications as part of a palliative approach to her illness. She has been missing her family, and when the staff ask Nell about her preferences she tells them that all she wants right now are her children and grandchildren, who all live interstate. She is distressed by the fact that she can only speak with them on the phone and cannot see them.

A staff member contacts her family and discovers that they all use social media, including Facebook. A support worker spends ten minutes per day teaching Nell how to use the Facebook Messenger app to make video calls so she can keep in regular contact with her children and grandchildren. As a result of the virtual contact Nell's mood is lifted, as she no longer feels separated. Although Nell does not see her children in person, she feels better now that she can see them while she talks to them and her anxieties are eased.

Why should you consider involving a support network to complement your care?

Practice Task 2

Question 1

What emotional impact can a diagnosis of a life-limiting illness have on a person when they are first told? Provide three examples.

1C Communicate about the person's pain, comfort and quality of life

Palliative care can be a setting where you encounter difficult human emotions, conflicts and behaviours.

Good communication can help you support the person and their family to attain a peaceful quality of life while in palliative care. When the person and the family feel that they can communicate openly, they are more likely to be confident you will support them and understand when they tell you what they need.

Building trust in the palliative approach

When the person first enters palliative care, the team will need to provide information and reassurance about what the approach will mean to them, and how it will benefit them.

It can be a source of great comfort for the person and their family to have confidence that they will be as free from pain as possible, that you will aim to make sure that those important to them will be with them, and that their social, cultural, religious and spiritual preferences will be considered and respected.

Make sure the person is not in any pain or discomfort when you are speaking with them. You need to be a good listener and build a supportive relationship with the person based on effective communication and honesty. It may take time for the person to respond, so when you ask questions give them time to answer and keep a record of what they tell you.

Explain	Let the family know the aims and principles of the palliative approach, and how they can contribute to increase the benefits.
Question	Ask the person what they really want for their comfort and quality of life.
Reassure	Provide reassurance that the team will listen and follow the person's preferences wherever possible.
Respect	Respect the customs, practices, protocols and beliefs of people from different cultures when communicating with them. For example, for some Indigenous Australians speaking the name of a deceased person may cause considerable distress.

Empowering the person to speak up

When a person decides on a palliative approach, their family and significant others might not always agree with their choice.

This can sometimes create conflict and anxiety. A family member might feel that the person is giving up, or that they are being selfish to want to change their treatment from a curative to a palliative approach.

People who are being supported by a team of health professionals can often feel that it is not their place to speak up for themselves. They might consider that the doctors or their family know better, that the medical team are too busy to listen or that what they think does not really matter. Sometimes the person might be trying to please others around them at the expense of their own comfort and quality of life.

Other common sources of anxiety, disagreement or conflict can include:

- misunderstandings about pain relief
- disagreements or arguments between family members about the person's pain relief and other treatments
- family members who do not get along being together in the same room
- the person being tired and not wanting their family to visit.

It is your role to be the person's advocate.

You can sometimes help to avoid such conflicts by talking to families about the need for the person to be in control of decisions about their life. You can explain the aims of the palliative approach and help them to recognise the person is at the centre of, and in charge of, decision making. This **empowers** the person to stay strong about their own preferences, rather than accepting the preferences of others.

Empowerment
The process of gaining strength and confidence to voice one's own opinion.

Remember that in the end the person chooses their relationships with their family. If you have provided them with support and information to speak up against others' opinions, it is their choice whether they choose to do so.

Example

Effective communication

Blaine has been receiving hospital-in-the-home care for two years now. Recently, he has become frustrated with the intense nature of his treatment which includes frequent injections, a high number of medications and seemingly never-ending visits from doctors and other specialists. Although he has very little family, he has a friendly relationship with one support worker, Martin. One day, Blaine calls Martin over and tells him that he does not feel like his old self and is wondering about alternatives to his current treatment schedule. "Is there a way for me to be treated without all of this nonsense?"

Martin asks Blaine why he feels this way. Blaine tells him that all he really desires now is a life without intense treatment. After listening, Martin suggests he talk to his supervisor about what he has said and explains to Blaine the possible pathways that could be taken. Blaine's doctor talks to Blaine about palliative care, how it can be adapted to his individual needs, and covers some advantages and disadvantages of each pathway. Blaine feels informed and decides, after some thought, that he is ready to be transferred to palliative care. Martin is able to act as an agent for Blaine, passing messages on to doctors as Blaine doesn't feel comfortable talking with them directly.

What measures could you introduce in your role to improve communication?

Practice Task 3

Question 1

Which of the following statements are correct? Select yes or no for each one.

a. Building trust can come from listening to the person rather than just talking to them.	Yes / No
b. The person is always their own advocate and this is not your role.	Yes / No
c. Empowerment means to build muscles and bones so that they are stronger.	Yes / No
d. If a person chooses to listen to their family, that is their choice.	Yes / No
e. Respecting the person's culture is essential for effective communication.	Yes / No

Question 2

List three examples of reasons why a person might not want to speak up about their wishes.

1D Adjust communication techniques to meet the individual needs of the person and their network

There are many ways to communicate: through words, pictures, body language or writing.

Information given can be interpreted differently depending on the person's culture, disability, cognitive ability and language spoken. It is not enough to hope that the person understands what you are saying when you communicate with them. You must adapt your information and questions for the person so that they correctly understand the message and so that you correctly understand their response.

Individual difference	Possible solutions
Language differences	• Provide information in the person's own language by using an interpreter. • Use written information translated into the person's language. • Use pictures. • Use translation apps.
Disability, such as hearing loss	• Make sure that the person is using aids and equipment that have been supplied to them. • Suggest aids and equipment that could be supplied to the person. • Use communication apps and other communication tools. • Use Easy English. • Reduce background noise.
Cognitive abilities, such as dementia	• Give one, simple piece of information at a time. • Check for understanding. • Use familiar words. • Reduce background distractions.
Geography, such as if the person's family lives far away	• Talk to the family member via phone. • Arrange virtual meetings over the internet. • Set up email or communication books.

Cultural differences	• Learn about the topics that might be taboo or painful for people of that culture, such as speaking the name of a person who has died. • Consider using a cultural interpreter, such as an Aboriginal and Torres Strait Islander community service. • Be aware of body language that might mean different things to the person. For example, pointing can be rude in some cultures.

If the person is not able or willing to hear information relating to their care, you will usually be made aware of who you can share information with in each personal network.

Avoid jargon or medical terms. Instead, speak clearly and in plain English.

For example:

- instead of NFR, explain that this means a request not to resuscitate the person
- instead of nasogastric tube, say feeding tube.
- even fluent English speakers may not have the medical or health knowledge to understand industry terminology.

Example

Communication techniques

Aan is of Hindu faith. He has cancer and has been advised by his doctor that he is nearing the end of his life. English-speaking doctors and nurses have struggled to explain key concepts to Aan such as his life expectancy, his treatment plan and the options he has when deciding what steps to take next. Even though they feel he understands, he gives little response. He often just grunts, which makes it difficult for the team to know exactly how much he has understood.

The team contact his family and Aan's son tells them that in their faith this type of information is always conveyed to the head of the family first. As his father is unwell, Aan's son is now head of the family and his father feels he is doing the wrong thing by his eldest son when hearing this information directly from the doctors.

As a consequence Aan's son is informed and invited whenever there are important decisions to be made or information to be passed on. While his son is present Aan is more open to communicating his wishes. When it becomes unclear what Aan wants, the team tries to communicate with him directly but clarifies any uncertainties with his family. The team is satisfied that he is being given the support that he wants for the remainder of his life.

Think about the communication techniques you could implement to improve your level of care.

Practice Task 4

Question 1

Which of the following actions can help adapt communication to suit a person with dementia? Tick all that apply.

☐ Use a language interpreter.

☐ Use a cultural interpreter.

☐ Reduce background noise and distractions.

☐ Use simple words and language.

☐ Provide one piece of information at a time.

Question 2

Which of the following statements are correct? Select yes or no for each one.

a. If the family live in another country, they cannot take part in communicating with the staff.	Yes / No
b. People from some cultures may read body language in different ways.	Yes / No
c. Always use the correct medical term for equipment that you are using.	Yes / No
d. You will always talk directly to the person, and never their family or network.	Yes / No
e. If the family speak a language other than English, it is not your responsibility to help them to understand and they must seek outside help.	Yes / No

1E

Respect and support the carer, family and others as an integral part of the care team

Carers and family members are an important source of knowledge about the person, and often one of the most important things in the person's life.

The people closest to the person you are supporting often know the person best. Primary relationships are much more important to the whole of the person's life than you are, no matter how long you have supported them for.

Family are who the person says they are. This is a very important principle in palliative care. Be sensitive to who is considered to be immediate family. Some people consider their family or their significant others to be:

- their primary family carer
- their opposite or same sex partner or spouse
- the people they live with
- biological or adopted relatives
- people in their community who share a common culture, such as the extended community of people from Aboriginal or Torres Strait islander backgrounds
- people who they gain support and friendship from, such as other members of an LGBTI community
- their friends.

Identifying and respecting the person's key relationships

- During an initial assessment the palliative team will have spoken to the person about who is significant to them, and who will help them make decisions. This will be recorded in the person's individualised plan or in their file notes. Sometimes one individual is given the responsibility of sharing information with the rest of the person's personal network. This means that information is not doubled up and the care team can focus on caring rather than answering repeated calls from family members.

Do not make assumptions about family members. You might assume that an older couple in a same-sex relationship are just friends, and it can be insulting to the person's partner or spouse if you and other support workers treat them with less importance than you would any opposite-sex partner. This can be a common and traumatic experience for people in long-term LGBTI relationships.

Recognise the person's chosen network as an important part of the care team

Our family are often our connection to our past, to our culture and to who we are. Whoever the person calls family, they often know more about the person than anyone else. This makes them a key source of information about the person's preferences, personality and needs than anyone else, especially if the person is unable to articulate them.

Some people enter a palliative care service after having been supported by a primary, unpaid, family carer at home. This person is still considered a primary carer when the person enters palliative care. You need to include the person's main network in discussions about their care whenever possible.

When the person is not capable of making decisions, the family member who has been given legal power to make decisions for the person stands in for them. In most cases their decisions must be acknowledged and respected. Respect the family member's knowledge of the person by asking questions when you cannot collect information directly from the person.

Some persons may prefer that only certain members of their family are involved in their care. They may wish to change who helps them to make decisions or provides additional support. This information should be reported to your supervisor, and added to the person's plan.

Here are some other ways that you can support family members.

Get to know the family member and gain their trust. When they like you and trust you, they are more likely to accept help.

Provide the care that is included on the plan but allow and encourage the family or significant other to do this themselves, or to even take over if they and the person would prefer this and if it is safe.

Ask questions and listen to what the family member tells you. Let them retain some control over the support that is given, as long as it is in line with the person's own wishes.

Provide timely information to the significant people in the person's life. This can include letting them know when there has been a change in condition, or about how they can access other services such as support groups.

Be kind and understanding with the family and significant others. Let them talk about how they feel but do not be intrusive.

Example

Meanings of family

First Nation's people often use the term family to mean extended community. They might call people they know and respect Uncle or Aunt, even if they are not blood relatives. If you yourself become a trusted member of an Indigenous community, especially if you work in rural areas, you might be considered a member of the family. In Indigenous culture, extended family members can all come together to help make decisions for and about the person's care. This must be respected.

Recognise the person's significant relationships

Being respectful of the family relationship means putting yourself outside of the family circle.

Some workers try to take over or act as though they are part of the person's family. This can feel intrusive to many families, and it is important to understand when complex family roles are not our business. Respect the network that the person has chosen, no matter what you think of their decision.

You cannot come between spouses and family members to tell them they are doing the wrong thing even if you think it is undesirable. Unless it is abusive, how family members communicate is not your business.

Here are some tips for being respectful of the person's own network:

- Avoid intruding on personal conversations between the person and their family member.
- Take a secondary role. Be there for support but remember that you are not a member of the person's family.
- Never judge the relationship between family members. It is not your business how often the family member visits, what they say or how they interact with the person, unless you suspect abuse.

Example

Respecting family relationships

Louise is a personal care worker in an aged care facility. Betty, one of her favourites, has been in the facility for a long time. Betty has now entered palliative care and Louise is resentful of Betty's daughter, Joan.

Joan never seemed to visit before but now she is here all the time. Louise finds Joan bossy and cold and Betty does whatever her daughter tells her to do. Louise thinks Joan is only around now to grab her inheritance after her mother dies. When Joan comes to visit, Louise sometimes deliberately stays in the room with them just to make sure that Joan does not boss her mother around. She sits with Betty and holds her hand while Joan spends time with her mother. This makes Joan uncomfortable and she feels that she and her mother miss out on time together during the visits.

No matter what Louise thinks of Joan her relationship with her mother is none of Louise's business. Louise is not privy to the complexity and history of their relationship and she is not respecting the importance of the connection between mother and daughter. As hard as it is for her to accept she needs to step back and give them their time together.

Consider why family relationships must be respected and acknowledged.

Practice Task 5

Question 1

Which of the following are correct about a person's network? Tick all that apply.

☐ Family is always who the person says it is.

☐ A person should be close with their blood relatives.

☐ A same-sex partner should be treated as the person's significant other.

☐ Extended family is common in Aboriginal and Torres Strait Islander families.

☐ Making assumptions about family is not good practice.

Question 2

List three examples of people the person might call family.

Summary

- Palliative care provides people with relief and comfort, and discontinues measures to extend the person's life.
- Palliative care enhances the person's quality of life and may also positively influence the course of illness by treating pain as well as physical, psychological, social and spiritual problems in a holistic manner.
- People can have different reactions to the news that they have a life-limiting illness.
- Communication between all members of the team is essential for providing support, pain relief and comfort to persons accessing the service.
- The person's own network are essential members of the care team and need respect, information and support.
- You may need to be the person's advocate.
- You can build trust and empower the person by using effective communication skills.

Learning Checkpoint 1

Apply the principles and aims of a palliative approach when supporting people

Part A

1. Match each of the principles to either a palliative or curative approach.

Aims to prolong life	Palliative
Focuses on treating the disease	Curative
Focuses on treating the symptoms	Curative
Dying is accepted and discussed as a part of life	Curative
Dying is the worst possible outcome	Palliative
Aims to neither prolong nor shorten life	Palliative

2. Which of the following statements are correct? Select all that apply.

- ☐ Holistic needs include physical, spiritual, cultural, social and sexual needs.
- ☐ A person's emotions while they are grieving are constant.
- ☐ Palliative care teams can include the family and allied health professionals.
- ☐ A diagnosis of a life-limiting illness can lead to feelings of fear, grief, or anger.
- ☐ Denial and bargaining are part of the Kübler-Ross stages of grief.

3. List two examples of why you might need to adjust your communication style to meet the needs of the person or their family.

Part B

Read the case study, then answer the questions that follow.

Case study

After a series of tests and assessments, Martha has recently been told by her doctor that she is in the early stages of Alzheimer's disease. Martha watched her own mother die after a five-year battle with Alzheimer's disease and this was very distressing for her. She has a same-sex partner, Tamara, and two adult sons.

1. Given that Martha is in the early stages of dementia, what adjustments might need to be made when you talk to her and her family about her needs and preferences?

Topic 2: Respect people's preferences for quality-of-life choices

2A Create a supportive environment for sharing information

2B Respect the person's individuality, values and beliefs in the context of support provision

2C Identify and refer needs and issues outside your scope

2D Communicate in a way that shows empathy and provides emotional support

2A Create a supportive environment for sharing information

Sharing information is a two-way process that requires active participation from all involved.

All members of the team can contribute information about the person. The details will constantly change as the person's needs and condition develops. A good working relationship helps the person's network to easily share information when the person's needs, preferences or condition changes. The person accessing the service and the people who are closest to them have the best understanding of the changing situation and they should be encouraged to share any information that can help you provide the best quality of care possible.

At the same time, the person and their personal network will often be grateful for knowledge and information about how they can contribute, what services and supports are available to them, how the person is feeling, and what the person still needs.

A supportive environment

Palliative approaches do not limit the person's network to just biological family.

The person's personal support network will often be acutely aware of the smallest changes in the person's condition. The person might talk to them first about preferences and new concerns or ideas.

People are more likely to share information if they know they will be listened to and their opinions valued. To help create a supportive environment you can:

- thank people in the person's network when they offer information and let them know that you will pass it on
- use a warm, friendly and open approach when you are talking to people in the person's network
- make sure family members know they can telephone a team member whenever they need to
- encourage and support regular visits from family and friends
- be positive and work with the person's network to get what the person needs
- ask them to let you know whenever the person's needs or preferences change

- listen to and act on family members' opinions, complaints and suggestions
- provide privacy when required so they can speak to you in confidence if they prefer.

Sometimes when a person is in pain or discomfort, they might feel uncertain about letting you know. Sometimes this can come from generational differences. Older people might think they should not bother you, or believe that they should expect and tolerate a certain level of pain without doing what they see as complaining. When this happens, the family or other network can be an important partner. They can let you know what the person has told them that they might be reluctant to speak up about to a non-family member.

Because the network knows the person well, they can also help make other suggestions about what the person might need. They also might notice signs that could indicate unspoken pain or distress.

Regular team meetings should include the person and any members of the network that the person would like to have present. These meetings can provide emotional support and an opportunity to discuss changes, new concerns and ideas about the person's needs and preferences. Any new information can often be used to improve the person's quality of life.

Providing information to the person and their network

The person and their family or other networks might also need information from you about a variety of things. Here are some examples of information you might be asked for.

- They might wish to know more about the palliative approach and what is best for the person.
- They may ask you how they can get external help such as spiritual or cultural guidance from a religious or cultural leader.
- They might want information about extra resources they can purchase to help keep the person more comfortable, such as bedding.
- They are likely to want to be informed about any changes in the person's condition.

You may already know some of the information they require or you might be able to research community supports and resources. In some cases, for example if you have been asked to give medical or legal information, you will need to refer the question or request to your supervisor.

Palliative Care Australia provides help and information to people receiving a palliative approach, their carers and staff: aspirelr.link/pal-care

Example

Creating a supportive environment

Dianne has end-stage Parkinson's disease with dementia and has become dependent on her family. They care for her at home with the help of the palliative care team and support workers who visit daily.

The team have built a good relationship with Dianne's family, who are at ease talking to the staff about how they feel. The team connect the family with Parkinson's Australia, who provide strategies to help the family to keep Dianne's muscles and limbs comfortable and to manage the distress of her tremors during the end-stage of the disease.

How might you create a supportive environment for someone in end-of-life care?

Practice Task 6

Question 1

Which of the following actions help to create a supportive environment for information sharing? Tick all that apply.

- ☐ Provide family members with the contact details of a team member who they can call whenever they need to.
- ☐ Encourage and support family and friends to visit regularly.
- ☐ Work with family and friends to get what the person needs.
- ☐ Ask the person's family and friends to let you know whenever the person's needs or preferences change.
- ☐ Listen to family members' opinions, complaints and suggestions but act on what you think is best for the person.

2B Respect the person's individuality, values and beliefs in the context of support provision

Every person is an individual and has the right to be respected for their unique value.

In the past, aged care and health services adopted a 'one size fits all approach' when addressing patient or client needs. Australia's population is increasingly diverse and there is now greater recognition and respect of diversity and individual rights and needs in aged care. This is also true in palliative care, whether given in residential aged care or other settings.

Human rights of people in palliative care

Human rights recognise the value of every person regardless of our background, where we live, what we look like, what we think or what we believe.

People who access the services of palliative care hold the same rights as every other individual in society. These rights extend through palliative care, while the person can still communicate, and continue after they can no longer communicate with others.

Standard 3, Requirement 3c of the Aged Care Quality Standards is about providing care to older people at the end of life. There is a strong focus on providing care and support that has been tailored to the individual person.

People's individual differences can include:

- cultural background
- language spoken
- religious background
- LGBTIQ status (lesbian, gay, bisexual, transgender, intersex, and questioning).

We all have different values and beliefs about death and dying, receiving care and concerning our own lifestyle choices.

Unless these choices could cause harm to others it is important to respect them and support them wherever possible. You must not judge or discriminate against a person based on their gender, beliefs, culture or lifestyle.

