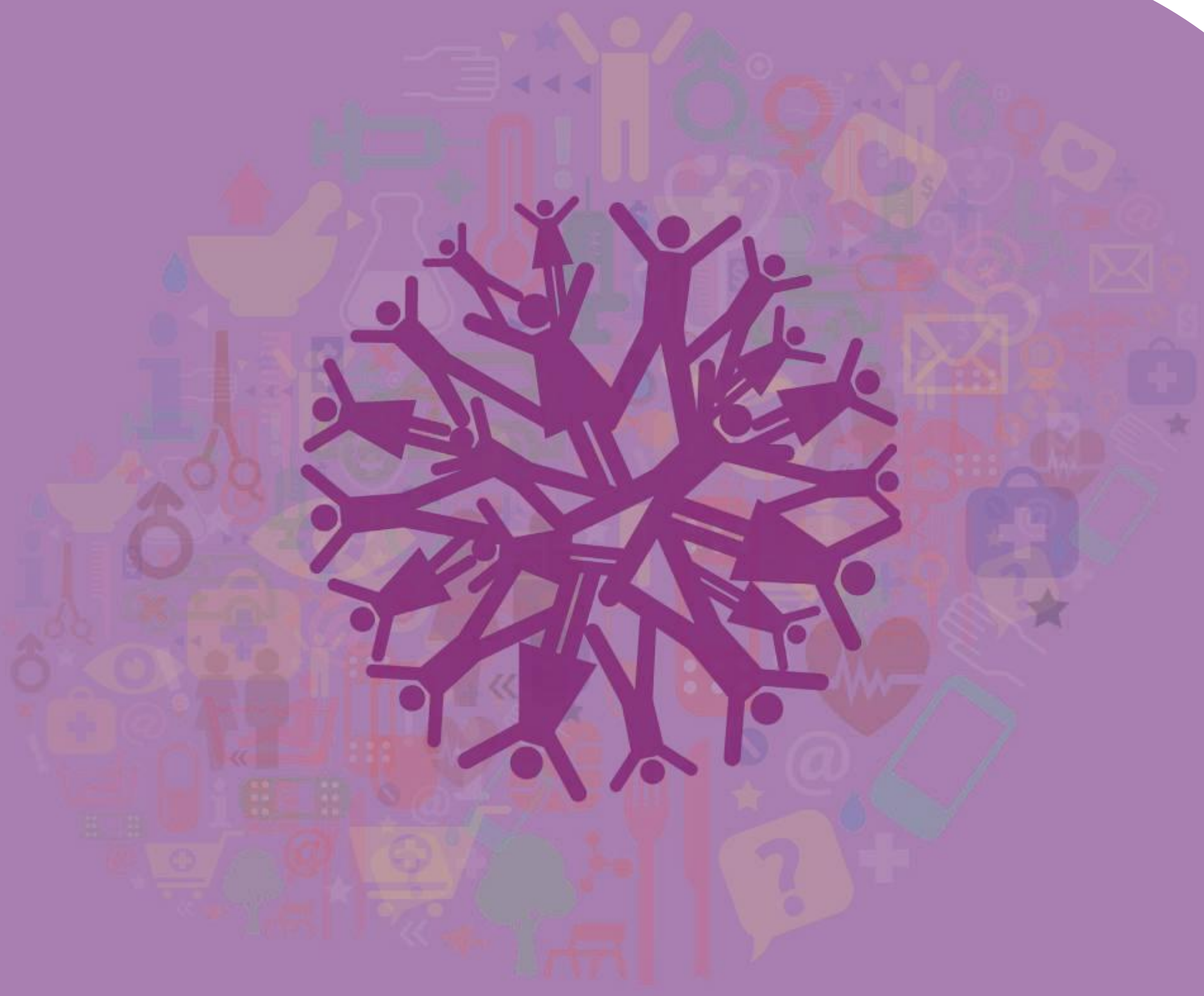
CHCPAL001
Deliver care services using a palliative approach

Release 2



Learner guide

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CHCPAL001

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Aspire version 1.3

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Version control and modification history

Version	Release date	Modification
Release 2, version 1.1	April 2017	First release
Release 2, version 1.2	February 2019	Minor corrections as part of our continuous improvement program and text reflowed
Release 2, version 1.3	July 2019	Updated to reflect the new Aged Care Quality Standards. Updated to reflect changes to voluntary assisted dying laws in Victoria.

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CHCPAL001 Deliver care services using a palliative approach Release 2

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Contents

Before you begin

This learner guide is based on the unit of competency *CHCPAL001 Deliver care services using a palliative approach*, Release 2. Your trainer or training organisation must give you information about this unit of competency as part of your training program. You can access the unit of competency and assessment requirements at: www.training.gov.au.