Palliative Care Australia's standards for providing quality palliative care for all Australians outline palliative care approaches to ensure the person's comfort and dignity are maintained. For more information, visit: aspirelr.link/pca-national-standards

People who identify as LGBTIQ

Palliative care aims to provide quality of life to all people, regardless of their gender identity or sexual preferences.

Here are some ways you can help to incorporate inclusion and meaningful quality of life into palliative care for people who identify as LGBTIQ.

- Avoid using heteronormative language in your work. For example, if you have just met someone, avoid asking them about their husband or wife and ask instead about a partner. The person will then guide you in the language they prefer.

- Do not make assumptions about who is important, or not important to the person. It is not for you to judge.

- A same-sex long-term partner or spouse has the same legal and moral rights as any other spouse. You must recognise and treat a same-sex spouse in the same way as you would a heterosexual partner.

- Keep in mind that people who identify as LGBTIQ, particularly older people, may have experienced discrimination, mistrust and abuse.
- Older people may have lived at a time when their lifestyle was illegal; and when judgement, harassment and abuse were common.
- If they introduce someone to you as their friend, or as their same-sex spouse, respect the amount of information you have been given, or have not been given.

- People who are transgender or intersex may have different health care needs. Speak to your supervisor about how you can find out more about the person's specific needs.

- Respect the person's gender preferences right up to, and after, death. This includes helping a transgender person to dress and groom, and later to be laid out in the way they prefer.

- There is no need to be afraid or cautious of conditions like HIV/AIDS that were once particularly associated with gay men.
- If you support a person with HIV, current medications and treatments are very effective, and mean the disease cannot be passed on to others.
- There is no need to treat the person differently in any way, including your infection control practices.

- If you support a lonely person who is LGBTIQ, you might suggest visits from LGBTIQ volunteer community visitors.

- As the person's advocate you must speak up about any discrimination or harassment that you might see or become aware of. Your workplace must not tolerate this behaviour from any person, including from other residents.

LGBTIQ+ Health Australia and the Silver Rainbow project are online resources to help staff and service users and their supports to access information about LGBTI rights in aged care, including at end of life: aspirelr.link/lgbt-end-of-life

Spiritual beliefs

Spirituality is not always about religion. For some people, spirituality is about connecting to themselves through meditation, nature, or other forms of healing.

Spirituality
An inner sense of something greater than oneself, which may be met through faith or religion.

Religious practices, rituals and beliefs may become very important to the person, and/or their personal network, even if they were not important previously. Some people may refuse or welcome treatment based on their religious or spiritual beliefs.

Embracing spirituality is a common response that can have a positive outcome for many people. It can help the person come to terms with their condition, feel content with their life, be able to close their affairs, feel they have control over their situation or regain a positive outlook.

Workers have no right to make judgements or voice concerns about these beliefs. You do not have to agree with the person's spiritual beliefs to be able to support them.

For example:

- you might sit with the person and pray with them if they ask you to, even if you do not share their beliefs
- you might arrange for the person to have regular visits from a pastor, priest, rabbi or other religious leader
- it might give the person comfort to have religious or spiritual objects and experiences in their room, such as healing crystals, music, a crucifix, books, rosaries or statues
- when the person needs time and space to perform spiritual practices, such as prayer or meditation, you can help by providing privacy and respecting their need for quiet
- you can suggest and help them to go to chapel or church services
- you can acknowledge and help them to celebrate religious festivals such as Ramadan, Good Friday or Rosh Hashanah.

Video: Spiritual care

Watch the video about spiritual care in aged care facilities: aspirelr.link/spiritual-aged-care

Pay attention to the various ways you can demonstrate spiritual care and action in your work with clients.

Cultural differences

Cultural differences can have a significant impact on the person's approach to death and dying.

Respecting the cultural beliefs of the people you support is not just good practice but is a legal requirement under the Aged Care Quality Standards. Be aware that not all people who belong to a particular culture follow all its cultural practices.

You can find out about specific cultural needs by:

- asking the person and members of their personal network to suggest how you can support their culture
- talking to cultural groups and community leaders such as Aboriginal and Torres Strait Islander community groups
- researching cultural practices from reputable websites.

Here are examples of how a person's culture may influence their choices and the care provided to them.

Gender rituals	• Women in some cultures wear black to show they are in mourning. • Jewish males may wish to wear a kippah to demonstrate their faith. • People from many cultures prefer to have a person of their own sex attend to their personal care needs.
Religious practices and beliefs	• People from some cultures and religions have specific prayers and rituals that help support the dying. • People who are Catholic might believe that they will not go to heaven unless they are given absolution and receive the Last Rites from a priest.
Language and communication	• In some cultures, it is disrespectful to look a person in the eye. • In some cultures the opposite is true, and it is polite to maintain eye contact when you are having a conversation. • A person may want you to call them by their surname and title; for example, Mr Gates.
Beliefs about death	• Indigenous Australians believe that the name or image of a person who has recently died should not be spoken or shown, because this disturbs the person's spirit. • Many Jewish people believe that the body of a deceased person must not be touched by a person who is not Jewish.

Example

Cultural influences

In Greek culture, family and friends typically play a very important role in the care of a dying person. Frequently the wife of a dying husband may wish to be directly involved in his care, as this fulfils her sense of duty and obligation. Some cultural influences might be that:

- specific conditions may be talked about as 'that terrible illness' or the 'situation' in order to avoid direct mention of illness or disease
- displaying strong emotional reactions is acceptable
- for some people there is a strong fear of using morphine as it is associated with death
- the role of the church can be very important in providing comfort and support.

Adapted with permission of the Palliative Care Council of South Australia Inc:, http://www.pallcare.asn.au

Health, lifestyle and dignity of risk

We might eat the wrong foods, stay up late, or not exercise. Sometimes people who have been told they have a life-limiting condition develop a 'why does it matter?' attitude to taking risks with their health and their lives.

Dignity of risk means granting all people, including those accessing palliative care, the right to make their own choices and to take risks; as long as they do not harm others and as long as they have the ability to understand the consequences of those decisions.

Dignity of risk
A person's right to dignity and choice, upheld in legislation and service standards, to ensure that duty of care or safety is not used as a reason to limit a person's freedom of personal choice.

For example, the person has the right to:

- continue to smoke or drink against doctor's advice
- refuse to take medications or other treatments or care
- walk or shower unassisted if they prefer, as long as they can understand potential safety consequences
- leave the facility if they have followed the service procedure, such as signing out and letting someone know
- meet their sexual needs or have sex with any consenting person in private
- eat a solid diet, even when their doctor has deemed them at risk of choking, if they can fully understand the consequences
- be alone or refuse visitors.

When the person's condition deteriorates, they may no longer be able to make decisions for themselves. However, legal decision-makers can make some of these same decisions on their behalf, especially if the person previously voiced or wrote down their preferences. For example, the person's decision-maker might refuse for them to be given certain treatments or care routines, if that was the person's own wishes or practice.

Duty of care

When a person makes choices that might cause harm, there must be a careful balance between dignity of risk and **duty of care**.

Duty of care
A moral or legal obligation to ensure the safety and wellbeing of other persons.

Here are some examples.

Your duty of care	Examples
• It is your duty of care to prevent and report the resident or client's behaviours or decisions that might cause harm to any other person. • You must not allow others to be at risk of harm, and you must report potential dangers to your supervisor as soon as possible.	• You cannot allow the person to drive a car or mobility scooter if they are clearly affected by strong drugs like morphine, even if they have a valid license. • They do not have the right to make decisions that could cause harm to staff, such as insisting on being lifted or carried instead of using a hoist to be transferred to a chair.
• It is your duty of care to take whatever measures you can to keep the person safe while they are practising their free will and choice.	• If a person who is shaky on their feet refuses to be helped with walking, you can suggest that you could stay close by instead and remove obstacles in their path.
• It is your duty of care to report certain dignity of risk decisions to your supervisor so that it can be documented and, if necessary, a waiver signed. • The waiver will help your managers to be certain, and prove, that the person understands the consequences of that decision.	• A person might sign a waiver to say that they do not wish to have a liquid diet, even if this has been recommended or ordered by their doctor.
• You and your service have the duty of care to provide information to the person about the consequences of their decisions. • If the person understands and accepts those consequences, it is their right to continue with their decision.	• If a person refuses a medication you will need to refer the person to a nurse or doctor who can explain to the person what the consequences might be.

- You have the responsibility called a duty of disclosure to report any suspicions or concerns that the person might self-harm, even if they have told you not to tell anyone.
- This legal requirement also applies to any concerns that the person might be being abused.

- The person might tell you that they intend to take an overdose of tablets. It is your legal responsibility to report this to your supervisor.

Example

Duty of care

Read the following example to learn more about applying duty of care principles to the workplace.

Henry is celebrating his hundredth birthday and, because of his old age, he has very few friends left in his life.

He is hardly ever visited by anyone outside of his facility, and staff begin to notice that he spends most of his time alone. On his birthday, support workers make an extra effort to make sure that he feels loved and included by the people around him. They sing him happy birthday and spend some extra time asking him about his feelings. He tells them that he often feels very lonely and would love to be visited in the facility. Seth asks him about what things he misses the most and Henry tells him he was a dog lover all his life. As a result of this conversation the care team organises a support dog to visit the facility once per week to spend time with residents. The dog sits with Henry and he tells the staff that it brightens up his day and makes his life feel less dull.

Practice Task 7

Question 1

Which of the following statements relate to dignity of risk? Tick all that apply.

☐ Palliative care workers must never allow a person to make choices that might cause them harm.

☐ It is my duty of care to find ways to reduce the risk if possible.

☐ The person must be able to understand the consequences if they make a choice that involves risk.

☐ People who understand the consequences have the right to refuse pain killers.

☐ A person should not be allowed to go against their doctor's advice and continue to smoke.

Question 2

Give a brief description of the concept of spirituality.

2C Identify and refer needs and issues outside your scope

Your work role boundaries are important; they can protect you from allegations or suspicions of abuse or taking advantage.

Work role boundaries can also protect the person from unintended harm. For example, you must never give medical, legal or financial advice to a person in your care or to their family or personal network. You or any other staff member must never be a witness or signatory to a will or other legal document. This applies even if you have prior knowledge or professional information about these matters.

In your day-to-day work, you may encounter issues and concerns that are outside your job description and level of authority.

If you are asked to perform tasks that you believe are outside your role or area of skills and knowledge, let your supervisor or manager know. Your supervisor is usually the person who has the responsibility to make these referrals.

Here are some situations that are outside your job role and must be referred to your supervisor.

Medical concerns or requests	Referred to a nurse and/or doctor • The person tells you that their pain relief medication is not working. • A person tells you they do not want any more morphine because they might become addicted to it. • The person or family member asks you how long they have to live. • The person tells you they want to die and wants advice about how to hasten their death.
Emotional or spiritual concerns	Referred to a counsellor, religious or pastoral workers, or the person's doctor • The person has deep regrets about something they did in their life and is worried that they will not go to heaven. • The person wants advice about a family conflict. • The person appears to be suffering severe depression and anxiety.
Legal concerns	Referred to a solicitor, legal aid or independent advocate • The person wants to prepare their will. • The person wants you to be a witness to a legal document. • The person wants advice about power of attorney.

Criminal concerns	Referred to the police • On their deathbed the person admits to having sexually abused a child during their lifetime. • The person tells you that a family member or staff member is abusing them.

In most cases, you have discharged your job role simply by reporting the request to your supervisor and you do not need to make the referral yourself. There are some situations where it is your legal responsibility to be certain that a report has been made to police or senior managers. For example, if a staff member has used physical force towards a resident the law requires a report to be made to the Aged Care Commission. If a person admits to child sexual abuse or tells you that they have been or might be being abused, there is a legal requirement in some states and territories to make a report to the police yourself, especially if your manager does not do so.

Example

Referral needs

Derek has cancer. He is distressed by a conversation he has just had with his brother about a new cancer treatment that his brother saw on television. He now feels confused about the advice his doctors have given him and asks James, his support worker, if he should listen to his brother about this new treatment.

James knows that there are many different claims of cancer treatments and that Derek's brother may have given him false hope. However, he does not say this to Derek, because he is not permitted to give medical advice. Instead, he tells Derek that he will let the nurse know about his questions. The nurse in charge mentions this to Derek's GP that afternoon and the GP comes and talks to Derek about the studies that his brother was referring to.

Derek has faith in his doctor and feels confident about his doctor's advice.

Why must you refer certain questions to your colleagues? What procedures could you follow to ensure accurate referrals?

Practice Task 8

Question 1

Match each of the following issues to the person that this problem would be referred to.

A doctor or nurse	The person wants to give a family member their enduring power of attorney.
A doctor or nurse	On their deathbed the person admits to having sexually abused a child during their lifetime.
Legal practitioner or solicitor	The person tells you that a family member or staff member is abusing them.
Legal practitioner or solicitor	The person requests morphine.
Police	The person wants to write one of their children out of their will.
Police	The person tells you they want to die.

Question 2

Which of the following actions are outside your role? Tick all that apply.

☐ Giving advice about what treatment the person should agree to

☐ Letting your supervisor know when the person tells you that they are worried about becoming addicted to a painkiller

☐ Listening to the person talk when they tell you they are depressed

☐ Witnessing a will

☐ Giving financial advice if you have previously worked in the financial area

2D

Communicate in a way that shows empathy and provides emotional support

You will experience and witness a wide range of emotions while working in palliative care.

The emotions you may encounter can range from fear, grief and despair to joy and gratitude. All of these emotions are important and valid.

Talking can be helpful for the person when they feel strong emotions. Some of the things people may want to talk about include:

- querying the meaning of life
- questioning the existence of God
- asking why God has deserted them
- wanting to know how to make amends for things they regret that they did in their life
- wanting to know if there is life after death
- wanting to know what will happen to their body after death.

Some family members, and even some staff, may refuse to have conversations about death and dying that the dying person would like to have.

When a person who is dying wants to talk about how they want to die, or needs to talk to work through their emotions, you might hear responses from others like:

“Oh, don’t be silly. You won’t die for a long time” or “don’t get yourself all upset over that, now. Let’s talk about something cheerful instead.”

This can be a missed opportunity that might be important for the person. Try to look for signs that the person wants to talk to you about their emotional or other holistic needs relating to their diagnosis and listen to what they want to say. It can be uncomfortable for you to have this conversation but can be very important to the person.

VIDEO: Palliative approaches

Watch the following video about how important it is to support the person to express their emotions in palliative care: aspirelr.link/yt-palliative-approaches

Pay particular attention to the emotional needs of residents and the important role workers have in supporting them when it is a struggle for family and friends.

Listening skills

Active listening means showing through your body language and eye contact that you are paying careful attention. Always let the person finish what they are saying before you respond. Never try to change the subject, make a joke, or respond with comments such as “it’s all for the best” or “at least they won’t suffer for long”. Try to ensure the environment has minimal distractions and that you both have time to talk.

Here are some strategies to keep in mind when listening to the person and their family.

- Face the person you are listening to, if it is culturally acceptable.
- Observe their body language.
- Be patient and do not interrupt.
- Do not finish their sentences for them.
- Do not assume you know what they are going to say.
- Repeat things to make it clear you understand.
- Summarise the points they make.
- Ask the person to repeat things if you do not understand.
- Give information based on fact. Do not give opinions.

Showing empathy

Empathy means to hear what the person is saying without judgement, to put your own opinions aside and see things from their perspective

- Apart from listening to them, some ways to show empathy include:
- using a tone of voice that matches the mood of the person and family. For example, avoid walking into a room where people are crying with an upbeat smile or laugh. Remember you do not have to make people happy at a sad time
- avoiding saying things like “I know how you feel”, or “you shouldn’t be feeling like that”, or “if I were you, I would…”.   True empathy respects the person’s feelings as unique and valid
- avoiding giving advice or trying to make things better when you can sense that the person really just wants you to listen.

Support the emotional needs of the person's family or personal network

These people play an important part in the overall care of the person and they also need support, especially if this is their first experience of a palliative approach or of an impending death. Family members and carers anticipating the loss of a significant relationship often describe this period as being on an emotional rollercoaster and many varied emotions may be experienced. The anticipated loss of a loved one may lead to feelings of guilt, anger, frustration, distress or to family conflict. Do not assume that a person's family is always supportive.

Providing emotional support
Acknowledge grief. Let the person and their family talk about it. Do not be embarrassed, and do not brush these conversations off with comments like "oh you will be here for a long time yet".
Recognise that everyone has their own way of grieving. Just because somebody looks like they are coping does not mean that they are. Some people cope by not showing emotion. All responses are valid; never judge a person's reaction.
Allow family members the opportunity and privacy to express their concerns and difficulties they are experiencing.
Provide reassurance if family members are feeling guilty for wanting it to be all over; or not wanting to be at the person's bedside all the time.
Use empathy to show you understand how the person is feeling. Give feedback and clarify the information to show you understand their problems.

Example

Demonstrating empathy

Gladys has end-stage renal failure and has been feeling angry about her diagnosis. One day, Gladys becomes upset about being asked some questions about her needs. She starts screaming at the staff. "You know nothing about me. You know nothing about how it feels to be me!"

Her support worker, Alex, stays calm and listens to Gladys talk about her experiences with her condition. He does not try to argue with her or cause her further distress. Instead, he says: "Gladys, I am so sorry that you have been so unwell and have had to deal with this. I am here to listen if you want to talk."

Think about the ways you might demonstrate empathy in your role.

Practice Task 9

Question 1

Which of the following statements would be considered as showing empathy towards a person who is dying? Tick all that apply.

- ☐ "Let's talk about something cheerful instead!"
- ☐ "I understand how you feel because I felt the same way once."
- ☐ "It's OK to feel that way."
- ☐ "I'm here if you want to talk about it."
- ☐ "You won't die for a long time yet, so don't worry about it."

Question 2

List three ways you can provide emotional support to the person and their network.

Summary

- A supportive environment is one where there is mutual trust.
- Sharing information between the person, their family and all members of the team can help to support the person's needs.
- People who are dying have the same human rights as other people.
- Spiritual, cultural and individual differences must be respected.
- You must balance dignity of risk with duty of care when the person wants to make choices that carry risk.
- As a palliative care worker you may encounter issues and concerns that are outside of your job description and level of authority. At these times you must follow the organisation's procedures and know to whom particular issues should be referred.
- It can be important not to miss opportunities for the person to talk through their feelings.
- You must listen to what the client, their family members and carers say, and use empathy to acknowledge the impact the illness is having on those involved.

Learning Checkpoint 2

Respect people's preferences for quality-of-life choices

Part A

1. Which of the following statements relate to the scope of your own job role? Tick all that apply.

- ☐ My role is to provide advice about anything the person wants help to decide.
- ☐ My role is to refer the person to my supervisor if they want medical advice.
- ☐ I can give financial advice as long as I am experienced in end-of-life financial matters, such as if I have had financial power of attorney for a family member in the past.
- ☐ If I do not agree with something the person says about their family relationships, I should let them know my feelings.
- ☐ If a person tells me they are being financially abused, I should report this immediately.

2. Which of the following statements are correct? Select yes or no for each one.

a. George has lung cancer but he has the right to continue to smoke against his doctor's orders.	Yes / No
b. Leo has told you that he wants to take an overdose of medications but tells you not to tell anyone. You must breach his confidentiality and report this.	Yes / No
c. All people who are Jewish expect you to know and understand Jewish customs relating to dying.	Yes / No
d. If a person requests a person of the same sex to care for them this should be respected wherever possible.	Yes / No

Part B

Read the case study, then answer the questions that follow.

Case study

Narla is an Aboriginal woman at the terminal stage of her illness. She has progressed to a semi-conscious state while waiting for her family to arrive from an outback community 900 kilometres away. The nurse on duty makes an assessment that Narla is in pain and requires more morphine to relieve the pain. In the meantime, the workers make a call to the Aboriginal health service, who have an Aboriginal worker arrive to support the family.

When her family arrive, they are upset as they are unable to communicate with Narla due to her condition. Communication is very important to them at this time. Casey, one of the family members, lets the Aboriginal health worker know that she does not think that Narla's restlessness is due to pain but is instead because she wants to communicate with her family and is finding it difficult to do so.

Narla's family, together with the Aboriginal health worker suggest that the nurses reduce the dosage of morphine to see if this would allow Narla to communicate with her family. The nurse informs the treating doctor of the family's decision and the dosage is reduced. Narla is then able to sit up, eat a small meal and share stories with her family. She dies the next day.