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. The features of this learner guide are detailed in the following table.

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 and case studies	▶ Examples of completed documents that may be used in a workplace are included in this learner guide. You can use these examples as models to help you complete practice tasks and learning checkpoints. ▶ Case studies 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.
Video clips	▶ Where QR codes appear, learners can use smartphones and other devices to access video clips relating to the content. For information about how to download a QR reader app or accessing video on your device, please visit our website: www.aspirelr.com.au/help v1234
Summary	▶ Key learning points are provided at the end of each topic.
Learning checkpoints	▶ There is a learning checkpoint at the end of each topic. Your trainer will tell you which learning checkpoints to complete. These checkpoints give you an opportunity to check your progress and apply the skills and knowledge you have learnt.

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.

The following table outlines specific foundation skills noted for your learning in this learner guide.

Foundation skill area	**Foundation skill description**
Learning	▶ Understanding your job role, organisational procedures and legal responsibilities ▶ Managing your work and seeing how well you are going and making goals for yourself at work ▶ Seeking professional development opportunities for continuous improvement
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
Teamwork	▶ Working well with other people by cooperating, collaborating, encouraging and building rapport
Planning and organising	▶ Planning your workload and commitments ▶ Implementing tasks ▶ Completing work on time ▶ Knowing how to deal with hazards and risks
Making decisions	▶ Understanding and applying decision-making processes ▶ Reviewing the impact of your decisions
Problem-solving	▶ Identifying problems ▶ Working out how to fix a problem using problem-solving processes and reviewing the outcome
Innovation and creation	▶ Recognising opportunities to develop and apply new ideas ▶ Generating ideas by thinking of new ways to do something ▶ Making suggestions to improve work

Foundation skill area	**Foundation skill description**
Technology and digital literacy	▶ Efficiently using digitally based technologies and systems correctly and safely ▶ Accessing, organising and presenting information ▶ Using equipment correctly and safely

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 outcomes**	**Rate your confidence in each section**
Topic 1 Apply principles and aims of a palliative approach when supporting individuals	1A Recognise the holistic needs of people accessing palliative care services extending over time	☐ Confident ☐ Basic understanding ☐ Not confident
	1B Support the person, families and carers to express needs and preferences	☐ Confident ☐ Basic understanding ☐ Not confident
	1C Communicate with the person, carers and family to promote quality of life for the person	☐ Confident ☐ Basic understanding ☐ Not confident
	1D Demonstrate respect and include the family and carer as an integral part of the care team	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 2 Respect people's preferences for quality-of-life choices	2A Encourage the person, carers and family members and/or significant others to share information	☐ Confident ☐ Basic understanding ☐ Not confident
	2B Use a non-judgmental approach to support the person's lifestyle, social, spiritual and cultural needs	☐ Confident ☐ Basic understanding ☐ Not confident
	2C Support a person's rights to openly discuss spiritual and cultural issues	☐ Confident ☐ Basic understanding ☐ Not confident

Topic	Key outcomes	Rate your confidence in each section
	2D Identify needs and issues outside your scope and refer to supervisor when necessary	☐ Confident ☐ Basic understanding ☐ Not confident
	2E Use effective communication skills to provide emotional support and empathy	☐ 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 needs and issues to appropriate personnel	☐ 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 a person's pain	☐ 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 Understand how to address misconceptions surrounding the use of pain-relieving medication	☐ Confident ☐ Basic understanding ☐ Not confident

Topic	**Key outcomes**	**Rate your confidence in each section**
Topic 5 Follow end-of-life care strategies	5A Identify changes that have been made and reviewed in the care plan	☐ Confident ☐ Basic understanding ☐ Not confident
	5B Provide a supportive environment for the person involved in end-of-life care, their family and carer	☐ Confident ☐ Basic understanding ☐ Not confident
	5C Provide care in accordance with the person's preferences and culture	☐ Confident ☐ Basic understanding ☐ Not confident
	5D Maintain dignity of the person at end of life and following death	☐ Confident ☐ Basic understanding ☐ Not confident
	5E Recognise signs of imminent death or deterioration and report to appropriate person	☐ Confident ☐ Basic understanding ☐ Not confident
	5F Provide emotional support to other people, carers and families when a death occurs	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 6 Manage your own emotional responses and ethical issues	6A Follow organisational policies and procedures when managing 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 with the appropriate person	☐ Confident ☐ Basic understanding ☐ Not confident
	6D Identify and implement self-care strategies to address the potential impact of your personal responses	☐ Confident ☐ Basic understanding ☐ Not confident
	6E Access bereavement care and support of other team members	☐ Confident ☐ Basic understanding ☐ Not confident

Topic 1

In this topic you will learn how to:

1A **Recognise the holistic needs of people accessing palliative care services extending over time**

1B **Support the person, families and carers to express needs and preferences**

1C **Communicate with the person, carers and family to promote quality of life for the person**

1D **Demonstrate respect and include the family and carer as an integral part of the care team**

Apply principles and aims of a palliative approach when supporting individuals

Palliative care is an area of health care that addresses the holistic needs of clients who have life-limiting illnesses or are in the final stages of their life.

Palliative care extends from the moment of diagnosis of a life-limiting illness, death of the person and care of the family for bereavement. Healthcare providers and professionals have a responsibility to ensure all people accessing palliative care services experience the best possible quality of life until their death. Standards for providing palliative care have been developed by Palliative Care Australia, the peak national body. Curative and palliative approaches have different principles and aims. Palliative care uses an approach that reflects the person's needs.

1A Recognise the holistic needs of people accessing palliative care services extending over time

It is important that you understand the difference between curative and palliative care approaches and the support needs of the person and the family for each approach. Curative care is given for illnesses that are curable and do not get progressively worse – what are referred to as 'non-malignant' illnesses. Curative care aims to:

- overcome a diagnosed illness
- identify and actively treat the source of the illness
- prolong life
- promote recovery
- focus specifically on the client.

These illnesses are controlled by medical treatments, medications and/or complementary and alternative therapies. An example of a non-malignant illness is a benign (non-cancerous) tumour that can be controlled by surgery, chemotherapy and radiation therapy.

Adequate curative treatment relies on an accurate diagnosis of the client's condition using imaging technology such as ultrasound, and laboratory procedures (pathology).

Life-limiting illnesses

Life-limiting illnesses are progressive and it is expected that death will be a direct consequence of the specified illness. People with a life-limiting illness may experience changes in their ability to undertake their activities of daily living. Their quality of life, their ability to communicate and their psychosocial wellbeing may also be affected.

When you are working with people with life-limiting illnesses or at the end of their lives, you must understand the terms listed here.

Malignant illness

A malignant illness usually becomes progressively worse and may cause death; for example, a cancerous tumour. Such tumours are made up of malignant (uncontrolled mutated) cells; they are invasive, usually grow rapidly, may recur after removal and cause death if growth is not stopped.

Incurable illness

An incurable illness is one that is not likely to be changed or corrected using medical intervention. The illness is beyond the power of skill or medical treatments and medications to remedy it.

Irreversible illness

An irreversible illness is of such severity that recovery is impossible.

Terminal illness

A terminal illness is expected to result in a person's death. This could be from an incurable, advanced and progressive disease, illness or medical condition.

A palliative approach

Palliative care is the specialised holistic care of people who are dying. It provides the person accessing the service with relief and comfort when there is no cure for their illness, and measures to extend their life are discontinued. A holistic approach incorporates the physical, psychosocial, emotional and spiritual care needs of the person accessing palliative care services. A person receiving palliative care has an active, progressive and far-advanced disease such as cancer, dementia or Alzheimer's disease, with no prospect of cure.

Here are two more-detailed definitions of palliative care; one from an international organisation and one from an Australian state government.

International definition	Australian definition
The World Health Organization defines palliative care as 'an approach that improves the quality of life of the person, their family and carers facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.	The NSW Department of Ageing, Disability & Home Care defines palliative care as 'the active total care of people whose disease is not responsive to curative treatment'. The aim of palliative care is to control and provide relief from pain and other distressing symptoms, offer support to clients until death, and regard dying as a normal process.

Palliative care standards

Palliative Care Australia's standards for providing quality palliative care for all Australians detail the responsibilities of those who provide specialist palliative care to ensure the person's comfort and dignity are maintained. The standards cover the physical, spiritual, psychological, social and cultural support required to achieve holistic care of the person.

For more information, visit the following website:

- http://aspirelr.link/pca-national-standards

Here are some of the key aims of palliative care.

Philosophies embraced by the palliative care approach
Palliative care enhances the person's quality of life and may also positively influence the course of illness by treating pain and other problems in a holistic manner.
Palliative care uses a team approach to address the needs of person's families and carers facing problems associated with a life-limiting illness.
Palliative care focuses on active, comfort-focused care and a positive approach to reducing suffering and promoting an understanding of loss and bereavement.
Palliative care incorporates a positive and open attitude towards dying and death by the palliative care team.