1. Why do you think Narla and her family might have trusted the Aboriginal health worker more than the doctors and nurses when talking about their feelings about the pain relief?

Topic 3: Follow the client's advance care directives in the care plan

3A Interpret and follow advance care directives

3B Comply with end-of-life decisions and legal requirements

3C Report the person's changing end-of-life needs

3D Monitor the impact of end-of-life needs, issues and decisions on families and carers

3E Deliver services to support the person's right to choose the location of their end-of-life care

3A Interpret and follow advance care directives

Advance care directives specify the person's wishes for their end-of-life.

Advance care directives
An advanced care plan, detailing a persons' preferences for future care that align with their own values and beliefs.

Advance care directive provide the palliative care team and the person's network clear instructions about what the person wants to happen in their last days and weeks. This gives the person control right to the end of their life.

The directives are recorded in a formal document which is then signed by the person and witnesses, including a doctor. The name of this document differs between states and territories but it is commonly known as an Advance Care Plan or Directive.

Often some of the advance care directives are transferred into an individualised plan so that all staff can follow them

- Advance care directives:
- are a legal document
- only come into effect when the person is no longer able to make or communicate decisions.

The people closest to the dying person can find it difficult to make clear decisions in the last days and weeks of life. They can also find themselves in conflict with each other, or having different ideas about what they think the dying person might need or prefer. Advance care planning relieves the burden of decision-making for the person's network, and often reduces conflict and guilt. The directives are written with the person's doctor, and frequently with their family or significant others, and will consider possible problems and sources of conflict. They provide a clear statement of 'this is what I want...' Additionally, advance care directives reassure the person that their wishes will be respected.

Example

Advance care directives

Read the following example to learn more about applying advance care directives.

Moira has recorded her wishes for her last weeks, or for when she is no longer able to communicate or make decisions. She wrote the directives by consulting with her doctor, her palliative care nurse, and her husband. Her doctor helped her to consider some considerations for medical treatments, such as pain relief and enteral, or nasogastric, feeding. Her nurse encouraged her to think about how she would like her loved ones to be involved with her directives. Her husband discussed with her things that provide comfort to her, and he outlined the best ways he can support her during her end-of-life care.

Medical advance care directives

These represent Moira's formal consent, and are legally binding in all parts of Australia.

- I do not give consent to any medications or treatments used solely to prolong my life, including enteral feeding or IV fluids, unless these treatments are necessary purely for my physical comfort.
- I want to be given as many painkillers as required to keep me free from pain, even if they make me drowsy or unconscious.

Preferred advance care directives

These are legally binding in most parts of Australia, except NSW and Tasmania.

- I would like to remain in my own home to die and not be taken to hospital, unless this puts undue stress on my husband Garry. I do not want him to feel stress.
- I would like to be able to listen to the music on my Spotify playlist during the day even when I do not respond.
- I would like my dog to be able to stay on my bed with me whenever she wants.
- I want my husband, Garry, to be able to stay in the room with me whenever possible, even when I am being given personal care. However I do not want him to provide the personal care himself including pad changes, bed changes or bed baths unless it is completely necessary for my hygiene or comfort.
- I do not wish for any religious practices or prayers to be held at my bedside.
- I do not want my estranged brother, Paul, to be contacted or present at my death.

Video: Indigenous advance care plans

Watch this video to learn about how advance care plans are used successfully in Indigenous communities: aspirelr.link/indigenous-advance-care-plans

Think about the various ways in which advance care plans can be used to generate discussion around key areas in a person's life

Practice Task 10

Question 1

Describe the purpose of advance care directives.

Question 2

Which of the following statements are correct? Select yes or no for each one.

a. You will sometimes see the person's advance care directives included in their individualised plan.	Yes / No
b. Advance care directives are a legal document.	Yes / No
c. Advance care directives come into effect as soon as the person and their doctor have signed them.	Yes / No
d. Advance care directives are the same as a will.	Yes / No

3B Comply with end-of-life decisions and legal requirements

All Australian states and territories have laws covering the use of advance care directives.

At some point during the person's illness, they may no longer be able to make decisions for themselves. This could be because the person has severe dementia, or they might be unconscious or unresponsive. Of course, not all people who are dying lose their decision-making or communication abilities. Some people suffering from illnesses such as cancer might only lose consciousness in the last days, or even hours, of their life. Others, such as people with dementia, require substitute decision making to be in place months or years before their death.

A doctor or psychologist usually needs to determine through a documented examination and report that a person is no longer capable of making decisions for themselves, or able to communicate their decisions in some way. At this point the end-of-life decisions that the person made in their advance care directive take effect, and the substitute decision maker begins their legal role.

Substitute decision makers

A substitute decision-maker may be a spouse, a family member or another trusted person. The names used for substitute decision-makers varies between states and territories. They may be called:

- a guardian
- an enduring guardian
- power of attorney
- an administrator
- a decision-maker.

Some **substitute decision-makers** are appointed responsibilities to only make decisions relating to specific parts of the person's life. For example, one individual might be appointed as an enduring power of attorney for financial matters and someone else might be appointed as an enduring guardian or enduring power of attorney for the person's health and lifestyle decisions.

Substitute decision-maker
Someone the person has nominated to take responsibility for making decisions for them.

Responsibilities of substitute decision-makers

Depending on the powers they have been given by the person or the courts, substitute decision-makers can make legal decisions and consent to treatments on behalf of the person.

They have the legal responsibility to follow the person's written or spoken advance care directives.

In some situations, such as when an unexpected problem has arisen and the person has not specified a response, the substitute decision maker may need to make the decision on their own. They must act in the way that they believe the person would have acted under these circumstances.

In most states the substitute decision-maker cannot override the person's decisions on their own. To do this, they must apply to the state or territory's Guardianship Board or Tribunal.

Making decisions in the substitute decision-maker's absence

Health care and personal decisions can be made by a close family member or friend if the person did not nominate a substitute decision-maker. States and territories have different legislation relating to how this person is chosen if there is conflict about the choice. In some cases it will need be decided by the guardianship tribunal, and on occasion it is the palliative care team or aged care staff who make the application for a decision to be made in the tribunal.

Following advance care directives

It is a legal and ethical requirement for you to follow the advance care directives by working with the substitute decision-maker.

Advance care directives are often transferred into the person's individualised plan to make it easy for you to follow, and the following items may be written into the individualised plan:

- The name of the substitute decision-maker/s.
- How pain should be managed.
- How to follow cultural practices that the person wishes to be observed.
- Where the person wants to die.
- What the person would like to have in their environment such as religious icons, flowers, music, sunlight.
- Preferences for personal care routines.
- It is important to respect the person's end-of-life decisions in the same way that

you would if the person was telling you their wishes themselves. Involve the substitute decision-makers if you are unsure about anything. The substitute decision-maker can take the place of the person, by letting you know what they feel the person would have wanted when a response is not outlined in the advance care plan.

To learn more about advance care planning and the law, visit: aspirelr.link/advance-care-planning-aus

Example

Compliance considerations

Goren is following the individualised plan for Harry who is in the severe stages of dementia. When he was first diagnosed with dementia, Harry wrote advance care directives that have now been written into his individualised plan.

Goren notices that the individualised plan requires Harry's war medals to be polished every morning and placed on his chest, as this was one of Harry's advance care directives.

Goren is uncertain about this because he is concerned he might damage the medals by using a cleaning product, and he is unsure where on Harry's chest to place them. Goren respects Harry's need to have this done correctly, so rather than making a guess he talks to Harry's daughter and substitute decision maker, Rachel.

Rachel knows that the medals are traditionally worn over the heart, on the left side. She thanks Goren for taking enough care to ask about this.

Rachel is not sure however, what type of cleaning product her father used to clean and shine his medals. She knows her father was very particular about the medals, as he was about most of his possessions, and she wants to do the right thing. She is also concerned about them being damaged so she rings her local RSL and asks their advice. The RSL suggest a non-toxic silver polishing cloth. This is kept by the bed and the individualised plan is updated to reflect these two specific requirements.

Why do you think it's important to ask for advice about directives you are unsure of?

Illegal or unprofessional requests contained in advance care directives

You and your colleagues cannot do anything that goes against your policy and procedures, professional code of ethics or that is illegal, even if it is written in the advance care directives. For example, the person might have requested marijuana to be placed in a vaporiser next to their bed. They might request to be given drugs to end their life in a state or territory where assisted dying is not legal. You must always follow the law, policies and procedures, over the advance care directives.

Voluntary assisted dying

Voluntary assisted dying (VAD) is when a health practitioner provides assistance to a person with a terminal illness, disease or medical condition to end their life. Providing appropriate medication to provide pain relief and manage symptoms for a terminal patient is not VAD. A person must still have legal decision-making capacity to access VAD. Laws that allow voluntary assisted dying currently operate in Victoria, Western Australia, Tasmania, Queensland and South Australia. VAD will commence operation in New South Wales on 28 November 2023. VAD is illegal in the Australian Capital Territory and Northern Territory. The laws allowing VAD in each state are similar, but the person must meet all of the eligibility criteria in their State to be able to access VAD.

Practice Task 11

Question 1

Match each term to its correct description.

The substitute decision-maker	Is what some states and territories call a substitute decision-maker.
A guardianship tribunal	Is when a medical professional assists a person with a terminal illness to end their life.
Power of attorney	Can decide if there is a dispute about the substitute decision-maker.
Voluntary assisted dying	Is usually decided by the person who is dying.

Question 2

What would you do if the advance care directives include something that is illegal?

3C

Report the person's changing needs and issues

When you work closely with a person who is dying, as their needs and circumstances change they may express wishes that are different from those documented in their advance care plan.

They might want to change, whether adding or deleting, the advance care directives that they have previously written. Or they may not have an advance care directive but begin to talk about end-of-life issues that are on their mind. They may tell you things that you think should be included in this type of document.

If you feel that a person wants to talk to you about their end-of-life wishes, let them talk freely but do not give advice. They might prefer to have these conversations with you rather than with their family. Let them say what they feel, and then encourage them to have the conversation with their family as well.

If they are ready to write down their wishes, or to allow someone to help them, an advance care plan can be developed or an existing one changed.

Reporting changes to the person's wishes

Changes can be made to the person's advance care directives, or a new plan commenced, at any time while the person is still able to make decisions and communicate them.

When the person has told you that they want to make a change to their end of life wishes it is crucial that you communicate and document this to your manager and to the person's appointed substitute decision-makers. Not doing this can mean that the person's final wishes are not met.

If the person's needs change after they are no longer able to express them, it is also still important to report these needs.

Example

Responding to changing needs

Tegan is working with Moira. Moira's advance care directives were outlined in Topic 3A. When Moira wrote the directives she was estranged from her brother Paul, and she specified that she did not want Paul to be contacted or be present at her death.

Today Moira started talking to Tegan about Paul and how much she regrets the family rift that happened several years ago. Tegan listens while Moira talks about her brother and about how well they got along as children.

Moira suddenly tells Tegan she would like to ring her brother. She phones him and talks to him. Moira and Paul have an emotional discussion during which the brother and sister both apologise for things they said and did to each other. Paul wants to visit Moira, and they agree to a visit sometime during the following week.

Later, Moira tells Tegan that she would like to change her advance care directive regarding her brother. She says she forgives him and would like to have him with her family when she dies. Tegan forgets to document or report this change and she fails to mention it to Moira's husband.

A few days later Moira slips into a coma. She does not regain consciousness. When Paul rings the facility to ask about her condition and to ask if he can visit, he is told that he is not to visit because that was Moira's wish. Moira's husband does not hear about the change either and refuses to allow Paul to be given information about her condition or to visit her.

In Tegan's case, Moira's earlier advance care directives would have been overruled if Tegan or Moira had told a manager or Moira's husband about the change. A verbal change can be recorded and directed in the person's end-of-life care by the substitute decision-maker if there is no time or ability to amend the written document.

Consider why you must recognise changing needs and respond to them appropriately.

When the person's needs change

Advance care directives should be reviewed periodically to ensure the wishes of the person at that point in time are appropriately reflected.

Palliative Care Australia recommends that advance care directives be reviewed every two years, or whenever the person's medical condition or other factors change significantly. Sometimes the person might become aware of new needs that they had not considered when they first wrote their advance care directives.

Be aware of changes and how they might affect the person's end-of-life wishes. You can be proactive about asking a person about their preferences as their situation changes, and must then document and report what you have heard.

If a person's end-of-life wishes change, you must:

- encourage the person to talk to their family about the change
- report to a relevant person; for example your supervisor, manager or the director of nursing
- document the issue or change in the person's file notes to inform other team members to take appropriate action
- follow-up to make sure that the advance care directive and individualised plan has been revised to reflect the change.

For example, it might become clear that the person is having trouble breathing because of excessive respiratory secretions related to their illness. The person might not have considered, or have not been warned by their doctor, that either medications or gentle suctioning of their respiratory passages might be needed to keep these fluids away.

The person might only begin to think about, or experience a reaction to this problem, when it starts to develop. They might have strong preferences about having, or not having, medications or suctioning.

When these new needs arise the staff should talk to the person as soon as possible about their preferences. New preferences and needs should then be followed up and documented on the person's individualised plan and advance care directives.

Practice Task 12

Question 1

Which of the following statements are correct? Select yes or no for each one.

a. Advance care directives cannot be changed once they have been signed.	Yes / No
b. It is recommended for the person to review their directives every four years.	Yes / No
c. Changes in the advance care directives can also affect the individualised plan.	Yes / No
d. If a person tells you they want to do something differently than outlined in their advance care plan, the plan takes precedence and must always be followed.	Yes / No
e. It is best not to report changes in the person's wishes in case it upsets the family.	Yes / No

Question 2

List two ways a person's changing needs can be reported.

3D Monitor the impact of end-of-life needs, issues and decisions on the person's personal network

The person's end-of-life wishes can sometimes cause stress and conflict within the family or personal network.

There might be items in the person's wishes that make continuing to care for them more difficult and stressful than it would otherwise be.

- One or more family members might not agree with the person's decisions to refuse medical treatment.
- The person might wish to die at home, creating physical and mental anguish for their spouse who cannot cope with their care.
- Dying at home might make some family members who do not feel welcome in the home feel prohibited from visiting.
- The family might feel that the medical staff are not following their duty of care by allowing an unconscious person to go without IV fluids or nasogastric feeds for weeks, if that was the person's wish.
- Different factions of an estranged family might be confronted with each other and arguments might arise.
- There might be conflict between the person's need for rest and quiet, and the family's desire to visit the person.

The aim of the palliative care team should always be to work towards the dying person's best interests and stated wishes.

This can be a balancing act that requires you to resolve or negotiate compromises and sometimes to advocate for the person, as you saw in Topic 1.

When you see signs of conflict

There are some things you must never do when there is conflict in families or networks.

You must never:

- join in the argument
- take sides

- give advice or opinions about the argument
- make judgements about how the person or their family reacts
- raise the problem or conflict with the dying person.

Instead, report stressors and conflicts to your supervisor as you become aware of them.

Your supervisor or the person's doctor will be able to talk to the family and/or the person about the issue, but they will always put the interests of the dying person first.

Sometimes these conflicts can be discussed rationally with the family and sometimes not. When the family realise that conflict might be affecting the person, they might negotiate decisions and problems with each other away from the person. The supervisor or doctor might point out that fighting in front of the person is causing them distress. Sometimes this is enough to help the family see the problem from the dying person's position.

At other times this will not be sufficient to put a stop to the conflict and your supervisor might need to set down rules about behaviour and visiting restrictions in the interests of the person. Your supervisor might suggest restricting visiting hours to meet the person's own preferences, or suggest staggered visiting hours so different family members will not cross paths.

When conflict arises because the medical staff, or another person who is close to the dying person, do not agree with the decisions made by the substitute decision-maker, they can apply to the guardianship board or tribunal.

Example

Mediating conflict

Ana is dying of cancer in an aged care facility and is no longer able to communicate. Her substitute decision-maker is her only son, Kristoff. Ana did not include preferences about pain relief in her advance care directives. Kristoff tells the nurses that he does not want his mother to have any more pain relief medications. He tells them that he believes that the morphine is killing her and argues that if the morphine is stopped she will wake up again, and possibly live for several more weeks or months.

The nurses can see that Ana is in severe pain, even though she is no longer able to say or communicate this. She groans and cries out when touched and her body is curled in agony. They try to discuss this with Kristoff, and ask the doctor to talk to him, but Kristoff refuses to change his position. The nurses and the GP have some concerns that Kristoff understands what they are saying but might simply not want to pay for the morphine.

After some discussion, the GP makes an application to the Guardianship Tribunal to have Kristoff's decision overruled. She argues that it is Ana's human right to be free of pain, and that Ana expressed her fear of dying in pain to the nurses several times when she was alert and able to talk.

The Tribunal agree with the GP's argument and grant her and the nurses the power to ensure that Ana is able to receive pain relief medication.

Think about a time you encountered conflict. How could you have mediated it better?

Practice Task 13

Question 1

List two examples of strategies that can be put in place if there is conflict between family members occurring in front of the person who is dying.

Question 2

What can a family member do if they do not agree with the decisions made by the substitute decision-maker?

Question 3

Which of the following signs might indicate that the person's end-of-life needs are negatively impacting on their family? Tick all that apply.

- ☐ There might be disagreement with the person's decisions regarding their refusal of medical treatment.
- ☐ Their carer or spouse may experience increased physical and mental anguish in trying to cope with their care at home.
- ☐ Family members may feel excluded and depressed by not being able to visit the person because they are not welcomed in their home.
- ☐ There might be disagreement with medical staff regarding the lack of treatment given to the person, even if it was that person's wish.
- ☐ There might be discussion amongst family members as to how they can best share care responsibilities in the home.

3E

Deliver services to support the person's right to choose the location of their end-of-life care

Many people choose to die in the familiar setting of their own home surrounded by their family.

While dying at home is something we might consider as a right, and as an easier way to approach death for ourselves and our families, this is not always the case. Dying at home can create a set of problems and stresses that the person and their network might not have considered when making this choice.

Many people who live in a facility or a hospice include in their advance care directives that they do not want to die in hospital. Hospitals can be frightening places for many people. They can have negative associations with disease and sickness and can feel cold and clinical. For some people, such those with Aboriginal and Torres Strait Islander backgrounds, there can be negative cultural and historical associations with western medicine.

Talk to the person about their choice of end-of-life location

Every person has the right to make choices about their end-of-life location, and should be given the correct information and resources that relate to their illness and their family situation. This can sometimes be a more complex decision than it might appear and is usually a conversation for the person to have with their doctor, along with their family.

Listen to what the person is saying and then refer them to your supervisor or a doctor. Do not give the person advice. Just because a family member or someone you know had a good or bad experience with their location of death, does not mean you are able to understand the complexities of the person's situation.

Example

Addressing cultural needs

Many Aboriginal and Torres Strait Islander people have a strong connection to their land and country. They might also have concerns with talking about illness or death with people outside their family. Aboriginal and Torres Strait Islander health workers, or the person's family, might be best placed to start the conversation with them to discuss the benefits of talking and planning an end-of-life location. An advance care plan developed by an Aboriginal and Torres Strait Islander health worker can help to reassure the person that they will not have to leave their own community and country to go to hospital.

Common stressors related to dying at home

Occasionally the person's wish to stay at home becomes difficult to fulfil.

For example:

Caring for a dying or unconscious person can be physically difficult and exhausting. The primary carer, such as a spouse, might be older or unwell or otherwise unable to cope with the 24-hour care of the person when the palliative care team are not present. This might mean the dying person is not getting the right amount of care, or safe care.

The nature of the family home might exclude certain people. For example, if the person is in a same-sex relationship the dying person's long-term partner might not be welcome, or might even be excluded from the home by the adult children, or vice-versa. This can cause stress to the dying person.

The person might need medical treatments, such as pain-relieving surgery, that cannot be performed in the home.

The person might live in a rural or remote area where palliative services are not able to attend.

Family members or friends who would not normally have intimate contact with the person might feel obliged to help with unplanned personal care needs, impacting the person's sense of dignity.

Every effort should be made to try and help the person's wish to die at home become a reality but this is not always possible. If you think the family is not coping, or there are factors that are causing distress to the dying person, let your supervisor know.

The palliative team can put measures in place to help. These can include:

- additional supports from visiting workers
- aids and equipment to help with turns and transfers such as a hospital bed
- referrals to family counsellors .