A palliative approach for people accessing the service

For the person accessing services, a palliative approach begins when there is a change in the goals of their care from curative (symptom control and supportive care) to end-of-life care due to a life-limiting illness. For many people with life-limiting illnesses, the transition from curative treatment to palliative care is gradual.

As a palliative care team member, you should understand when a person is moving from curative care to a palliative approach. Recognising this change in the type of care required by the person is very important, as it gives you an opportunity to provide tailored support for them, their family and carers. You must also ensure that all stakeholders fully understand the shift in treatment from curative care to palliative care and the impact this may have.

Where palliative care is provided

Palliative care services are provided in a range of settings, listed below. People who are dying must be able to move freely between these places to meet their medical care and support needs. Palliative care is usually best provided in close proximity to the client's local environment and community.

Wherever possible, palliative care is provided in the environment of the person who is accessing the service's choice. In the course of their illness, some people may receive palliative care in all three of the possible settings, depending on their needs.

A significant proportion of anticipated deaths still occur in hospitals and many people are identified as needing palliative care while in a hospital. In many cases, the person prefers to return home in the final stages of their lives, to die with dignity in familiar surroundings.

The three possible settings for palliative care are listed here.

Settings for providing palliative care

- Community settings, such as an aged or supported care facility or the person's home
- Purpose-built hospices
- Designated palliative care beds in hospitals, which are in-patient beds used specifically for palliative care people

The benefits of a palliative care approach to meet needs of people accessing the service

As a palliative care worker, you are part of a support group that contributes expertise and specialised skills and knowledge to care for a person with a life-limiting illness. You must understand your role and responsibilities and follow the person's care plan. Always ask your supervisor if you are unsure of anything. Above all, remember the philosophy of a palliative approach is to provide high-quality care involving all aspects of the person's life, over the period of the person's illness, not just at the end of their life. It is your job to ensure the person's needs are met within your level of authority and by following the instructions in the person's care plan.

Many people with life-limiting illnesses may have similar needs.

Needs of people with life-limiting illnesses include:

- knowing when death is approaching and what to expect
- maintaining a sense of control and independence and have their wishes given preference
- being afforded dignity and privacy
- continuing to maintain social contacts and friendships
- having control over pain relief and other symptom control
- having access to information and high standards of palliative care
- having access to spiritual and emotional support as required
- maintaining cultural and religious beliefs and practices
- not having life inappropriately prolonged.

Apply the principles of a palliative care approach

High standards of palliative care require the expertise of highly skilled and trained people, such as doctors, nurses, pastoral workers (chaplains), social workers, administrators, support workers and carers, who understand life-limiting illness and can support the person's discomfort and needs. No-one works in isolation; everyone works together, contributing their own expertise to promote high standards of both palliative and end-of-life care for people accessing palliative care services.

The healthcare team

A palliative care team is made up of individuals with varied and specialised skills and knowledge. Important palliative care team members are listed here.

Palliative care team members

- Allied health professionals – social workers, physiotherapists, occupational therapists, psychologists, pharmacists, dietitians
- Support workers – nurse assistants, personal care attendants and diversional therapists
- Medical practitioners – general practitioners (GPs), palliative care specialists and other specialist physicians with a related interest
- Nurses – generalist and specialist nurses in community, hospital and in-patient palliative care settings, and independent nurse practitioners
- Families
- Carers
- Aboriginal and Torres Strait Islander health workers
- Alternative therapists skilled in massage, aromatherapy, relaxation music or colour therapy
- Bereavement counsellors
- Spiritual carers from a range of pastoral, spiritual and cultural backgrounds
- Professionals with language skills and cultural knowledge of ethnic groups
- Volunteers

Your role in the palliative care team

It is essential for you to understand your specific role in the palliative care team; that is, how you contribute to the person's care. This depends on the person's illness, their treatment, the wishes of the person's family, where the care is being delivered and your own job role. Your role in the palliative care team and the goals of the team are explained below.

Your role

- Understand the role of all team members
- Communicate effectively
- Cooperate and collaborate well
- Attend regular meetings
- Plan time efficiently
- Be aware of the goals of each person's palliative care plan

Team goals

- Support the person with a life-limiting illness by treating and managing symptoms to ensure the best-possible quality of life
- Help the person to self-manage their condition and make decisions relating to their care
- Educate the person's families and carers about death and dying, bereavement and loss

Apply a palliative approach in your work

Healthcare providers must understand the main beliefs, values, philosophies and aims of a palliative care approach so they can apply them when working with people with a life-limiting illness or those who are at the end of their life.

There are seven main points you should understand; each of them is equally important.