Again, the primary goal should be to consider the best interests of the person.

Example

Addressing issues of dignity

Doris wishes to die at home where she lives with her long-term partner, George. George and Doris are both in their seventies. A palliative care team attached to the local hospital attends the house every day, and support workers visit twice a day to help Doris.

One afternoon, some time before the care team is due to arrive, their son-in-law Matt is visiting. Doris is in bed and George and Matt are sitting with her when Doris experiences faecal incontinence. While she is still conscious enough to be very embarrassed and distressed she is not strong enough to speak. George has severe arthritis and cannot change and clean Doris on his own. He asks his son-in-law to help him to turn her, change the soiled bed and wash her groin and buttocks. It does not occur to either of the men that Doris would be mortified by this and they do not consider other options. Doris's final days were marred by the humiliation and lack of dignity she felt because of being washed by her son-in-law.

What might be an alternative approach in this situation?

Practice Task 14

Question 1

List two examples of places where a person might choose to die.

Question 2

Which of the following explain why it might not be possible for a person to die at home? Tick all that apply.

☐ The support worker thinks it is best that the person dies in the aged care facility.

☐ The primary carer, such as a spouse, might be older or unwell, or unable to cope with the 24-hour care of the person when the palliative care team are not present.

☐ The person might need medical treatments, such as pain-relieving surgery, that cannot be performed in the home.

☐ The person might live in a rural or remote area where palliative services are not able to attend.

☐ The person's family do not get along; therefore certain members of the family would not be welcome in the home.

Question 3

List one way workers can support the person's right to choose the location of their end-of-life care.

Summary

- Advance care directives are the person's wishes about how they want to die, and a legal consent or refusal for treatments.
- They take effect when the person is unable to make their own decisions.
- When people are no longer able to make decisions for themselves, a substitute decision-maker makes decisions for them, and helps to ensure that the advance care directives are followed as the person would have wanted.
- Advance care directives are often documented in the individualised plan and must be followed wherever possible.
- Changes to the directives can be made at any time until the person is no longer able to make decisions.
- Report any changed wishes or preferences to your supervisor so that they can be documented and followed through.
- Family or significant others might be impacted by the person's wishes and needs, and this can have negative consequences for the dying person.
- Respect the person's wishes to die in the place of their choice, and report concerns or problems to your supervisor.

Learning Checkpoint 3

Follow the client's advance care directives in the care plan

Part A

1. Which of the following statements relate to advance care directives? Tick all that apply.

- ☐ They are the same as a will.
- ☐ They come into effect as soon as they have been written and signed by the person.
- ☐ They only come into effect when the person can no longer communicate their wishes.
- ☐ They can be changed at any time while the person is able to make decisions.
- ☐ They are the same as an individualised plan.

2. Match the people to their role in advance care directives.

The doctor and the person	Leads decisions after the person is no longer able to communicate.
The substitute decision-maker	Must sign the advance care directives.
The person who is dying	Must follow the individualised plan.
The support worker	Can make changes to the directives at any time.

3. What should you do if a person tells you that they want to make a change to their advance care directives?

4. Briefly describe what voluntary assisted dying (VAD) is, and explain how it can be accessed.

Part B

Read the case study, and then answer the questions that follow.

Case study

Moira has recorded her wishes for her final weeks, or for when she is no longer able to communicate or make decisions. She wrote the directives with the help of her doctor, her palliative care nurse and her husband, who will be her substitute decision-maker. Her doctor helped her to consider medical treatments such as pain relief and enteral, nasogastric, feeding. Her nurse encouraged her to think about additional stress that might be placed on her loved ones by her directives and showed her how to work around the needs of her family. Her husband talked to her about a range of family situations that could occur and how she could avoid conflict or embarrassment.

Here are her medical advance care directives:

- I do not give consent to any medications or treatments used just to prolong my life, including enteral feeding or IV fluids, unless these treatments are necessary only for my physical comfort.
- I want to be given as many painkillers as needed to keep me free from pain, even if they make me drowsy or unconscious.

Here are her preferences of care directives:

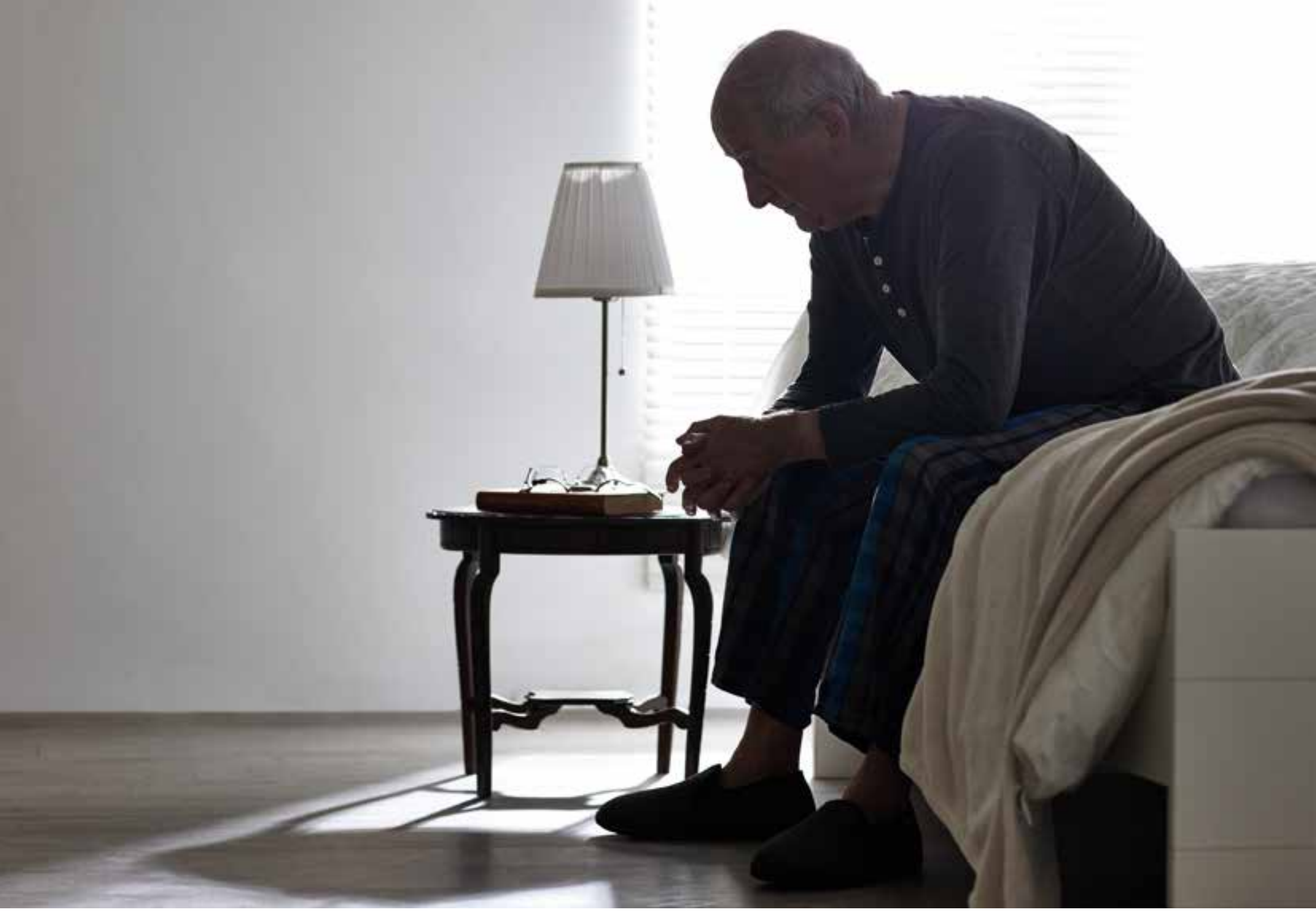
- I would like to remain in my own home to die and not be taken to hospital, unless this puts undue stress on my husband Garry. I do not want him to feel stress.
- I would like to be able to listen to the music on my Spotify playlist during the day, even when I do not respond.
- I would like my dog to be able to stay on my bed with me whenever she wants.
- I want my husband, Garry, to be able to stay in the room with me whenever possible, even when I am being given personal care. However I do not want him to provide the personal care himself including pad changes, bed changes or bed baths, unless it is completely necessary for my hygiene or comfort.
- I do not wish for any religious practices or prayers to be held at my bedside.
- I do not want my estranged brother, Paul, to be contacted or present at my death.

1. After she is unconscious and no longer able to communicate her needs, Moira's family request for her to have IV fluids to keep her alive. She appears comfortable and pain free. What does the law say about this?

2. Moira wants to die at home. Does she have the right to put conditions on this? Who would make the decision about whether these conditions can be changed?

3. What actions could you take to make Moira's wish to die at home more likely to happen?

4. If there is conflict between Garry and Moira's family about her going to hospital to die versus staying at home, what are the responsibilities of the palliative team to reduce conflict?



Topic 4: Respond to signs of pain and other symptoms

4A Observe and document pain and other symptoms

4B Implement strategies to manage pain and promote comfort

4C Evaluate and document the effectiveness of pain management strategies

4D Recognise and report concerns about the use of pain-relieving medication

4A

Observe and document pain and other symptoms

One of the most important aims of palliative care is keep the person as free from pain as possible.

Pain and pain management are major concerns for many people in palliative care. Pain can be one of the most difficult and frightening things to cope with at the end of life and symptoms that cause discomfort to the person should be reported as soon as possible.

Pain can be due to a single factor or a combination of factors. For example, it can be caused by their disease, by reduced mobility and by the ageing process. Pain may be either:

- acute: severe and sudden onset, or short-lasting, or
- chronic: ongoing and continual.

Acute pain	Chronic pain
• May last minutes, hours, days or weeks but is relieved by time or medications. • Often comes with other symptoms such as increased blood pressure, increased heart rate, sweating and pallid skin. • Is often highly distressing. • Can cause the person to be inactive until they recover. • May require temporary pain relief.	• Often caused by an illness such as arthritis or cancer. • Starts slowly and often becomes progressively worse. • Might not come with other symptoms because the body adapts to the pain. • May cause the person to be distressed, depressed, withdrawn and tired. • Needs regular ongoing pain relief.

Expressions of pain

You must never judge the person's expressions of pain or assume that they are exaggerating or attention seeking.

In aged care, and in palliative care in particular, if the person says they are in pain then they are in pain. It is important to assess pain regularly and without waiting for the person to tell you.

Studies have shown that many older people are not given adequate pain relief. There can be many reasons for this.

Here are some examples.

Reason	Example
Inability to express pain	• People with dementia or other cognitive conditions may not be able to voice their pain. • People who are frail might find talking about their pain too exhausting, especially when staff ask a lot of questions.
Generational attitudes to pain	• Many older people believe it is brave to be stoic and to put up with pain, and that it is a sign of weakness to admit to pain. This can sometimes be truer for older men than women. • Many older people grew up at a time when it was accepted that they did what authority figures told them they had to do. This can mean that they think that it is better not to bother you, and that they should wait until asked to tell you about their pain.
Cultural and language barriers	• People from some cultures may feel that it is undignified to call out or complain about pain. • If the person has English as a second language, or speaks a language other than English, they may have difficulty describing or expressing pain.
Staff misconceptions andbeliefs	• Many people who work in aged care have misconceptions about pain relief such as concerns about addiction, or a ‘let’s wait and see’ attitude.

Assessing pain

Palliative care workers must monitor the person closely to identify whether they are experiencing pain or other symptoms.

There are several ways to recognise that a person might be in pain.

1. Ask them	• If the person is able to communicate with you, ask them regularly whether they are in pain.
2. Watch them	• Look for signs that might show that the person is in pain.
3. Listen to them	• Older people might use other words to say they are hurting. • If the person cannot talk, listen for sounds that might indicate pain.
4. Use a pain scale or pain assessment tool	• Pain scales, and other pain assessment tools, can help you to understand the person’s level of pain.

If the person is at end-of-life or cannot communicate with you, sometimes it is best to assume that they have pain, especially if they have cancer or another chronic source of pain. It is better to provide pain relief than for the person to be in pain, even if you are not sure.

Asking the person about their pain

When you ask the person if they are in pain, try to question in a way that makes them feel able to reply honestly.

If you are rushed and say: “do you have pain?”, as if you are just following a routine they might answer “no”, so they don’t feel as if they are bothering you.

Instead, use an open-ended question like: “How is your pain right now?” or “how can I make you more comfortable?”

If their pain is not chronic and ongoing you might need to ask them to describe the type of pain they are having; how bad it is, when it starts, how long it lasts and where it is located.

Here are some others questions you might ask about the pain:

- Where is the pain located?
- Does it spread from one area to another or is it in the one place?
- How does the pain feel; for example is it throbbing, piercing, sharp, dull?
- Is the pain ongoing or does it stop and start?
- Does the pain occur when you are lying down or sitting up?
- Does the pain get worse when you are walking?

Pain in other languages

If the person does not speak English, it is easy to learn the word for pain in other languages, or you can use apps like Google Translate on a phone or tablet.

Here are some examples:

Italian	Dolere
French	Douleur
Vietnamese	cơn đau
Chinese	téng tòng
Sudanese	alem

Watching and listening for signs of pain

If the person cannot tell you about their pain, or if they are reluctant to talk about it, watch and listen for signs such as:

- an anxious expression on their face
- holding a part of their body tightly

- constantly changing position
- a curled-up body
- guarding: this is when they reach out to protect themselves when you come near or when you touch a certain area
- groaning, sighing, heavy breathing
- crying out or screaming.

The person might talk about their 'nerves' or 'discomfort'. Be alert for signs that they might be trying to express pain in their own way and in their own language.

Pain assessment scales

There are several commonly used pain scales in palliative care and aged care settings.

Pain Assessment in Advanced Dementia (Painad)

	0	1	2	SCORE
Breathing Independent of Vocalisation	Normal	Occasional laboured breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations	
Negative Vocalisation	None	Occasional moan or groan. Low level speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial Expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
Body Language	Relaxed	Tense. Distressed pacing. Fidgeting	Rigids. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
			TOTAL	

To use a Painad scale:

1. Observe the person for five minutes
2. Look for body language and vocalisations such as crying or groaning.
3. Give the person a score from 0-10 points.
   - 1-3 = mild pain.
   - 4-6 = moderate pain.
   - 7-10 = severe pain.
4. Compare the scores after pain relief is given to help assess whether pain is getting worse or better.

Wong-Baker FACES® Pain Rating Scale

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The Wong-Baker FACES® Pain Rating Scale is used for people who are able to understand how to select a face to describe their pain.

This tool can be a helpful way to gauge the level of pain without annoying the person with constant and complex questioning. Remember that:

- it should not be used for people with dementia
- it is for the person to point to, and not to be used for comparison of their facial expression by staff.

Abbey pain scale

The Abbey pain scale is a commonly used tool used to assess pain in people with dementia or those who cannot verbalise. It is scored by observing the person and answering six questions.

How to use the scale: While observing the person, score questions 1 to 6.	
Q1. Vocalisation For example: whimpering, groaning, crying.	☐ Absent 0 ☐ Mild 1 ☐ Moderate 2 ☐ Severe 3
Q2. Facial expression For example: looking tense, frowning, grimacing, looking frightened.	☐ Absent 0 ☐ Mild 1 ☐ Moderate 2 ☐ Severe 3
Q3. Change in body language For example: fidgeting, rocking, guarding part of body, withdrawn.	☐ Absent 0 ☐ Mild 1 ☐ Moderate 2 ☐ Severe 3
Q4. Behavioural change. For example: increased confusion, refusing to eat, alteration in usual patterns.	☐ Absent 0 ☐ Mild 1 ☐ Moderate 2 ☐ Severe 3
Q5. Physiological change For example: temperature, pulse or blood pressure outside normal limits.	☐ Absent 0 ☐ Mild 1 ☐ Moderate 2 ☐ Severe 3
Q6. Physical changes For example: skin tears, pressure areas, arthritis, contractures, previous injuries.	☐ Absent 0 ☐ Mild 1 ☐ Moderate 2 ☐ Severe 3

Add the scores for 1 - 6 and record here:

Total pain score ☐

Now tick the box that matches the total pain score:

☐	☐	☐	☐
0-2 No pain	3-7 Mild	8-13 Moderate	14+ Severe

Finally, tick the box that matches the type of pain:

☐	☐	☐
Chronic	Acute	Acute on chronic

Source: Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B. Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002

Other tools commonly used in Australia for pain assessment include:

Modified Resident's Verbal Brief Pain Inventory	• This scale asks the person a series of standard brief questions and asks you to draw the position of the pain on an outline of the body.
Numeric rating scales 0 1 2 3 4 5 6 7 8 9 10 0 = No pain 10 = The worst pain possible	• A simple way to assess pain in a person who does not have dementia can be to ask the person to rate their pain on a scale from one to ten. • You can then circle or chart the person's answer. • This method can help you to compare the person's own expression of pain to their previous expression of pain. This allows you both to assess whether their pain relief medication is working and to report higher levels of pain than usual.

Video: Abbey pain scale – Community Setting

Watch the following video which demonstrates how workers can use the Abbey pain scale to assess pain in a person with dementia: aspirelr.link/abbey-pain-scale-youtube

Pay particular attention to the way the worker communicates with the person and their family: how does she demonstrate respect and understanding?

Example

Assessing pain

Mr Cane is 87 years old and has lived in an aged care facility for many years. He has a reputation for being an attention seeker because he has a demanding manner and complains a lot about pain and discomfort.

Now that he is dying, that reputation continues. The staff tend to assess his pain on whether he looks like he is in pain, rather than what he says about his pain. If they feel he is simply asking for pain medication because he wants attention they don't ask the nurse to give him pain relief.

It is not until a new nurse, Georgie, starts at the facility and performs a comprehensive pain assessment that this practice is stopped. Georgie explains that the staff cannot use their own past judgements about whether or not Mr Cane is in pain. She helps them to understand more about pain in aged care and warns them that their judgemental practice is in breach of the Aged Care Quality Standards.

With Georgie's help Mr Cane's doctor puts him on regular four-hourly pain medication. After a few days of this Mr Cane becomes a different person. He no longer has to experience the humiliation of eye-rolling and looks from staff when he complains of pain. He is automatically provided with effective pain relief that works, he stops complaining that he is in pain and he becomes more interactive with other residents. The staff realise that seeking attention is Mr Cane's right and should not be considered to be a nuisance. They spend time talking to him, and because he is brighter and more relaxed they start to enjoy his company, and vice versa.

Georgie reminds other staff members that they should never presume to know what a person is experiencing.

Why must you listen attentively when responding to pain complaint? What procedures could you follow to ensure you assess a client's pain professionally?

Other symptoms that cause discomfort

There are a number of other symptoms commonly seen in palliative care settings that should be treated as they arise and reported to your supervisor.

These symptoms can be the result of the person's disease such as cancer, or the result of pain relief and other medications they are taking. In some cases they can signal that the person's body is beginning to shut down.

Dry mouth and lips

Dry mouth and lips can occur as a result of a disease, from dehydration or from oxygen or medication that is being given to the person.

Report and document signs such as:

Lips	Dry, cracked, blistered or chapped.
Tongue	Coated, ulcerated, swollen, red, cracked.
Gums and tissues	Red, shiny, swollen, bleeding, patchy.
Teeth	Natural teeth may break, or decay. Dentures may not fit.
Pain	Dental pain may occur.

Dry mouth can be treated by:

- a review of the person's medication
- frequent mouth care
- chapsticks or barrier creams on the lips
- artificial saliva drops
- extra fluids to drink
- ice to suck.

Shortness of breath

Shortness of breath is often called dyspnoea. Dyspnoea can occur due to:

- tumours in the airway
- coughing/wheezing
- pneumonia
- anaemia
- low blood oxygen levels
- fear
- panic
- anxiety.

Immediately report shortness of breath to your supervisor and document it. The person may be prescribed medication or oxygen by the doctor to treat dyspnoea. Try to help the person to avoid exertion, assist in positioning the person to provide comfort and monitor improvement or deterioration.

Nausea and vomiting

Nausea and vomiting can be a distressing symptom for a person at end-of-life. The following list includes some causes of nausea and vomiting:

- Constipation, bowel obstruction.
- Toxins from cancers in the blood.
- Treatments such as chemotherapy and radiotherapy.
- Pain, anxiety, fear.
- Tumours that press on the vomiting centre in the brain.
- Other medical conditions such as Meniere's disease.