Aims of a palliative care approach

Take a positive approach
The philosophy of palliative care is based on a positive approach to relieve symptoms and maximise the quality of life for people with a life-limiting illness. A palliative care team actively anticipates prevents and treats the person' suffering and aims to make death as comfortable as possible when it occurs.

Do not delay care
Care is not delayed until the end stages of a person's illness.

Address needs
The focus of all healthcare providers and healthcare professionals providing 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.

Provide holistic care
A palliative approach centres on the holistic care of the person, their families (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates), carers and other support networks before and after the death of the person. A palliative approach usually refers to the person's family as the unit of care.

Encourage independence and choice
A palliative approach assists the person to feel independent and allows them to access information and make choices.

Be flexible
Palliative care is flexible so it can continue to meet the needs of the person, families and carers as conditions change.

Minimise the distress of dying
Palliative care services respect dying as a shared and unavoidable consequence of life and reduce the personal distress associated with dying.

Philosophies of a palliative approach

Following are some examples of how to apply the underlying philosophies of palliative care when carrying out your daily duties.

Philosophies of palliative care

Understand the person accessing service's needs

- Understand that the person needs to maintain their quality of life for as long as possible.
- Understand that the person needs to retain their dignity.
- Understand that the person needs to be provided with information so they are able to make their own choices.
- Be familiar with each person's care plan.
- Understand the person's physical, social, psychological, spiritual and cultural needs.
- Discuss with the person their hopes, fears and wishes so you can plan ahead for the client, their family and carers.

Identify the person, family and carer as the unit of care

- Ensure you know each member of the person's unit of care, including:
  - biological relations, such as siblings and parents
  - spouses
  - partners
  - friends
  - carers
  - advocates
  - guardians.

Provide support using a palliative approach

- Explain to the person, their family and carers what a palliative approach means.
- Ensure decisions are made with the person, their family and carers.
- Ensure all communication is open and clear so everyone understands what is involved, and effective decisions can be made – this avoids conflict and confusion about palliative care goals.
- Let everyone know about their rights and responsibilities regarding decision-making, which is often the responsibility of family members.

Participate in a team approach

- Understand the roles of each team member.
- Establish an effective, professional relationship with team members.
- Build respectful and trusting relationships with the person, family and carers.
- Follow organisational policies and procedures.

Seek advice from appropriate people when necessary

- Always ask for advice or information from your supervisor, manager or palliative care team members when necessary.

Maximise self-care and self-determination for the client

- Encourage the person to be as independent as possible, where appropriate.
- Ensure the person is always given the opportunity to make their own decisions.

Assist in the psychological and spiritual aspects of care for clients

- Understand the person's psychological and spiritual needs.
- Ensure all interactions with the person respect and allow for their psychological and spiritual needs.

Recognise symptoms of pain and discomfort

- Understand the signs and symptoms of pain and discomfort.
- Understand and follow procedures to reduce or eliminate the person's pain and discomfort.

Recognise the signs that death may be imminent

- Understand the signs of imminent death.
- Discuss end-of-life issues and anticipation of death in an honest and sensitive manner with the person, their families and carers.

Understand the impact of a palliative approach in an organisation

- Maximise the person's quality of life.
- Keep the person, their families and carers up-to-date with appropriate information.
- Provide a support system to families and carers.
- Be an active member of the healthcare team.

Maintain the person's dignity

- Relieve the person's suffering and discomfort as advised.
- Promote the person's sense of dignity by listening to their wishes and helping them remain as independent as possible.
- Remain sensitive to the values of the person, their families and carers.

Holistic care

Holistic care and support takes into account emotional, psychological, social, cultural and spiritual needs as well as the physical needs that are experienced uniquely by each person, their family and their carers. In relation to palliative care, it means all aspects of a person's life are considered and everything possible is done to maintain a good quality of life.

Part of providing palliative care is to ensure the person can access a range of pain control methods. A person's care plan may take a holistic approach combining conventional as well as complementary and alternative therapies that focus on comfort, pain relief and management of other distressing symptoms. Complementary and alternative therapies may supplement conventional therapy and provide symptom relief and non-invasive palliative care with minimal side effects. They may also enhance the person's physical and psychological comfort. Some alternative therapies used in a holistic approach may include homeopathy, naturopathy, chiropractic, herbal medicine and aromatherapy.

Holistic approach to palliative care

Taking a holistic approach; that is, viewing the person as a whole and taking into account all aspects of their health and wellbeing, will assist you to tailor supports and daily activities around their needs.

Here is further information on the main areas of health.