Nausea and vomiting need to be referred to the doctor or registered nurse for assessment. The doctor can order medication to treat the cause or alleviate the symptom for the person.

Other care can include:

- small frequent meals
- sitting upright
- reducing anxiety.

Constipation

Constipation may be due to lack of fibre, exercise, fluids or medication. In some, less frequent, cases it could be caused by an obstruction in the bowel, a tumour or a result of the bowel becoming twisted.

Constipation
A state of the bowel in which evacuations are hindered or stopped.

Symptoms of constipation include:

- bloating
- flatulence
- change in bowel motions: dry and hard stools
- pain when passing a bowel motion
- bleeding when passing a bowel motion
- nausea and vomiting.

Bowel motions will be recorded on a bowel chart. Report and document signs of constipation, or when the person has not had a bowel movement for more than two days.

> The Victorian government has put together information on common symptoms experienced by people receiving palliative care and ways these symptoms can be addressed: aspirelr.link/manage-physical-symptoms-palliative

Practice Task 15

Question 1

Which of the following people are in the best position to assess the person's level of pain? Tick all that apply.

☐ The doctor

☐ The palliative care nurse with a certificate in pain management

☐ The person's family

☐ The person

☐ The support worker.

Question 2

What should you do if a client experiences nausea or vomiting?

Question 3

As long as a person's shortness of breath is noted in their individualised plan there is nothing further a worker needs to do. Do you agree with this statement? Explain your answer.

Question 4

Which of the following statements about pain assessment are correct? Select all that apply.

☐ A pain assessment tool is a document to help you assess pain.

☐ People with Alzheimer's disease do not feel pain.

☐ A dry mouth can be caused by dehydration.

☐ A PAINAD scale is used to assess pain in people with advanced dementia.

☐ Guarding and groaning can be signs of pain.

4B Implement strategies to manage pain and promote comfort

Palliative care aims to control the person's symptoms, relieve pain and remove discomfort.

There are many ways in which pain can be relieved. In palliative care settings the person should have been thoroughly assessed to determine the most effective way to manage their pain. It is best practice to use more than one type of pain relief technique.

Following the plan

You must be aware of what you can and cannot do regarding pain relief.

It is important to read the person's plan every day and to understand your role in helping to manage pain. The instructions will describe how pain relief is managed, when it is provided and who will provide it. Pain relief must be constantly reviewed as a person's condition may change and their care plan must remain current.

Your role often requires you to:

- observe and ask about pain regularly
- report pain to the correct person so that the pain can be managed or, if your job role permits, provide pain relief medications from a dose administration aid
- document the pain and what was done to relieve it
- let a nurse or doctor know if the pain routine is not working, or if the pain becomes worse.

As a support worker, you must never:

- give injections, even in an emergency, unless it is from a dose measured pen and then only if your policy and training allow you to do this. This might happen in rural and remote areas where a nurse is not available.
- give a medication that has not been prescribed, even if it is a common medication such as paracetamol.

Medications to treat pain

Your service will have policies and procedures relating to which members of the team are qualified to administer pain medications.

In most cases this will be a nurse. In palliative care the person is more likely to need stronger pain medications such as morphine or other schedule 8 drugs protected by strict laws. Only doctors, pharmacists or division 1 and 2 nurses can assess, handle, administer and store these drugs.

In other cases you may have received training to administer medications to the person, such as from a dose administration aid. There are two ways this can be done:

Regular medications	You might be asked to give pain relief as part of the person's regular medication round. These are given at the same time or times each day, whether the person is in pain or not.
PRN medications	PRN medications are given only when needed. You might be permitted to administer PRN medications from a special PRN dose administration aid.

One of the most important tasks you can do in your role is to report pain. Let your supervisor or nurse know as soon as you observe, suspect or are told by the person that they are in pain.

The sooner the pain is treated the less likely it is to become worse, and the more effective the medication will be.

Here are some different ways that medications can be given to relieve pain.

Oral medications	• Tablets or capsules. • Liquids, if the person has difficulty swallowing a tablet. • Take longer to work than other types of medicines, between 20 to 30 minutes. • Cannot be taken by people with swallowing problems, or people who are no longer responsive. • Are not as effective as other delivery methods for very strong pain, such as cancer pain. • Can be given as a regular dose or as a PRN medication.
Patches	• Applied to the person's skin. • Release a slow continuous dose of pain medication. • Absorb very slowly. • Used only for chronic pain.

Intermittent injections	• Are given by a division 1 or 2 nurse or doctor. • Usually contain strong pain relief such as morphine. • Are injected into the muscle or just under the skin and work quickly, about 5 to 10 minutes.
Continuous infusion	• A continuous infusion is sometimes called a 'pump'. • Medication is locked in a small chamber that is attached to the person and pumped slowly through a butterfly needle inserted and left under the skin. • Is the most effective way to administer strong medications such as morphine, and is often used in palliative care. • If the person is able, they can control the pump themselves, especially if they are in their own home. • Method is the least disturbing to the person as it does not hurt, and can run for many hours without being touched. • Used only for chronic pain.

Alternative pain relief techniques

In addition to medications there are other ways to relieve a person's pain and promote comfort. These can be used as well as, or instead of medication, depending on the person's preference or the level of pain.

Here are some alternative approaches to pain management.

Massage

The sensation of touch is soothing and provides reassurance. Massage can help to ease muscle tension, relieve headaches and reduce anxiety.

Massage should be used with caution and delivered by those with specialised training in aged care and palliative care settings. It can be dangerous for people with cancer, deep vein thrombosis, skin conditions and arthritis. Always check the person's care plan and speak to your supervisor or a physiotherapist before giving a gentle massage.

Diversional therapy and music therapy

Diversional therapy is used to divert a person's attention away from their pain, such as while waiting for a pain killer to take effect. Diversional therapy can include listening to music, physical activities, relaxation and social interaction.

Meditation and mindfulness

Guided meditation can be helpful during brief episodes of pain or during painful procedures. There are many excellent free apps that can be downloaded onto the person's tablet or phone to help guide them through these techniques.

Hot and cold applications

Applying heat and ice packs can reduce pain caused by muscle spasms. These can be dangerous for older people or when used incorrectly, so must be used strictly according to your organisation's policy.

Moist heat therapy packs are usually the only type of heat pack allowed to be used in aged care settings.

Aromatherapy

Aromatherapy uses plant and essential oils to provide therapeutic relief from pain. Oils may be added to an oil burner and inhaled.

Care must always be taken when using essential oils. The oils used should be chosen for the person by someone who is knowledgeable about the benefits of the various essential oils used in aromatherapy.

TENS

TENS sends an electrical impulse through the skin to the area of pain. It is provided through a small portable machine and it can help with some types of pain.

Acupuncture

Acupuncture is performed by trained specialists and can help certain types of pain

Gentle exercise

If the person is capable, they can be helped to perform gentle exercises to help loosen muscles and increase blood flow. A physiotherapist can show staff how to exercise the person's limbs for them.

The Cancer Council NSW has helpful information on a range of complementary therapies that can be used to relieve pain: aspirelr.link/cancer-council-mind-body-techniques

You can also listen to their podcast on meditation and relaxation. A link is available through the same web page.

Example

Managing pain

Read the following example to learn about how support workers can help manage pain in a workplace setting.

Percy lives in an aged care home and has been given morphine for the first time to help cope with his pain. He is concerned about how long it will take for the medication to begin alleviating some of his pain and has asked a support worker to sit with him while it takes effect.

The support worker, Alice, notices that his position looks uncomfortable. She asks him if he would prefer for his bed to be reclined so that he can lie down flat. He tells her that he would like that.

Alice also gives him a heat pack, and stays with him for about ten minutes so that he feels comfortable waiting for the pain relief to begin working.

Once his pain begins to ease as the morphine takes effect, he tells Alice that he is no longer worried about the medication and is feeling comfortable enough to be alone. He thanks her for her time.

Practice Task 16

Question 1

Which of the following statements relate to who can administer a schedule 8 drug such as morphine? Tick all that apply.

☐ A doctor

☐ A nurse

☐ A support worker

☐ A visitor

☐ A person with dementia

Question 2

List three methods apart from medication that can be used to treat pain by a support worker.

4C Evaluate and document the effectiveness of pain management strategies

Keeping good records is a very important part of the pain management process.

Careful documentation allows doctors and other staff members to assess how well the person's pain is being managed, including what is working and what is not.

The way that you document pain will depend on the type of service you work in. It may be written:

- on the medication chart if you have helped administer the medication
- on a pain chart
- on an assessment tool such as Painad scale or FACES
- in the communication book, if you work in the person's home
- on the person's digital or hard copy file.

When documenting detailed pain observations you should write down exactly what you observe and what the person tells you. Be brief and concise when you write and use simple sentences. Most records should include the following information:

- Date and time.
- What you observed or what the person told you about the type, intensity and location of the pain.
- To whom, and how, you reported the pain.
- What you did to relieve the pain.
- Whether the measure was effective.

It is essential that you follow up with the person once the pain relief technique has been given time to act and record the effect of the measure. This can help the palliative team to assess whether new pain management strategies should be introduced.

Observe and document:

- any changes in the person's behaviour that might tell you that the pain is better or worse
- how the person feels; for example, if they say their pain seems better or worse or has moved to another area
- how long the strategy is effective; for example, whether the person asks for more pain relief medication before the next dose is due

- whether the person has a continuous and consistent level of pain or if the strategy removes it
- any side effects from medications, such as vomiting, drowsiness, confusion and constipation.

If the strategy was not effective

Sometimes the pain relief strategy might not work; this too needs to be documented and reported.

If you have waited for the strategy to work and the pain is still present, report this to the nurse or your supervisor and try a new strategy or, if possible, ask the nurse to increase the dose.

If the prescribed dose of a medication does not work more than three times, then the doctor should be asked to write a new order with an increased dose or a different type of drug.

Example: Documenting strategies

File notes	
Client name: Joe Ricardo	**Date of birth**: 4 October 1930
Date of entry: 10 January 2023	**Time of entry**: 12.15am
Observations: At 11.15pm, Joe looked pale and uncomfortable and was anxious and unsettled. Joe described a burning pain in his abdomen. He rated his pain as 8/10.	
Action: I gave Joe a moisture heat pack at 11.20pm as per the individualised plan. I notified the night duty nurse at 11.20pm, who gave Joe his PRN morphine. Joe asked me to stay with him and play some music until the medication started working. Joe stated that the hot pack took the edge off the pain. The pain started to get better after about twenty minutes after the morphine was administered. At 12.00pm he rated his pain as 2/10. I gave him PRN paracetamol from the Webster-pak and another warm hot pack to help reduce the pain further. At 12.15pm, he gave his pain a 1/10.	
Worker name: Bruno Agulera	**Signature**: Bruno Agulera

Practice Task 17

Question 1

What is your responsibility if you are concerned that a person is still in pain after they have been given their pain medication?

Question 2

Which of the following about documenting pain is correct? Select all that apply.

☐ Write down what you observe and what the person tells you.

☐ Follow up with the person after the pain medication has had time to work.

☐ You should ask family members what their impressions of the person's pain are levels.

☐ It is better to write in a way that is brief and concise.

☐ The palliative team can use your records to help determine how effective the medication is.

4D Recogise and report concerns about the use of pain-relieving medication

There are some common misconceptions about pain relief that can influence how well the pain is reported and managed.

When you understand the aims of palliative care you can help the person and their family to avoid possible misconceptions and concerns, so that they report pain as soon as they feel or notice it. This will mean it can be treated quickly before it becomes severe.

Concerns and misconceptions can be experienced by staff, family or the person themselves. They should be dealt with as quickly as possible to ensure everyone understands the importance of pain control and how it is carefully managed.

Here are some commonly expressed concerns about pain and some ways you can respond. Remember to follow-up by suggesting that the person should talk to their nurse or doctor for more information and reassurance. Report to your supervisor and document the conversation yourself so that any concerns can be looked into.

I/they might become addicted	It is much more likely that the person will experience distress from not having pain medication than from becoming addicted. It is important to talk to your doctor about this concern.
Pain relief should only be given if I am in pain right now	Chronic pain is best managed with regular pain relief medications. If it is given at regular intervals, before the pain begins or before it gets severe, it works much more effectively. If you wait for the pain to get worse before taking medication, both the medication and your body have to work harder to beat the pain.
Doctors and nurses are the best judge of my pain	The only person who can really understand their pain is the person themselves. Everyone is different. You are the expert on yourself, and your pain is whatever you say it is.
People should not receive pain relief until the cause has been determined	This is not true and is not in line with the palliative approach. Relieving the pain right now is much more important.

Morphine can hasten death	One of the principals of pain management in palliative care is to give no more or no less medication than is needed to manage your pain. It is more likely that you will suffer from the pain if you do not have the medication than from respiratory problems if you do. The doctors and nurses will monitor you carefully.
The person will be too drowsy to communicate if they have more medication	Yes, some pain relief medication may cause the person to feel very tired and they may not be able to communicate with you. They may even fall asleep. It is important that we talk to the person, or refer to their advance care plan, about how they feel about getting the right balance between pain and drowsiness.
Using too much morphine now might reduce its effectiveness in the future	This is not true. Morphine and other opioids are very effective pain-relieving drugs that can safely be taken for a long period of time; if a person's pain is severe enough to need opioids, they should be used.
Morphine is only used when death is close	Morphine may be used when people experience moderate to severe pain at any time, not just when they are dying. People may require morphine for their pain relief for many months and not everyone who is dying requires morphine.

Example

Managing misconceptions

Read the following example, and pay attention to the actions you can take when concerns about medications arise in the workplace.

Harriet has a condition which causes her significant pain all over her body. In the last few weeks, she has stated that her level of pain has become intolerable. The doctor has recommended to her that she begin taking pain relief medications but she declines, without giving a reason.

However, she later tells a support worker that there has been a history of addiction in her family and she is worried that she will become addicted to pain medication if she begins taking it. She asks the support worker for advice.

The support worker tells Harriet that she cannot give medical advice but reassures her that she will talk to her supervisor about her concerns.

The doctor speaks to Harriet and lets her know that there are very few concerns about addiction and that managing her pain is much more important. Harriet trusts that the medical team will do what is best for her. She starts to take morphine and is relieved to find that she no longer has to suffer or worry about pain.

Practice Task 18

Question 1

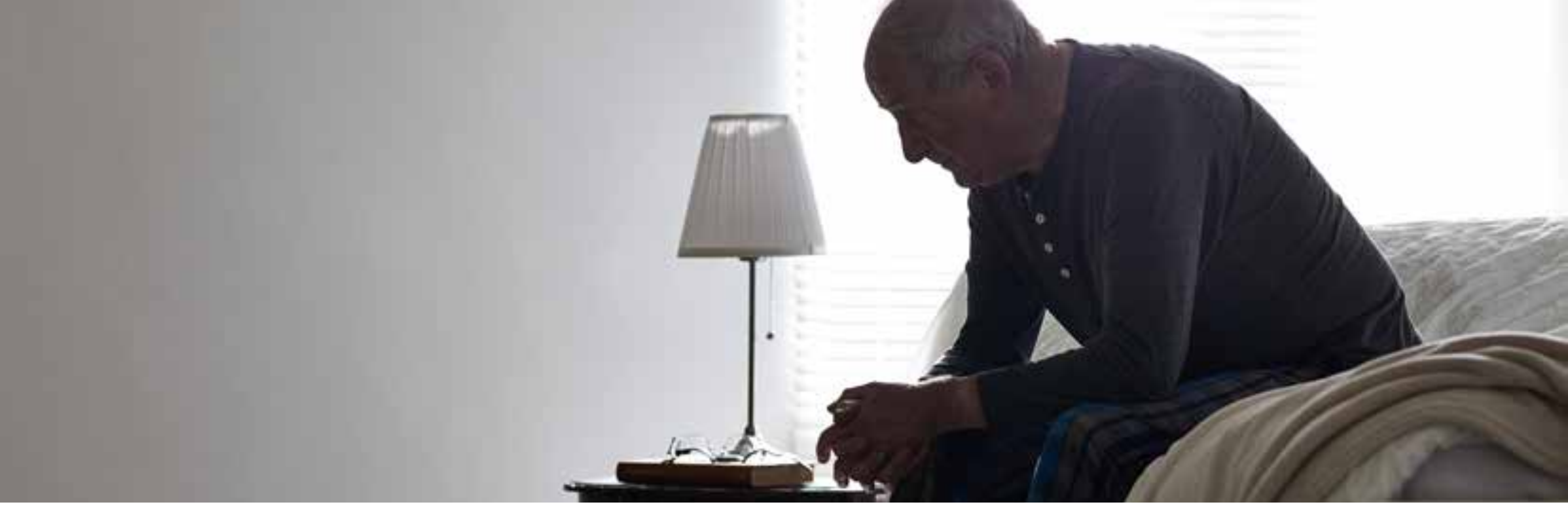
Which of the following statements are correct? Select yes or no for each one.

a. Morphine can make some people drowsy.	Yes / No
b. Morphine is very addictive.	Yes / No
c. It is better to give pain relief before the person feels pain rather than waiting until they do.	Yes / No
d. Morphine should only be used when the person is nearing death.	Yes / No
e. Using too much morphine can reduce its effectiveness.	Yes / No

Question 2

Which of the following statements relates to how you should respond if a person tells you that they think they will become addicted to pain relief? Select the correct response.

- ☐ Accept the person’s decision.
- ☐ Provide them with names of reputable websites where they can research the facts because everyone should do their own research.
- ☐ Report the person’s statement to your supervisor or nurse.
- ☐ Let them know that this is correct.
- ☐ Suggest they change to a different medication.



Summary

- Pain management is one of the most important parts of palliative care work.
- Pain may be either acute, that is brief and severe; or chronic, that is long lasting.
- There are many tools and methods to help you identify and assess the person's pain.
- The client's individualised plan will guide you in how to respond to their pain.
- Reporting and documenting pain are crucial ways to ensure the pain is managed well.
- Pain management strategies can include medications, heat, diversion, meditation and other interventions.
- Generational differences, language differences and cultural beliefs can affect the person's ability and desire to communicate about their pain.
- Misconceptions about pain can mean the person is not given adequate pain management.

Learning Checkpoint 4

Respond to signs of pain and other symptoms

Part A

1. List two common misconceptions about pain medications.

2. What should you do if a person tells you they believe something about their medication that is not true?

3. Which of the following about pain relief are correct? Select all that apply.

- ☐ Pain relief dosages are determined by the care worker.
- ☐ When the person has pain PRN medications are given outside of their regular medication times.
- ☐ Ice chips can be given to reduce feelings of dryness.
- ☐ Patches release medication slowly into the person's body.
- ☐ Hot packs can reduce muscle spasms.

Part B

Read the case study, then answer the questions that follow.

Case study

Katie is in the final stages of her life. She has returned home and is being looked after by her family. Family members have been actively involved in all aspects of Katie's care and understand the approach being taken by the palliative care team.

Katie's granddaughter Molly is a registered nurse and acts as the communication link between the palliative care team and the family. Molly participates in care plan discussions about her grandmother and informs the family of changes to Katie's care.

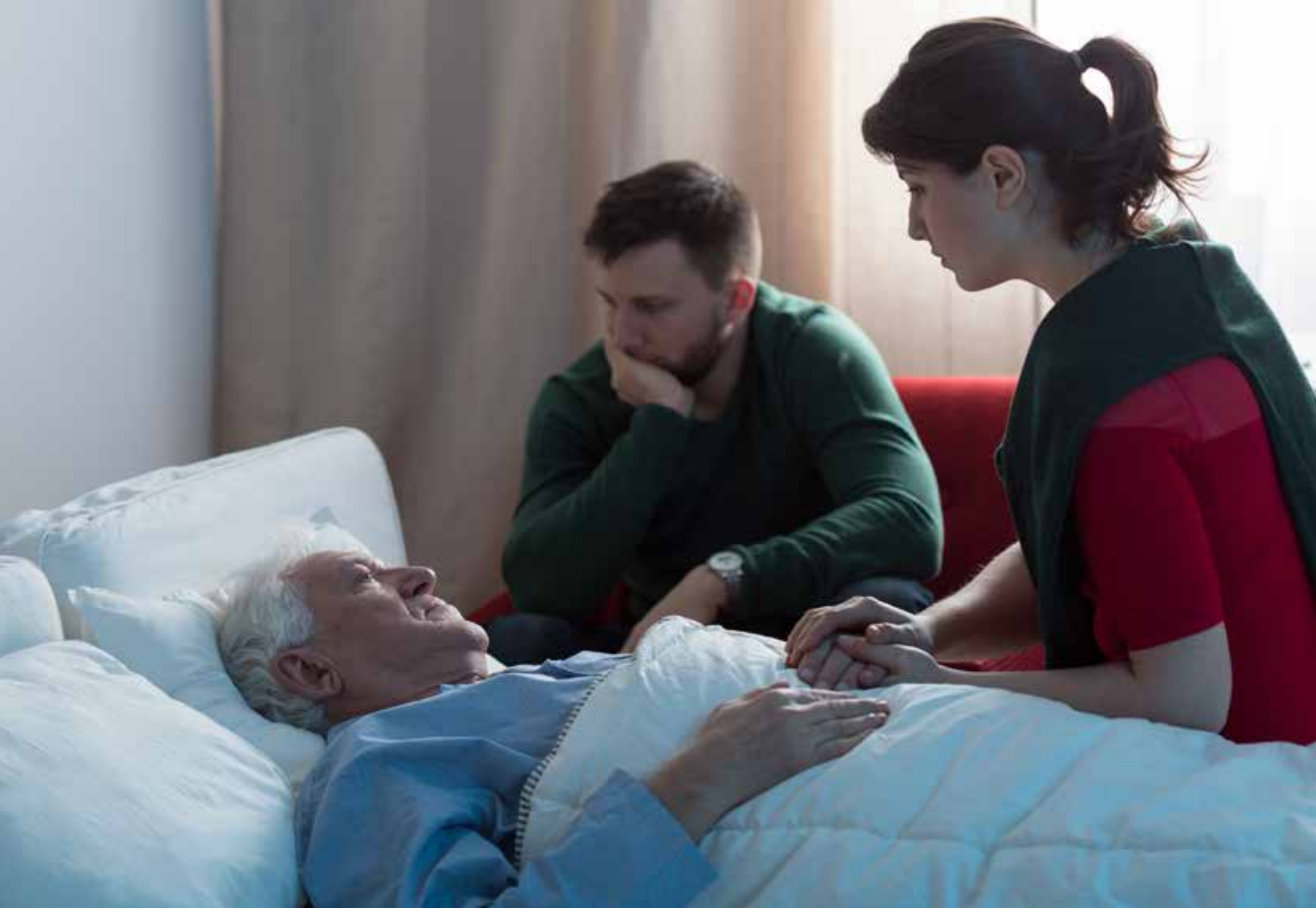
At the latest meeting, Molly tells the care team of her father's belief that Katie seems to be experiencing severe pain as she regularly moans and appears restless. Molly's father is concerned that increasing the morphine will hasten Katie's death. The care nurse, Val, agrees that the family needs additional information about Katie's condition. She reassures the family that although Katie's condition is deteriorating, the care team regularly monitor and review pain and symptom management.

Val advises the family that she will perform a comprehensive pain assessment and discuss the outcome with Katie's doctor. As a result, Katie's doctor prescribes appropriate medication to help reduce her pain. At the next assessment, Katie's pain has reduced from severe to mild and she has become more interactive with family members and the care team.

1. Apart from pain medications, list three care strategies that the personal support workers could implement for Katie to assist in managing her pain

2. What observations might the support worker have used to help the nurse and doctor assess Katie's pain?

3. Where should the workers document the effect of the pain relief strategies, and why is this important?



Topic 5: Follow end-of-life care strategies

5A Regularly check for changes in the individualised plan
5B Provide a supportive environment for the end-of-life
5C Respect and support the person's preferences and culture
5D Maintain dignity at end-of-life and following death
5E Recognise and report deterioration or imminent death and dying
5F Provide emotional support to others when a death has occurred

5A

Regularly check for changes in the individualised plan

Good end-of-life plans allow the care needs of the person and their family to be met.

In palliative care settings, end-of-life usually refers to the last weeks, days or hours of the person's life. Planning needs to consider the changes that happen during this period.

It can be very difficult to predict when a person will reach the last weeks or days of life. Sometimes the approach is slow and gradual, and sometimes the deterioration is sudden. It is seldom as depicted on television or in the movies, however. People rarely die in the middle of a conversation; it is frequently a slow, drawn-out process which can be difficult to observe. A person might spend a long period of time prior to their death unconscious or semi-conscious and show signs of changed, slowed, breathing.

Signs that death is imminent

As a support worker, and part of the care team, you play an important role in recognising the signs that a person is in their last days of life. Some signs to look out for are listed below:

- Severe weakness and tiredness.
- Lack of interest in food or drink.
- Not wanting to get out of bed.
- Restlessness, agitation.
- Confusion.
- Difficulty swallowing.
- Semi-consciousness.
- Slowed breathing.
- Cool, pallid skin.
- Weak pulse.
- Incontinence.

Video: Symptoms of approaching death

Watch the following video on the symptoms people may display when approaching end-of-life: aspirelr.link/symptoms-of-approaching-death

Reflect on how important it may be for family and friends of the person to be given a timeframe for their approaching death.

You will notice that care staff might reduce the time spent turning or repositioning the person at this stage. There will no longer be a concern about pressure care or contractions.

Practices like mouth care and eye care can be continued to keep the person comfortable.

- Repositioning is done only to make the person comfortable.
- If they are sleeping it is usually not necessary to wake the person to perform personal care.
- In some services, the person is repositioned only when they begin to groan or show signs of discomfort.
- Wash or clean the person as needed for their comfort, such as when they have been incontinent or if they are sweating excessively.
- Always wait until the effects of painkilling medications have taken place before repositioning or washing the person.
- Good quality, more absorbent incontinence aids can reduce the amount of time spent changing and repositioning the person.

Confirming changes to the care plan

The Aged Care Quality Standards require you to regularly discuss the plan with the person and to check with them that they agree with what is on it. If the person is no longer able to communicate, you can talk to the family about the plan and what is included in it. This can be an excellent way to help the family or network to feel involved and, if appropriate, for them to provide further suggestions about the person's care.

As the person draws closer to death there are often frequent changes to the care delivery to meet the changing needs of the person.

These can include changes that reflect:

- increasing severity of symptoms such as pain
- new symptoms, such as incontinence
- loss of consciousness
- overnight visits from family and friends
- the need for additional comfort
- the need to spend more time with the person
- when, and who, to contact from family and friends if the person's death is near.

Here is an example of an individualised plan for a person in the final stages of life.

Individualised plan
Client name: Hamish Briggs Date of birth: 11/08/1931 Gender: Male Diagnosis: Dementia
Personal details Hamish is Scottish and 85 years old. He has always liked listening to blues and jazz music. He also enjoyed reading detective novels and being outdoors.
Pain management Assess every 30 minutes for pain and discomfort. Signs of pain include restlessness and calling out. Pain is relieved via continuous infusion of morphine. For breakthrough pain: • try a heat pack • change his position • let the nurse know immediately if there is no relief from pain within 15 minutes.
Physical needs **Bowel and bladder** • Check incontinence pads every 2 hours. • Report signs of constipation. **Skin care** • Gently apply barrier cream to Hamish's buttocks and thighs daily. • Apply Sorbolene to lips and nostrils when they appear dry. **Nutrition and hydration** • Regularly offer ice to suck. • May take small spoonfuls of custard or ice cream. • Sit the bed at a minimum angle of 45 degrees and monitor swallowing. • No solid foods.
Emotional needs • Hamish has a tablet with Spotify playlists of his favourite jazz and blues music. Alternate between playlists and play softly during the day. • Spend time with Hamish when his family are not present. • Read excerpts from his detective novels or talk to him about hiking and biking. • Family have requested to stay overnight. Please set up the cot bed in his room when they are staying. • Family have requested that his favourite hand-knitted red rug is kept over him unless he appears hot.

Ensuring changes to the individualised plan reflect advance care directives

Respecting the person's advance care directives wherever possible is central to the principles of palliative care and to the dignity of the dying person.

When the person enters this stage, or when any change is made to the individualised plan, the directives should be checked carefully to ensure they are being followed.

Sometimes the person's directives cannot be safely followed because something unexpected happens. For example, the person might have requested not to be taken to hospital but an accident, such as a fracture, that requires hospitalisation occurs. In these situations, there are very specific laws that must be followed by the medical team and the substitute decision-maker for this request to be overturned.

Advance care directives relate to the end-of-life period when the person is no longer able to communicate.

Example

Changes to the care plan

Marilyn is dying at home. She amended her advanced care directives last month to request for her dog to stay on her bed with her. Marilyn's son Henry does not like the dog. Once his mother is unconscious he removes the dog and puts him outside. The palliative care staff remind Henry about his mother's wishes. Henry is angry but the staff know that it is part of their role to advocate for Marilyn now that she cannot do this herself. In a kind and caring manner, the staff explain to Henry how Marilyn's preferences are still important.

Henry reluctantly brings the dog back in. Later, after his mother has died, he tells the staff that he is grateful to them for standing up for his mother's wishes.

Consider why you should be alert that changes to the care plan are implemented

Practice Task 19

Question 1

Match the term to its correct description.

Advance care directives	Include slowed breathing and semi-consciousness.
The Aged Care Quality Standards	Are used at the end-of life-period.
End-of-life signs	Require you to discuss the plan with the person or their family.

Question 2

List three signs that death may be imminent.

Question 3

Which of the following changes will need to be reflected in a person's individualised plan as end-of-life approaches? Tick all that apply.

☐ The person's need for additional comfort

☐ Day visits from family and friends

☐ New symptoms

☐ Loss of consciousness

☐ Increasing pain

5B

Provide a supportive environment for end-of-life

When a person is nearing end-of-life it is useful for the team to meet with the family so that a pathway of care can be planned together.

At this time the family's emotional needs, and the person's physical needs, become the two most important factors in the holistic spectrum of care. If you look after the family well this gives them energy and time to look after the person they love.

Family members and carers may require a greater level of support at this time and may experience:

- anger
- grief
- denial
- guilt
- hopelessness.

They may also become depressed, anxious or confused. These are common reactions to death.

Support strategies
• Inform the family and carers of changes to the person's condition as soon as possible.
• Respond kindly to complaints or dissatisfaction expressed about the care being given. This can sometimes be about the family member's need to feel useful when they feel they are losing control.
• Encourage family members to have an active role in caring for the person.
• Suggest counselling services or refer them to a pastoral care worker or social worker if appropriate.
• Encourage and allow visiting or staying with the dying person 24-hours a day, without limits. This is their right.
• Give the person and their family privacy to spend precious time together.
• Suggest ways family members can feel more present with the unconscious person such as reading to them or playing their favourite music.

Support strategies
• Most facilities offer a private room for visitors to gather together. This can give them a break from the room of the dying person and allow them to grieve together privately.
• Small things can help more than you think and can mean a lot. Offer cups of tea, talk about the things you liked most about the dying person and ask questions about the person's life. At the same time recognise when your presence is obtrusive. This can be a balance. Be guided by the family and by other more experienced staff in this.

Example

Providing a supportive environment

Huong is a Vietnamese lady who is dying in a hospice. Her son Tran is her primary carer and he sits by her bedside every day. He organises bowls of fruit and food for visitors and lights incense and candles at the family shrine. Tran is very emotional and finds it difficult to speak. The staff have brought Tran a meal and offer him hot drinks. They notice that every now and again Tran's head drops and he closes his eyes. It seems that Tran is quite exhausted and he eventually admits that he has not slept for two or three days.

Tran is anxious about not being there for his mother if she stops breathing. Teresa, one of the support workers, gently explains to Tran that he needs rest as only then can he give his mother the care and love she needs. She arranges for a cot bed to be brought into Huong's room so that he can sleep beside her. The staff reassure Tran that they will sit with Huong while he rests, and that they will wake him if there are any signs of deterioration.

Why do you think a supportive environment improves care services?

Practice Task 20

Question 1

List three examples of how you can help support a family as the person nears end-of-life.

Question 2

Which of the following statements relate to the change in support needs at end-of-life? Tick all that apply.

☐ The person's needs are mainly about their physical comfort.

☐ The family should be encouraged to spend less time with the person so that you can provide care more effectively.

☐ If the family is making complaints about the care they are just being ungrateful.

☐ The family might need more emotional support.

☐ The person will not be able to hear so it no longer matters what you say or do around them.

5C

Respect and support the person's preferences and culture

Spirituality and culture can take on very important meanings for many people in the last days and hours of life.

This is often true even when the person and their family have previously not been very religious. For many people the care of their spirituality, and what happens to their soul, is more important to them and their family than physical factors like pain relief and comfort.

Talking to the family about spiritual and cultural needs

We cannot possibly know all spiritual, religious or cultural needs that a family might have unless we ask them.

We often know the person's own preferences about what they want for their last days and hours because they may have written advance care directives, or told us their wishes. We can also be guided by signs that the person is not comfortable and can provide care that meets their comfort preferences.

Be aware that not all people from the same culture or religion want or believe in the same things, so it is important to never make assumptions.

Be open about your lack of knowledge if the person belongs to a culture or religion that you are not familiar with. It can be a good idea to ask the family if they would like you to get in touch with a spiritual or community cultural leader, to help support and advise about cultural practices and undertake religious and cultural rituals.

Here are some examples of practices to ask about and include where requested.

Access interpreters if the family speak a language other than English
• Face-to-face interpreters are usually best, but you can also access free interpreters online or via telephone through the Government funded Translation and Interpreter Service (TIS). • The interpreter can help you to ask questions about the cultural and spiritual needs of the person and their family. They can also help you to understand words which are considered taboo and should not be used.

Recognise cultural sensitivities around language and communication

- For some cultures talking about death, dying or about how long the person has to live might be seen as bad luck, an attempt to bring death on sooner, or a sign that they want the person to die.
- Be aware that for many cultures, the words death, dying and cancer should be avoided or treated with sensitivity.

Respect cultural attitudes towards pain relief

- Some cultures may believe that they must accept and feel pain. They might believe that pain relief will reduce the person's alertness that is needed as they face the next life. They might refuse pain relief for this reason. This should be respected unless the person's wishes said otherwise.

Accept, respect and welcome cultural and religious rituals

- People from some cultures might wish to bring in food, light candles and burn oils.
- They might hold prayer rituals.
- Some religions, such as the Catholic religion, have a tradition of a priest performing a ritual called the Last Rites. Many Catholics believe that this is key to their souls being able to enter heaven.
- Ensure wherever possible that these rituals are upheld.
- Provide privacy and space for rituals to be held and do not interrupt them. For many families, nothing is more important, because these rituals can help the person's soul to enter eternal life.

Remember that family is still who the person says it was

- Give the same respect to the person's idea of family as you did when they were conscious.
- If family is large and extended, continue to provide access and support for them as they wish.
- Same-sex partners must always be given the same support as any heterosexual partner.

Visit this link to learn about various ways you can provide spiritual and cultural support to a person as they approach end-of-life: aspirelr.link/emotional-spiritual-cultural-care

Example

Respecting cultural preferences

Read the following example to learn more about respective cultural preferences when providing care.

The Greek Orthodox Church guides the behaviour of people in bereavement and has set rituals and beliefs that must be followed. The body is considered to be highly sacred. Practices include:

- clothing the body in a white sheet under their clothing
- holding a vigil in the funeral parlour with the body placed facing east
- after the funeral service the body is buried as cremation is not permitted
- a memorial service is held after the funeral and further services are held on the 9th and 40th day and the 3rd, 6th, 9th and 12th month after death
- candles are lit during services to symbolise the celebration of life and eternal faith
- people attending the funeral and memorial services traditionally wear black.

Example

First Nations perspectives

Death and dying can be a very personal and private thing for many First Nations people. An Aboriginal Health Worker or Liaison Officer can help you and your service to understand and follow the family's spiritual and cultural rituals.

Many Aboriginal people see or hear previously deceased ancestors and family members around them when a close family member is close to death. There may be large numbers of visitors and the person's room might need to be large to accommodate them.

Never place judgement on or try to remove or dispel visitors unless the person themselves requests it, or unless you need to provide privacy to the person for their personal care. The family members themselves may wish to take over this task. You must respect this.

Practice Task 21

Question 1

Which of the following statements relate to cultural and spiritual practices at end-of-life? Tick all that apply.

☐ People from particular cultures always want the same routines performed.

☐ For some cultures death is a private, family matter.

☐ You are expected to know everything about every culture.

☐ Cultural and religious rituals can be performed around the needs of the staff.

☐ In some cultures the words cancer or death should not be spoken.

Question 2

Visitors who stay too long always need to be given limits so that the person can rest. Do you agree with this statement? Why or why not?

5D Maintain dignity at end-of-life and following death

At the end stages of life, and after death, the person deserves and should be given the same respect and dignity that they were given in life.

Use the person's preferred name
• Continue to call the person by the name that they preferred to be used. This might be Mrs, Mr, Ms, Doctor, their first name or even a nickname. • Use this name when referring to or about the person, whether talking to the family or to other staff.
Assume the person can hear you
• Even if the person is unconscious or semi-conscious talk to them about what procedures you are about to do. • Never talk about the person as if they are not there. Do not make personal remarks about the person or their family even if you think the person can no longer hear. • Continue to provide reassurance and kind words to the person after they are no longer conscious.
Respect privacy
• If you or the family want to discuss something sensitive about the person, such as incontinence, do not hold these conversations in front of people who the person would not wish to know these sensitive details, such as friends or distant relatives. • Do not ask the family questions that are none of your business, such as the details of a family conflict. • Continue to use routines that respect the person's privacy even after they have died, such as shutting the door or curtains and covering private areas during personal care. • In some cultures you might ask the family to briefly leave the room while you are changing the person's incontinence aid, or washing the body after death, to give privacy to the person's body. In other cultures it might be considered the family's role to perform these tasks. Be respectful of balancing culture with the person's privacy and dignity when performing these tasks.
Treat the body with deep respect
• Treat death with the solemnity that it deserves. Even if the family are not present, the room of a person who is dying or has died is not the place to laugh with colleagues. • After death, handle the person's body gently and respectfully.

Example

Maintain a person's dignity

Siobhan is a support worker in a large aged care facility. Gilda is a much-loved resident who died this morning and had no family or friends with her during or after her death. Siobhan's manager asked her to stay with Gilda as she died, and Siobhan saw it as a privilege to spend Gilda's last minutes and hours with her. She talked to Gilda and reassured her that she would stay with her. She held her hand and made sure that she was warm and comfortable.

Later in the morning an orderly arrived to move Gilda's body to the morgue, to await the funeral directors. The orderly was in a jovial mood and pulled Gilda's body across to the trolley with a loud thump. He laughed and made a joke about the dead not being able to feel anything. This upset Siobhan who took the orderly aside and told him quietly that Gilda deserves respect in death, as in life.

Think about why you must maintain a person's dignity, even when they are no longer aware of your actions.

Practice Task 22

Question 1

Give four examples of how you can maintain the dignity of the person when providing end-of-life care.

5E Recognise and report deterioration or imminent death and dying

Recognising the signs of imminent death can be useful because it can prompt a phone call to, or going to wake up, the family so that they can be with the person.

While this is a tremendous gift that you can give the person and their family it is not always possible to know when a person is about to die. The most senior member of staff is often the person who can recognise these signs earlier or more effectively. If you suspect that a person has reached this phase let your supervisor know as soon as you can.

Cheyne-Stokes breathing	• Cheyne–Stokes breathing, sometimes referred to as 'Cheyne-Stoking' is a common end-of-life symptom that means the person will die within hours. • This is a pattern of breathing that involves rapid shallow breaths which suddenly stop. It appears that the person might have stopped breathing but, after a period, the breaths start up again. • This happens because the build-up of carbon dioxide in the person's body triggers them to start breathing again. • Cheyne-Stokes breathing can be confronting and confusing the first time you see it. The person's breathing might seem laboured and distressed.
Shutdown of the body systems	• Often the person will become pale, cold and clammy to touch. This can signify that the body's capillaries are beginning to shut down. • The person's urine output might slow or stop altogether. • Periods of being awake or semi-conscious might stop, and the person might become unresponsive and unconscious. They might show no signs of response to movement or pain. • Some people take on a yellowish or brownish tinge to their skin and eyes called jaundice. This signifies that the liver is shutting down.
Changes to breathing sounds	• Some people take on a gurgling sound as they breathe, because fluid and secretions collect in the lungs and mouth as the person stops swallowing saliva. • In the past this has sometimes been referred to as the 'death rattle', but this is an undignified term to use in front of the person or their family.