Physical health

Physical health includes mobility, and whether mobility aids are required, vision, and whether visual aids are required, hearing, and whether hearing aids are required, illness or disease, and whether medication is required, allergies, and digestive system issues; for example, appetite, special dietary requirements and bowel movements. Maintaining physical activities assists the person to remain living independently for as long as possible.

Emotional/mental health

A person's emotional health is very important to planning support. The activities you support the person with need to be appropriate for them and fit with their emotional state. Emotional health may include depression, melancholy, anxiety, stress, grief, loneliness and fear.

Spiritual health

Spiritual health refers to the spiritual ideas or groups a person identifies with and how engaged the person is in spiritual life. A person's spiritual life or beliefs may be related to an organised religion; a philosophy; praying; meditating; or engaging with a spiritual community such as a church.

Cultural activities

Culture is the basis of a person's way of doing and believing. It can be based on ethnicity, language and social connection. A person's cultural needs must be considered in all activities.

Social health

Social health refers to a person's ability to be around and get along with others. Issues include isolation, cultural and communication barriers, and mental health issues. Socially engaged people have been found to live healthier, happier lives. For example, people with dementia greatly benefit from social interaction as it engages cognitive functions and can minimise emotional side effects.

Cognitive health

A person's cognitive health relates to their brain's ability to function. Cognitive health issues include memory loss, confusion, illiteracy and communication issues. Cognitive skills can decline due to disease or illness. Activities that engage the person's mind can improve their overall health and wellbeing.

Example

Respect the person's wishes and needs

Bernard lives alone and has a chronic, degenerative condition that requires hospital visits and frequent overnight stays. When he is no longer able to care for himself at home, Bernard is admitted to a high-care facility.

He makes his wishes quite clear: 'If I'm ever in the position where I can't answer for myself, please take me to St Mary's Hospital. They have a huge file on me there and know me well. They'll say "Here comes Bernie again" as I come through the door. If it ever gets to the stage where they can't do anything for me, they can send me back here to my second home.'

This request is recorded and the form signed by Bernard. Two weeks later Bernard suffers a brain stroke and is immediately transferred to St Mary's hospital for diagnosis. A comprehensive advance care plan outlines his needs and preferences; however, it is anticipated that Bernard will not regain consciousness. Through consultation with the hospital, it is agreed that Bernard should return to the high-care facility for a palliative approach. Bernard dies one week later surrounded by his family. His preferences were respected and the amended goals for care were achieved.

Practice task 1

1. What is the difference between curative and palliative care?

2. List the seven aims of palliative care.

Click to complete Practice task 1

1B Support the person, families and carers to express needs and preferences

Have you thought about how you would like to be treated when you reach the point of needing assistance with a life-limiting illness? How would you like people to address you? What control would you like to have over your own life? Your responses to these questions may help you realise the importance of treating people with palliative care needs in ways you would like to be treated yourself; that is, with dignity and respect.

Use an approach that reflects the person's needs

Here are some ways carers can provide high-quality end-of-life care.

Providing high-quality end of life care

- Provide the desired physical comfort and emotional support.
- Promote shared decision-making.
- Respect the dying person.
- Respect the person's cultural and social beliefs and values.
- Provide information and emotional support to family members and carers.
- Help the person accessing services to maintain quality of life and independence for as long as possible.

Understand how care can be adjusted for the individual

The pattern of care may differ for every individual faced with a life-limiting illness or who is at the end of their lifespan. Factors that influence a person's pattern of care include where the person lives, the services in their area, their specific needs, beliefs, values, spirituality and culture and the needs and desires of their family members and friends.

These factors must all be taken into account and a care program implemented and maintained as soon as a person is admitted to palliative care – not just when death is imminent. This involves the development of a care plan to ensure the person's needs, as well as those of their family and carers, are acknowledged in line with their wishes. In Victoria, voluntary assisted dying is available to terminally ill people to choose the timing and manner of their death. The wishes of the terminally ill person need to be respected and supported.

Care plans

Care plans are written documents developed by the palliative care team, the person accessing the service, their family and carers that outline the care needs of the person. A clear and comprehensive care plan ensures that care planning is holistic and meets the person's physical, spiritual, psychological and cultural needs as well as the wishes, needs and expectations of the family.

The care plan outlines:

- the person's care needs determined during an initial assessment
- treatment decisions and choices
- the type of care preferred by the person
- the person's wishes for medical care in the future when they may no longer be able to be involved
- the goals of care at the person's end of life
- strategies and actions (interventions) that are intended to help the person achieve or maintain those goals.

Gather information for the care plan

All members of a care team must read and understand the person's care plan and their role in delivering it. Supervisors advise team members on how the care plan relates to their roles and responsibilities.

The important information to gather when developing the care plan is explained below.

Information for the care plan
The person's personal details; for example, their name, date of birth, gender, values and beliefs, culture, religion, education, likes and dislikes
The person's environment; for example, are they in their own home or in a hospital or hospice?
The person's condition and the symptoms they exhibit
The person's physical needs; for example, a healthcare professional assesses the person's pain and discomfort and describes the appropriate intervention
The person's psychological, social, cultural and religious needs

Information in care plans

Care plans contain information about the person's health, mobility, eating preferences, religion, traditions, and likes and dislikes. They may also contain information about medication, managing the client's pain and any behavioural and safety issues you need to be aware of.

You should report any changes that you notice in your client's mental or physical state that differ from the information in the care plan.

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Develop responsive care plans

The benefits of preparing a detailed advance care plan are to ensure that, when the person is no longer able to make decisions for themselves, they receive the treatment and care they prefer. Advance care planning also relieves the burden of decision-making for the family and carers.

Care plans must be regularly reviewed and discussed with the person, their family and carers, doctors and palliative care team members. This ensures that the wishes of the person, their family and carer are still current.

Care plans must be responsive to the changing needs of the person, their family and carers and the development of the person's illness. How you can assist in developing a responsive care plan is explained below.

Assisting in the development of a responsive care plan

- Have a caring attitude, which involves sensitivity, empathy and compassion, and demonstrate concern for the person and all aspects of their suffering.
- Provide a non-judgmental approach in which personality, ethnic background, ethical considerations, religious beliefs or any other individual factors do not prejudice the delivery of optimal care.
- Take cultural considerations into account, including ethnic, religious and other cultural factors that may have a profound effect on a person's suffering.
- Ensure cultural differences are respected and the care plan is developed in a culturally sensitive manner.
- Ensure effective and sensitive communication between all members of the palliative care team.

Example

Care plan

Here is an example of the structure of a care plan for a person with a life-limiting illness prepared after initial assessment.

Care plan

Client name: Hamish Briggs

Date of birth: 11/08/1931

Gender: Male

Diagnosis: Epilepsy and dementia

Personal details

Hamish is a Scottish male. He is 85 years old and an atheist. He likes listening to blues and jazz music. He also enjoys reading, the outdoors and dancing.

Environment

Hamish has his own room in a residential aged care facility. The family has asked for a cassette recorder so he can play his favourite music. They have also requested a wheelchair because Hamish is almost bedridden. Hamish has a rug knitted by his wife that sits at the side of his bed. He uses this to put over the top of his legs when sitting outside during the day to read a book.

Client's condition

Hamish is withdrawn and has some mental confusion. He shows signs of depression (low mood) and may display disruptive behaviour. He often suffers from a lack of sleep and is sometimes fatigued by the medication he takes to control his epilepsy. The treatment of Hamish's dysphagia is impacted by mild cognitive decline, which results in a loss of appetite. He also has bowel and bladder incontinence.

How to meet the person's physical needs

Hamish is assessed regularly for any pain and discomfort and the appropriate intervention is taken. The appropriate amount of the prescribed medication is provided to manage depression, confusion, insomnia, pain and epilepsy. Medication is also provided for side effects such as vomiting, nausea and diarrhoea. A formulated care plan is available if Hamish has a major seizure. Alternative therapies are also used, such as massaging neck, shoulders and hands with essential oils and listening to music. An appropriate amount of liquid nutrition and hydration is provided four times a day. Rest time has been allocated during the day.

How to meet the person's psychological, social, cultural needs
Contact social worker to organise social contact and volunteers to visit and engage Hamish in social activities such as a book club, bingo, music nights and chat sessions with other people.

Services available
For the person: Support groups, complementary therapies, volunteer groups and social groups

For the family and carers: Social workers, counsellors, funeral services, will services, religious ministers

Reported to (if needed): Registered nurse (RN) and care team supervisor

Worker's name: Amanda Smart

Assessment date: 18 August 2016

Practice task 2

1. List two items of information to include in a care plan.

2. Identify three factors that would influence the care planning activities.

Click to complete Practice task 2

1C Communicate with the person, carers and family to promote quality of life for the person

Quality of life is the general wellbeing of a person and is determined by the person. It includes the physical, social, psychological and spiritual dimensions of a person's life. A person's needs may change, so their care plan must be regularly reviewed and updated. Persons, their family members and carers should be offered information, education, comfort and support across all phases of the life-limiting illness. This includes information to help them understand the person's illness and treatment options, and offering decision-making autonomy according to the person's cultural needs to promote quality of life for the person.