When death is imminent

The family are the most important people at this time. If you identify any signs or symptoms of impending death, follow your organisation's procedures.

This may mean:

- informing close family as a priority
- being sensitive to family members who might be present and leaving the room so that they can be alone with the person while they die
- staying with the person yourself if the person has no family or friends present.

Remain respectful of your secondary role. Avoid asking the family to leave the room unless it is absolutely required for the person's safety or privacy, and then only for the shortest amount of time necessary. You might check occasionally if the family have any needs, or offer food or drink, but be careful not to imply that you want them to leave.

After death

Avoid implying that there is any kind of rush or urgency for you to attend to the person. Instead, let the family know that they are welcome to spend as much time as they need with the body, and reassure them that you are nearby if they need anything.

Help the family to tidy the bedding if necessary and to reposition the person onto their back, so that they look comfortable, warm and peaceful.

While their body is still warm close the person's eyes, replace dentures and place their arms comfortably by their side or folded over the chest, depending on the family's preference.

Ask the family if they need anything from you. Then give them privacy and time alone.

In the Chinese culture the body must not be seen by other people at certain times of the year, or by people under a certain age. Check with the family about these details to ensure you are respecting their wishes.

Washing the body

Washing and preparing the body for the morgue or funeral director should take place no more than two to four hours after death.

After this, the body starts to become stiff and will no longer move into a dignified posture. This is called rigor mortis.

If the family wish to take care of the body themselves:

- this should be the preference
- they will need a basin of warm water, washcloths and towels and soap
- ask the family what clothing they would like the person to wear and respect these choices. If they are not sure the funeral director can help them with this.

If you and other staff will be performing this task you will need to ask the family first about cultural preferences. For example:

- in the Jewish culture a non-Jewish person should not touch the body
- in the Muslim culture a female body should only be touched by another woman.

If the family are not present or available when a person from certain faiths dies, community volunteers are available to call on in most metropolitan and regional areas. These are sometimes collectively called burial societies. You can find these local organisations online.

In the Jewish faith this organisation is called Chevra Kadisha. Members will ensure that the Jewish person is prepared for burial according to Jewish traditions.

The following procedures will help guide you if you are asked to care for the body:

- Wash your hands and wear gloves. The body fluids of a person who has died can still transfer disease and illness. After death these fluids can contain rapidly dividing bacteria.
- Close the door and respect the person's privacy and dignity at all times.
- Wash the body gently with warm water and soap in the same order as you would for a person who has not died. This means beginning with the eyes and face.
- Gently close the person's eyes if they are open. Replace their dentures.
- Dress and position the person on their back in a dignified and peaceful position. If your service policy or the funeral director requires, position a rolled hand towel under the person's chin. This will help stop the chin and face from moving forward. If necessary, this can be done after the family have left to retain the person's appearance and dignity.
- If the family have finished spending time with the body you may cover the person's face with the sheet if your policy requires this. If the family will be returning to the room, leave the bed covers neat and folded near the person's neck and chin.
- Dispose of any waste containing body fluids into a biological waste bag. Remove your gloves and wash your hands thoroughly.

Legal policies and procedures

Each state and territory has its own legal requirements in relation to the death of a person, such as notification requirements and certification of death.

When a person in palliative care dies it is usually considered an expected death. This means that you do not need to ring the police or ambulance if the person dies at home, as you might need to in unexpected situations.

In most states and settings a doctor must write a death certificate (called a Medical Certificate Cause of Death) within 48 hours. This verifies that the person has died and is a legal requirement.

Funeral directors

The funeral director can take the body once the death certificate has been signed.

The choice of funeral director is up to the family or may be included in the person's own preferences in their file.

Calling the funeral director, and arranging a time for collection of the body, can be done by staff once the family feel ready for this to happen. In hot climates or during a heatwave this might need to happen more quickly than in average or cold temperatures.

Documentation requirements

The death of a person is followed by a series of legal requirements, whether the person dies at home or in a facility.

If you are present when the person dies subtly take note of the time as this will later become the official time of death.

You may be asked to record details about the death. Do this carefully. Autopsies or investigations into cause of death are rare in palliative care but they can happen, for example if subsequently there is a question about the cause of death, or if suicide is suspected.

Write down the series of events leading up to death, and what was done for the person and their family after death. This can include:

- the signs and symptoms that the person had prior to death
- how you and other staff kept the person comfortable, including pain relief medications
- the time of death
- who was present at the time of death
- cultural or religious practices that were observed
- care of the body
- a list of the person's valuables, including whether they were kept on the body or removed, who they were returned to or how they were stored
- requests relating to the care or removal of the body by the family or funeral director
- the name and details of the funeral director
- the time the body left the home, ward or facility.

Example

Islamic considerations

Read the following example to learn more about applying Islamic considerations to your care.

Islam is the religion followed by Muslim people. The Islamic religion prefers the person to be buried as soon as possible and this can mean that the body must be prepared quickly. The body is handled only by people of the same sex, especially for females. Some Muslim people will also prefer the body to only be handled by other Muslims. The body should be positioned so that the person faces Mecca. Washing rituals are very specific and must be done by the family or others within the Muslim community.

Practice Task 23

Question 1

Match the term about dying to its correct description.

Chevra Kadisha	Used to describe breathing that stops and starts.
Cheyne-Stokes	Used to describe yellowing of the skin and eyes.
A Medical Certificate Cause of Death	A group of Jewish people who attend the body.
Jaundice	Completed by a doctor.

Question 2

What should you do if you suspect the person is displaying signs of imminent death?

Question 3

Which of the following statements relate to practices that are the responsibility of the support worker in their own job role after death? Tick all that apply.

☐ Documenting the person’s end-of-life

☐ Protecting the person’s personal belongings and valuables from theft

☐ Choosing a funeral director

☐ Completing a death certificate

☐ Taking care with the person’s body fluids

5F Provide emotional support to others when a death has occurred

Your ongoing support can be very important over the next hours and days.

The previous section looked at how you can ensure that the family are treated with respect, privacy and sensitivity following the death. Additionally, there will be other people who will need to be treated with sensitivity, including other staff and residents in a facility.

Supporting other residents

It can be difficult or distressing for other people who live in an aged care facility, or who are patients in a hospice, when they learn that someone has died.

They might have been friendly with that person, or they might feel distressed at the idea of their own mortality. Staff members who have cared for someone leading up to their death can also feel grief, especially if they have known the person for a long time.

In the past there was often little or no thought given to acknowledging this grief. Today many aged care services have procedures in place to help celebrate and acknowledge the person's life, as well as providing emotional support for residents and staff who might be feeling the loss of that person. Some of these procedures include:

- letting residents who were close to the person know about the death in a sensitive way
- lighting candles and placing a photograph of the person in a prominent place
- holding prayers or a service for the person in the facility for residents to attend
- starting a condolence book that will later be given to the family.

Supporting the family

Some people find it hard to communicate at this time. They might be quiet and withdrawn or they might be emotional and distressed. Some families feel a sense of relief and even joy that the person they love is no longer fighting or suffering. They may smile when they talk about the person. All of these, and other, emotions are valid.

- Acknowledge their feelings and allow them to talk. As this is about them, not you, do not interrupt.

- If it is appropriate offer your own memories and fond feelings about the person. The family can be very perceptive to, and warmed by, these stories at this time.
- If the family members were not present at the time of death provide reassurance that you stayed with the person and cared for them well. Let them know that the person was given pain relief and comfort.

Provide the family and friends with practical written information about the steps that follow. This can very helpful when they might not be thinking clearly.

Your service might have a hardcopy brochure or booklet of this information or it might be provided by the funeral director.

The booklet will include information such as:

- where the body is going
- how they can collect the death certificate
- the funeral director's processes
- who they can call if they need help or support.

It can also be useful to help them to know what other organisations will need to be contacted such as Centrelink, banks and solicitors. The funeral director can often help with this. You can also refer them to The Australian Government Department of Human Services website for information on what to do following a death.

Most facilities and services provide a follow-up phone call to the family after death. If you knew the family well or were with them at the time of death, you might ask to be involved in this process. This helps to check if the family need further support or referral, and you can discuss the collection of personal items.

Example

Providing emotional support

Lael has been a resident in an aged care facility for over five years. Because of her long time in the facility the staff have become well acquainted with Lael's family and friends.

Lael has just passed away and a nurse has called her family and friends to let them know of the death. They come to visit the facility and when they arrive a support worker greets them with a hug. She reassures them that Lael died peacefully and tells them that they can have as much time in Lael's room as they would like. The support worker gives them the time and space that they need and they spend over an hour with Lael's body before coming out of the room visibly distressed. The support worker does not want to overload them with matters such as collecting her possessions. She asks the family if they would like to discuss these issues now or if they would prefer to wait. They tell her that they are not ready just yet.

How could you provide emotional support to your client's family and friends?

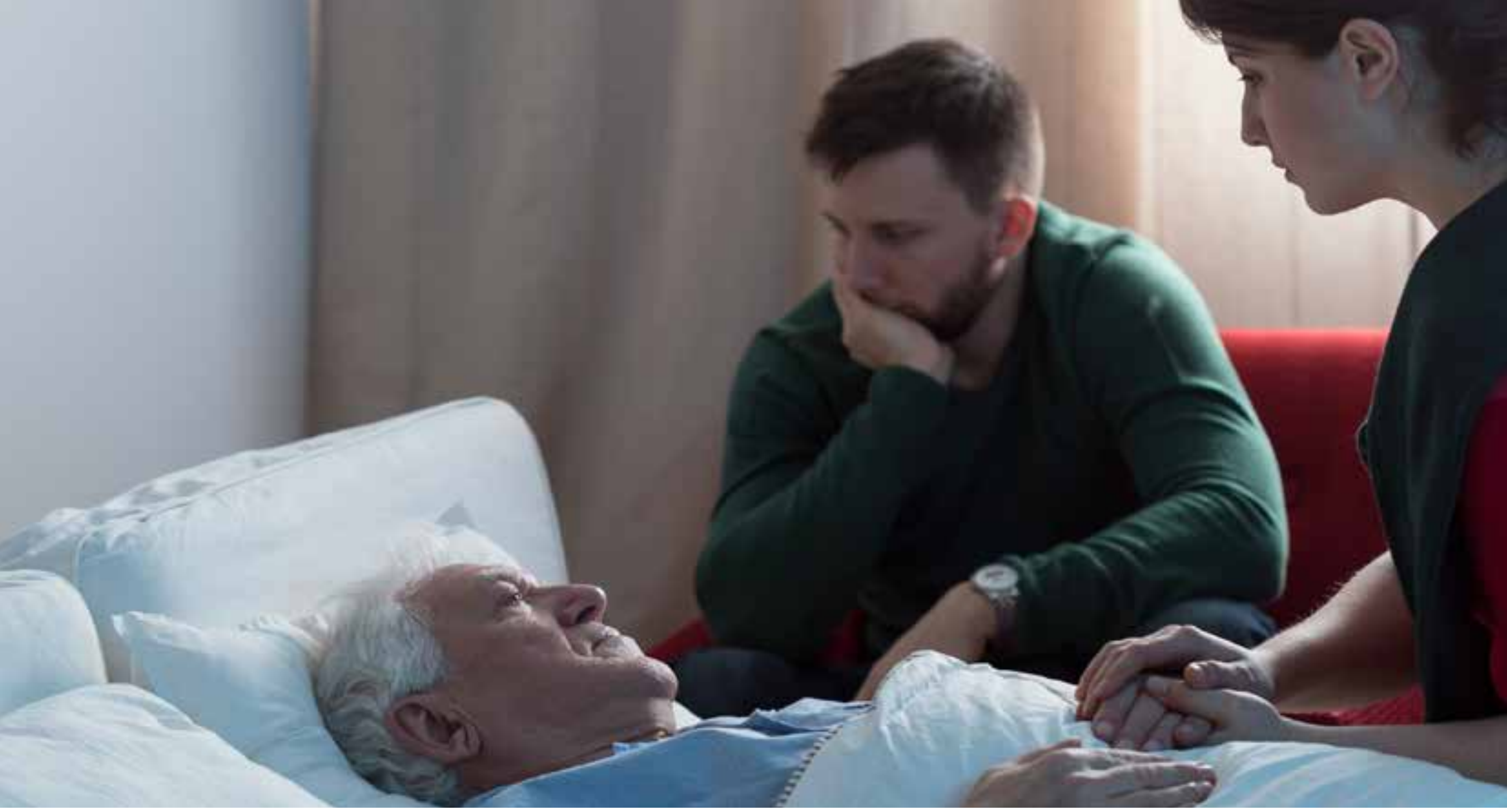
Practice Task 24

Question 1

List two examples of how you could support other residents after a death in an aged care.

Question 2

Give three examples of how you could support families when death has occurred.



Summary

- Changes to the individualised plan need to take the person's advance care directives into account.
- In the last days and weeks of life the person's needs will change.
- A supportive environment is one that keeps the spiritual, cultural and emotional needs of the person and their family at the centre.
- People from different cultural and religious backgrounds depend on workers to respect and follow important practices and rituals.
- The person has the right to the same level of dignity after their death as they did while they were alive.
- Report the signs of deterioration that might indicate death is near so that senior staff can contact family and put practices for managing death in place.
- It is important to understand that people may react in different ways and to recognise their emotional needs and provide support when a death has occurred.

Learning Checkpoint 5

Follow end-of-life care strategies

Part A

1. Which of the following statements are correct? Select yes or no for each one.

a. When the person enters end-of-life, or when any change is made to their individualised plan, the person's advance care directives should be checked carefully to ensure they are being followed.	Yes / No
b. It is more important to provide personal care to a person whose death is imminent than to allow the family to be with them for long periods.	Yes / No
c. In the last days or hours repositioning should be done only for comfort, rather than for the purpose of preventing pressure injuries.	Yes / No
d. A medical certificate, Cause of Death, is only completed when there is doubt about how the person died or when the death is unexpected.	Yes / No
e. Your service may be able to access a free interpreter through government funding.	Yes / No

2. List two ways you can respect and support the person's preferences, such as cultural and religious beliefs, when providing end-of-life care.

3. Which of the following about respecting preferences at end-of-life are correct? Select all that apply.

- ☐ Cultural and religious practices can include the Last Rites.
- ☐ Dignity can be supported by treating the person's death with solemnity and their body with gentle respect.

☐ Women should be supported by ensuring they have appropriate makeup applied.

☐ Families can be supported by allowing them 24 hour access to the person.

☐ Comfort can be increased by allowing pain medication to work before providing personal care.

4. List three signs or symptoms that might indicate that a person is near death and identify who these should be reported to.

5. Which of the following statements relates to infection control after the person has died? Tick the correct response.

☐ The person's body fluids can still be infectious so the rules for infection control still apply.

☐ The person's body fluids are no longer infectious so to preserve dignity the rules of infection control no longer apply.

☐ Hand-washing rules still apply but it is not necessary to wear gloves when handling the body.

☐ You must wear a mask, bootees, gown and two pairs of gloves when you are in the room with the body.

☐ You only need to wear gloves when handling the person's belongings.

Part B

Read the case study, then answer the questions that follow.

Case study

People from Chinese backgrounds can often have superstitions surrounding death.

The family may not want to hear words such as death, dying or cancer. Shortening of life may be considered a punishment for something the person did during their life. The number four might represent death and bad luck. They often do not like to discuss how long the person might have to live.

1. If you are supporting a Chinese person who is dying, how could you determine whether the person and their family have these cultural preferences in their individualised care plan?

2. What type of emotional support might be helpful for this family?

Topic 6: Manage your own emotional responses and ethical issues

6A Manage emotional responses and ethical issues

6B Identify and reflect on your own emotional responses to death and dying

6C Discuss ethical issues or concerns

6D Determine and implement self-care strategies

6E Access bereavement care and support of other team members

6A

Manage emotional responses and ethical issues

Palliative care workers need to know how to deal with their own reactions and responses to people who are receiving palliative care, and to their family members and friends.

People accessing a palliative approach will die at some point in the service's care. The way that you respond to death and dying can also have an impact on others.

Family, and the person, can find it either confronting, intrusive or kind to see varying degrees of emotional responses from you and other workers. Family members and friends may be demanding or take their grief out on the care worker, and co-workers can be influenced by the behaviours and responses of other workers.

There may be times when you experience feelings of anger. However, you would be overstepping your professional boundaries if you show anger in response to how a family behaves when managing the person's pain or when visiting them.

Sometimes emotions are difficult to keep in check. You might have experienced a loss in your personal life that causes you to feel triggered by a death at work. Your service might be experiencing a number of residents' deaths in quick succession that might feel overwhelming.

While you might shed some tears or display some emotion in front of families, always remember that you are a professional. Avoid loud or intrusive displays of grief, as it can be insulting and upsetting to the family.

As difficult as it may be, try to avoid letting your own feelings of grief interfere with the grief of the person or their family.

Try to keep a separation between your work and your personal life. Feelings of anxiety and worry are not healthy if you take them home with you.

When palliative care workers put the needs of the person who is accessing the service above their own for a long period of time, they can develop what is sometimes called compassion burnout.

Your service will have policies and procedures to help you if your work role is making you feel overwhelmed by sadness, anger, distress, grief or depression. This is a requirement of work health and safety legislation in all states and territories in Australia.

Talk to your supervisor about how you feel. You can do this in confidence and your supervisor must treat it as confidential.

You might be given support that could include:

- counselling through an Employee Assistance Program (EAP)
- debriefing support in the workplace
- paid or unpaid leave or sick leave
- other types of support.

Responses to ethical issues

Dying and ethical conflicts can often be closely interwoven.

You might have your own cultural or personal ideas about some of these ethical issues. Your opinions are not relevant however, unless you feel that a practice is illegal or abusive.

You might have conflicting beliefs about:

- the role of pain relief at end-of-life if the person or a family member refuses it
- the ethics of assisted dying in states where it is legal
- curative approaches vs palliative approaches
- withdrawing food and fluids from a person who is dying
- conflicts between family members, especially if they argue in front of the person
- morphine given to reduce suffering vs the effect of suppressing breathing and shortening life
- family members going against the express wishes of the person
- a person who dies alone, or who is only visited by their family members when they are dying and about to leave an inheritance.

If you feel strongly about an ethical issue in the workplace never raise it with the person or their family. Instead, talk to a supervisor or other senior member of staff. They can often help you understand the reason behind the ethical decision or treatment, and why it has been deemed in the person's best interests.

People from some cultures can have difficulty coming to terms with the palliative approach. For example, people from some Asian countries might have cultural beliefs that they should do everything possible to help their parents to live a long life. If the older person wants to commence a palliative approach this can go against the cultural expectations of their children, who might see this as giving up. If you believe strongly that the palliative approach is the person's right, you might find yourself angered by their children's responses.

In some states of Australia, the law allows certified doctors to administer medication to end the person's life at a time of their choosing. It is never your role to judge or advise people about their rights to access assisted dying. These questions must be passed on to your supervisor and the person's doctor. You must not imply or say what you do or do not believe about this law.

Example

Ethical issues

Ada is a support worker. She has always been against the introduction of voluntary assisted dying but it has recently been legalised in her state. She believes that it is 'playing God'. Michael, an older resident with a terminal illness, has spoken to his doctor to arrange a voluntary assisted death. Ada feels very passionately about the issue and feels that she should talk to Michael to try and convince him not to go ahead. However Ada is aware that Michael has made a decision that is his legal right. She decides that it is not her place to encourage Michael to change a personal and difficult decision. Instead, she decides to provide him with any support that he needs, such as making sure that he is comfortable. Even though she does not agree with voluntary assisted dying, she is able to put her opinions aside and maintain professionalism when providing him with a comfortable death.

Think about the ethical considerations you should take when providing support.

Practice Task 25

Question 1

Which of the following statements are correct? Select yes or no for each one.

a. You are allowed to have your own private feelings about ethical and religious issues.	Yes / No
b. In most ethical situations you should keep your own opinions to yourself.	Yes / No
c. It can be harmful to you if you bring strong emotions from work into your home life.	Yes / No
d. It is not the responsibility of your workplace to support you if you are struggling with strong emotions.	Yes / No

Question 2

What should you do if you feel overcome with emotions and need to draw on your service's support?

6B Identify and reflect on your own emotional responses to death and dying

You may experience a range of emotions and reactions towards death and dying.

The most important thing to do when you are feeling strong emotions is to recognise and acknowledge them. If you try to ignore them the chances are that they will have a greater impact on you.

When you are aware, and reflect on how certain things make you feel, it can be easier to detach the emotions from the behaviours that might follow. Here are some examples.

Feelings of powerlessness that you cannot do more for the person	• You might feel a sense of personal failure • You might feel stress and anxiety in your work and your home life.
Sadness when a resident you liked is no longer there	• You may be personally affected and grieve as if the person accessing the service was your own family member. • This can affect your home life and personal relationships.
Anger at a family member who you feel does not care enough or you think is making the wrong choices for the person	• You might feel uncomfortable or ill at ease with this family member. • Your feelings might show, and this can have an impact on their relationship, or be distressing to the family member and/or the dying person.
Overwhelming feelings of needing to avoid further pain or distress	• Some people who work in palliative care can experience something called compassion fatigue or burn out. • This can lead to you feeling nothing or feeling too much. • Burn out can impact on your work and your home life.

If you are experiencing strong emotions that are impacting on your work or home life, or are feeling overwhelmed, talk to your supervisor or a senior colleague you trust. It is best to talk about these emotions; sometimes simply talking about them can help ease the feeling. Also, if your supervisor knows about how you are feeling, appropriate support can be provided to avoid you burning out.

Unconscious bias

Unconscious bias
Where you express or show your feelings about an issue without realising that you are doing it, or even without realising that you have those feelings.

Unconscious bias and disagreement can be felt by anyone, no matter how much they think they can control their own beliefs or believe that they are not biased.

For example:

- you might feel that a family member does not visit their parent often enough or does not communicate warmly when they are there
- you might disagree with a person's decision to seek out assisted dying in states where it is legal to do so
- you might think that the person who refuses to take pain killers because they want to be brave is being foolish
- you might prefer supporting people or families whose company you enjoy and neglect, even in small ways, the people whose company you find less appealing
- you might have feelings about certain cultures or religions that stem from your own past experiences, from the media or public opinion.

It is understandable for you to feel these things, but not to express them.

Palliative care is a unique and personal experience between the person and their loved one. Your feelings or beliefs should not be communicated to the person or their family. If you express or show your feelings, even unconsciously, this can have a negative effect on the person's experience, or it can make them want to change their mind about something simply to please you.

The first step to avoid unconscious bias is to recognise it. Be aware of how you feel about certain issues; think about how your feelings could be biased.

Imagine that you do not agree with the beliefs of a particular religion. You might need to think carefully about this. Here are some steps to follow to help you do this:

1. Recognise what you feel.
2. Think about how this might become bias, such as not attending to the person's needs as thoroughly as you should.
3. Consider what effect this could have on the person who is dying, such as if they do not receive as much care or attention as they deserve.
4. Think carefully about how you can overcome this bias. You do not need to change your opinion, but you will need to avoid any actions that arise from it.

Example

Personal reflection

Read the following example to learn more about applying personal reflection when providing support.

Mika is a support worker. He is looking after Rita who has been advised that she does not have very long left to live. Although Mika and Rita get along well, Rita has one particular family member who Mika finds loud and obnoxious. Mika finds that whenever this family member is visiting he subconsciously avoids Rita's room. One day, when walking past Rita's room, Mika realises that he has not checked up on her in some time. He pauses and begins to pay attention to how he feels. He recognises that he has been avoiding the room due to thoughts he had not considered. Upon reflection he realises that this unconscious bias is unfair to Rita who feels neglected by Mika. He enters her room, smiles at the family member, and asks Rita if she needs any assistance. For the rest of Rita's life, Mika is able to simply greet the family member with a smile and put his feelings to the side.

Practice Task 26

Question 1

Which of the following statements relate to your emotional responses in the workplace? Tick all that apply.

- ☐ When you reflect on how certain things make you feel, it can be easier to detach the emotions from the behaviours that might follow.
- ☐ The most important thing to do when you are feeling strong emotions is to ignore them.
- ☐ Unconscious bias is where you express or show your feelings about an issue without realising that you are doing it, or sometimes without realising that you have those feelings.
- ☐ It is a very human thing to react emotionally to other people's behaviours or preferences.
- ☐ Burn out can impact on your work and your home life.

Question 2

What effect could unconscious bias have on a person you care for, or on their family?

Question 3

What should you do if you realise you are feeling overwhelmed at work?

6C Discuss ethical issues or concerns

As you have seen, the principal of palliative care is neither to hasten nor to prolong life. Palliative care does not involve any intention to end the person's life.

People in palliative care settings might sometimes ask you to help them die, or they might talk about or hint that they are intending to take their own life. Sometimes the person's loved ones might make these comments or requests.

Wanting to die can be the result of several different emotions including:

- physical suffering
- emotional distress
- extreme anxiety or depression
- fear of what they might have to experience
- acceptance of death and lack of interest in living.

While you should listen to the person's concerns and fears, as a support worker you must never give a person advice or directions about their desire to die. It is important that you do not weigh into these decisions with the family or the person. There could be serious legal consequences for doing so.

Instead, always refer these conversations to a nurse or doctor. These feelings need to be discussed with the medical team as soon as possible and addressed straight away. Sometimes, such as when the person is fearful of the future, being given reassurance about pain relief and other interventions stops them wanting to die. At other times the person's request may be well considered and the medical team might need to talk with the person and the family about legal and medical options and consequences.

It is best practice for this to be discussed between all members of the palliative team, rather than being left with only one person.

Here are some medical and legal definitions relating to hastened dying.

Assisted suicide	• Assisted suicide is to deliberately help or encourage a person to end their own life. It is illegal to do this.
Euthanasia	• Euthanasia occurs when a doctor administers a lethal dose of medication to a person to help stop suffering, and this causes the person's death. This is legal in some states of Australia.

Withholding and withdrawing treatment	• This means that the person is deliberately not given life-saving medications or treatment. For example, a person with a heart condition stops being given medications that keep them alive. • This is legal inside a palliative approach but must be used with caution where the person is not able to make this decision themselves, such as when they have dementia.
Voluntary assisted dying (VAD)	• Voluntary assisted dying is an act performed in accordance with the legislation in the state or territory. This occurs usually by the person self-administering a fatal dose of a medication prescribed by the doctor. • Laws enabling a terminally ill person to seek medical assistance to die under limited circumstances have now been passed in five of Australia's six states: Victoria, Western Australia, Tasmania, South Australia, and Queensland. • Only Victoria and Western Australia's VAD laws have commenced operation at this point. • It must be the person's choice, and they must have the ability, the capacity, to understand the decision.

You can find out more about End of Life Law in Australia here: aspirelr.link/end-of-life-australia

Medications that hasten death

Sometimes medications such as morphine are given to reduce the person's pain and suffering.

Since morphine can also slow the person's breathing, it can bring forward an already inevitable death. This is called a double effect. This is legal so long as the doctor's intention was to reduce pain and suffering, and not to deliberately speed up the person's death.

Withholding food and hydration

Nourishment and fluids must be provided for as long as the person can take them and wants them. When the person chooses not to be given food and water it can be distressing for some workers to be able to do all that they can for the person. They might see not feeding the unconscious or semi-conscious person as cruel, or as a failure by the family to care properly for their parents or loved one.

Some family members might wish to keep giving the person oral food and drinks even when it is not safe. Or they might insist on the person being given nasogastric feeds or PEG feeds. This can often create tension between the family and the medical team as it becomes an ethical decision when the person can no longer communicate their own wishes. If the person did not provide instructions about this in their advance care directives, this decision needs to be made carefully by the substitute decision-maker and the medical team. The person's best interests can only be decided through clear communication. The doctor will talk to the family about the best and most comfortable options for the person and sometimes they might compromise by providing fluids in other ways.

If the person is still capable of making and communicating these decisions, it is legal for them to refuse to eat or drink even if it will result in their death. You must respect this decision even if you do not agree with it. However, you must never suggest or encourage this as doing so could make you responsible for assisting suicide, an illegal act in every state in Australia.

Sedation

Palliative sedation means the person is given a medication to stop them from being agitated, or to reduce their emotional distress. This is different to anti-depressant or anti-anxiety medication because a sedative works by making the person sleepy or by changing their behaviour.

Sedation used in aged care is considered a restrictive practice under new laws that came into place in July 2021. It can only be used in aged care and other palliative care settings as a last resort, after all other measures have been exhausted and in line with restrictive practice legislation. It must not be given with the intention to directly hasten or end life.

Sometimes the person's family will request or demand sedation when they see their loved one suffering. A specialist palliative care service should be involved if this is being considered.

Resuscitation

There are usually clear directions in place for staff, such as a Do Not Resuscitate (DNR) or Not For Resuscitation (NFR) order. Sometimes, however, you might experience a family begging you to resuscitate a person who has stopped breathing. This can be difficult and distressing for you, especially if you are aware the person has a DNR order.

In these circumstances you must seek immediate help from a senior member of staff. Such situations can be avoided through clear communication with the family and the senior members of the palliative care team. If a family member suggests to you that they do not agree with these orders, even if the person is not close to death you must always let a senior member of staff know so that this can be discussed to avoid conflict and distress later.

In most palliative settings, resuscitation should have been discussed and agreed on between the person and the team.

Withholding the truth from a dying person

Some older people do not want to know their diagnosis and this is their choice.

In some cultures it is common practice to avoid telling an older person that they have cancer or another terminal illnesses. This is done with the intention of reducing distress but can however sometimes have unintended consequences. For example, some older people in these cultures might not actually be dying but might be convinced they are, and that their families and doctor are withholding this information from them.

This practice is called collusion. It does not align with the concept that a person has the right to make decisions based on truthful information. For this reason, collusion can be a common source of ethical conflict between doctors and families. This a discussion that must happen between the family and the doctor. They must find a balance between cultural respect, the person's right to choose and the best interests of the person. Sometimes an 'Elder' or cultural leader can help to mediate. Never tell a person their diagnosis if they are unaware as this is outside your role. It can lead to extreme distress to the person and their family and it is important that you refer such issues to a senior member of the team.

Example

Respecting a person's wishes

Daniel is terminally ill and has no friends or family to visit him; because of this he is lonely and depressed. He tells a support worker that he does not want to eat or drink anymore as he would rather let himself drift away. The support worker feels confident that he has the cognitive abilities necessary to make this decision for himself. She informs her managers who talk to Daniel about his wishes. The team ultimately respect Daniel's decision. She offers him physical support and comfort but does not actively encourage or discourage Daniel to eat.

What considerations could you make to ensure your respect a person's wishes while they're under your care?

Practice Task 27

Question 1

Match each term to its description.

Assisted suicide	The person is deliberately not given life-saving medications or treatment.
Collusion	A doctor administers a lethal dose of medication to a person to help end suffering, and this causes the person's death.
Withholding and withdrawing treatment	Withholding the truth from a person about their diagnosis.
Voluntary assisted dying	To deliberately help or encourage a person to end their own life.
Euthanasia	A fatal dose of a medication prescribed by the doctor taken in accordance with the legislation in the state or territory.

Question 2

How should you respond if a family member tells you that they do not agree with Do Not Resuscitate orders?

Question 3

What should you do if a person you care for is refusing food and drinks?

6D

Identify and implement self-care strategies to address the impact of personal responses

Working in a setting where people are dying can be emotionally difficult, even if you feel you cope well with stress.

It can be very useful to follow a self-care routine that both prevents, and helps you manage, signs of stress.

Talk	• Discuss your feelings with your supervisor or another experienced person. • Talk to other staff members who understand how you feel. • Make an appointment with the counsellor through an employee assistance program. • Speak to a religious or cultural leader, or another community contact, but keep in mind the privacy and confidentiality of the dying person and their family.
Detach	• Some people find it useful to purposely find routines to switch off from work and restart your home life. You might find that a routine such as exercise, meditation, having a shower and changing out of your work clothes can help you 'switch'. • If you find yourself thinking about work at home in a way that is upsetting or distressing, it is important to try and let go of these feelings and focus on yourself and your own wellbeing. It does not make you a bad person to want to have your own life. You and your family do not need to take on the problems of the residents and families at work.
Exercise	• Exercise is known to help reduce anxiety and depression and lift mood. Find an exercise routine that you enjoy and that suits your needs and abilities.
Rest and recharge	• Get enough rest and sleep. Eat a healthy diet when you can and allow yourself time to do activities that you enjoy.
Meditation and mindfulness	• These activities can help you to learn to refocus and be present in your own life. There are many in-person options, or online via self-guided apps, if you wish to participate in these types of self-help.
See your GP	• If you are struggling with feelings of grief or other emotions, you might prefer to see your GP. He or she can help you to work through your feelings and help you to access government funding to have subsidised visits to a registered psychologist.

Video: Practising self-care

Watch the following video on how to practise self-care when working in palliative care: aspirelr.link/practising-self-care

Pay attention to the various ways workers practise self-care and how they see self-care as a key responsibility.

Visit the Self-Care Matters website by Palliative Care Australia. It has a wealth of information and resources, including videos, on how to plan for and practise self-care when working in palliative care: aspirelr.link/self-care-matters

Example

Implementing self-care strategies

Anish is a support worker in an aged care facility. Before he began working here he had never seen a person die, but in his first few months in this role he has already seen several residents die. He finds this quite confronting and feels his work is taking a toll on his mental health. He tells his manager that he needs some support. His manager tells him that counsellors are available and reminds him how important and valuable his work is for many residents; however, he explains that it is important for him to look after himself as well. He decides to begin speaking to a counsellor, where he learns a range of strategies to help him overcome his distress. He now feels that being with a person as they die and caring for their body is an important part of the cycle of life. He considers this role a privilege rather than a burden.

Consider why self-care is so important. What strategies could you implement to ensure you are looking after yourself?

Practice Task 28

Question 1

List three self-care strategies that you can use to prevent and reduce negative effects or emotions.

6E

Access bereavement care and support of other team members

You and the team have the right to formally acknowledge a loss, and to have access to adequate bereavement assistance and support when required.

Palliative care work relies on a team approach where everyone provides support to each other. To be an effective team member it is important to be able to recognise when you, or others, require this type of support and take action to give or receive it. Be aware that everyone is different and some people require more support than others.

Employee assistance programs

Employee assistance programs (EAP) are programs that link the service to an external counsellor, bereavement service or psychologist.

These programs are confidential and funded, so are either low-cost or free for you to use.

Ask your supervisor for help or check your service handbook for details.

Structured debriefings

Both formal and informal debriefings can be an effective way for palliative care staff to avoid burn out.

After an incident, or series of incidents, remind and encourage your supervisor to hold a structured debriefing session. This is your right in the workplace and it can benefit your team to work together to help yourselves, and each other. These sessions can be run by professional counsellors or psychologists or by a person in the workplace who is trained to hold a structured debrief.

A debriefing is a meeting that gives staff the opportunity to:

- talk about the death
- express their emotions
- discuss what they did well
- consider what could be done better
- discuss how the person will be honoured and remembered in the facility
- provide staff with information about counselling and other additional support.

Workplace rituals

Rituals can be helpful ways to work through feelings of sadness or grief. They also help to honour the person and create an impression that the staff have done one last nice thing for the person. Here are some examples:

Condolence books	Staff, families and visitors can contribute their thoughts, feelings and memories to a condolence book kept at the service. This gives them an opportunity to voice and reflect on their feelings and emotions. The book can later be given to the person's family.
Memorials	A memorial for a person who has died in the service can help staff and other residents to remember and acknowledge the person. Memorials can include photos, candles or a memorial wall.
Prayers and services	Your service might hold a prayer service or a minute of silence for a person who has died.
Guard of honour	Some facility staff hold a guard of honour as the person's body is taken away.
Attending funerals	Many aged care and palliative services encourage and support staff who were closest to a resident to attend the person's funeral. The staff represent the entire service. This may need to be worked around staffing and rosters but it is important that you and other staff speak up if you feel this would help you, and would be appreciated by the family.

Example

Bereavement care

Read the following example to learn more about bereavement care in the workplace.

Lui was a resident at an aged care facility for two years. She had immigrated from China in the 1990s and had only a handful of family members and friends in Australia. Two staff members, Kerry and Lucy, requested to attend Lui's funeral. They were both rostered on the day of the funeral so their manager Thomasina rostered on an extra staff member that day so that they could leave work early to attend the funeral.

Lui's funeral was a traditional Chinese funeral. They asked Lui's friend Lin what cultural practices they should know before they attended. Lin told them that you should not wear bright colours, especially red, to a Chinese funeral. Because their work uniform was red, both workers changed into a dark-coloured shirt before they left for the funeral. Lin appreciated that they were there.

Kerry and Lucy spoke to the rest of the staff the next day about the funeral, and how grateful Lin was to them for attending. They also passed on that a formal thank you was given to the aged care staff during the funeral.

Practice Task 29

Question 1

Match each term about bereavement care to its definition/description.

Employee assistance program	A place where people who knew the person can contribute their thoughts, feelings and memories
Structured debriefing	A place to remember the person, such as a table with photos and candles.
Condolence book	A meeting held by professional counsellors or psychologists, or by a person in the workplace who is trained to hold a structured debrief.
Memorial	A support service that links you to an external counsellor, bereavement service or psychologist.

Question 2

Give three examples of things that might be discussed in a structured debriefing with colleagues.

Summary

- In some circumstances a worker may experience strong reactions to death such as sadness, confusion, fear and anger.
- Your reactions might have impacts on others and on your own mental health.
- Palliative care can be a place where ethical issues conflict with your own beliefs.
- It is important to talk to others about ethical conflicts.
- You must try to avoid allowing unconscious bias to interfere with your role.
- Palliative care work relies on a team approach and one in which everyone provides support to each other.
- There are a few professional bereavement support services your organisation can suggest or that you can approach yourself.
- Your service is likely to have rituals and practices designed to support staff and other residents after the death of a resident.

Learning Checkpoint 6

Manage your own emotional responses and ethical issues

Part A

1. List two examples of policies and procedures that exist to support you if you become overwhelmed with an emotional response.

2. Give an example of an ethical conflict that would need to be reported to a supervisor.

3. Which of the following statements relate to how you should react to strong emotions that you might be feeling? Tick all that apply.

   ☐ Try to ignore your feelings while you are at work.

   ☐ Talk to the person and their family about your grief.

   ☐ Talk to your supervisor.

   ☐ Reflect on your feelings with colleagues.

   ☐ Cope with these feelings alone, no matter how hard it is to manage them.

4. Explain how nutritional and hydration requirements are determined during a palliative approach.

Part B

Read the case study, then answer the questions that follow.

Case study

Joan is in the last few weeks of life. Her support worker is Sophie. Joan's family have rarely visited their mother during the year that Joan has been in aged care. Sophie resents the family who are now suddenly arriving to visit in large numbers and making constant demands of the staff.

Sophie wonders where these family members were when Joan was alone over the last year, and she suspects that they all want a share in her inheritance.

Sophie finds herself feeling angry and upset.

1. Should Sophie speak up about her feelings to Joan and her family? Why or why not?

Glossary

Advance care directives

An advanced care plan, detailing a persons' preferences for future care that align with their own values and beliefs.

Constipation

A state of the bowel in which evacuations are hindered or stopped.

Dignity of risk

A person's right to dignity and choice, upheld in legislation and service standards, to ensure that duty of care or safety is not used as a reason to limit a person's freedom of personal choice.

Duty of care

A moral or legal obligation to ensure the safety and wellbeing of other persons.

Empowerment

The process of gaining strength and confidence to voice one's own opinion.

Life-limiting (terminal) illness

A chronic disease that does not respond to curative treatment and leads to a terminal diagnosis.

Life-threatening illness

A disease that might lead to death, depending on complications and how successful treatments are.

Spirituality

An inner sense of something greater than oneself, which may be met through faith or religion.

Substitute decision-maker

Someone the person has nominated to take responsibility for making decisions for them.

Unconscious bias

Subconsciously forming social stereotypes about certain people and expressing these.