Actively support the person's quality of life

The palliative care team needs to actively participate with the interdisciplinary team, which means communicating with all members of the team, carers and families and the person accessing the services. All members of the team have unique information to contribute to the care of the person and the information will constantly change as the person's needs change.

The palliative care team can actively support quality of life for a person by:

- identifying the person , their family members and carers as the unit of care and providing support for them
- understanding the holistic needs of the person who is approaching the end of their life
- participating in a team approach to address the needs of their families and carers, ensuring a palliative approach
- seeking advice from appropriate people
- understanding that the person's needs may change and that their care plan should be regularly reviewed and updated accordingly
- maximising self-care and self-determination for the person
- assisting in the psychological and spiritual aspects of person care
- recognising symptoms of pain, discomfort and other symptoms
- recognising the signs that death may be imminent
- practising an approach that reflects an understanding of the impact of a palliative approach in an organisation
- maintaining the person's dignity.

Information strategies

People with palliative care needs or their carer/s may tell you they are having trouble with something. They may ask you how they can get help with something. You may be able to assist them through your own service. If not, you need to inform them of where they can obtain further information and support. You may already know of other services that can help or you may need to ask your supervisor.

Here are some strategies for informing people with support needs.

Information strategies

- Print brochures in other languages.
- Print material in large print.
- Record material onto a CD.
- Use an interpreter.
- Explain the information in person.
- Re-write the information so it is easy to understand.
- Ask questions to ensure the information is understood.
- Provide information more than once.
- Answer questions.

Communication and the team

Effective communication with people accessing services and other members of the palliative care team is essential. The team should conduct regular meetings to ensure everyone is aware of the person's current situation and the care provided. This helps reduce any misunderstandings and disagreements. These meetings should also involve the person, their family members and carers, where possible, to allow them to receive current information about the person's status and an opportunity to voice their concerns.

Consider the following to help develop effective communication skills.

Question

Ask the person who they want involved in their support and the level of involvement. Be sensitive to who is considered to be immediate family and next of kin, as friends may play the role of relatives for some people.

Clarify

Clarify who the decision-makers are within the family and who you should share information with; for example, the person, family members or a community representative such as a community elder or religious leader.

Jargon

Understand the communication styles and patterns of interaction within the family and communicate in ways that are appropriate. For example, avoid the use of jargon; speak clearly and in plain English. It is easy to misinterpret information even if a person speaks English fluently.

English as a second language

Do not assume the person, family members or carers understand English, as it may not be their first language. Provide information to culturally and linguistically diverse (CALD) people, their families and carers in their own language by using an interpreter. Do not presume people have low literacy levels or levels of understanding, as making these assumptions may result in a person feeling patronised.

Culture

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.

Values

Be aware of your own values, beliefs, expectations and cultural practices and consider how these may affect how you communicate with people from cultures different from your own.

Grief

Develop communication networks with cultural representatives who can support the palliative care team to identify ways to assist grieving families and to access bereavement support while respecting beliefs and attitudes. Different people and cultures may have different reactions towards death.

Two-way conversation

Ensure everyone understands what you are saying. A one-way conversation where you talk at people, rather than with them, may result in miscommunication or misunderstandings. For example, consent to medical treatment cannot be given unless the person demonstrates they have a clear understanding of what the treatment involves. Rephrase sentences if you think someone may not understand and ask if you can clarify anything for them.

Build relationships with the person, families and carers

You may like to use certain micro skills to build positive relationships to encourage communication with the person, families and carers. Gerard Egan (2002) outlines some micro skills (nonverbal aspects) that have proven successful in building relationships with others. He developed the SOLER theory for active listening; an acronym which stands for the processes to use.

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Here is what SOLER stands for.

S	Sit or stand Squarely to the person – usually at a 5 o'clock position so as not to startle them.
O	Use an Open posture at all times to ensure you do not set up any physical barriers to communication. For example, don't cross your arms.
L	Lean slightly toward the person to show you are interested and engaged in the conversation with them.
E	Maintain appropriate Eye contact. You will need to consider any cultural needs here. For example, you would make less eye contact with an Indigenous Australian person.
R	Take a Relaxed approach. If you are relaxed, then the other person will be as well.

Interpersonal exchanges

A combination of strategies will help you to support the person, family and carer/s to become more empowered, share information and express their needs and preferences. Here are some examples of approaches.

Person-centred

Support workers can promote empowerment by adopting a person-centred approach when they support individuals. This means ensuring the service meets the person's needs. People in receipt of support services have the authority to make decisions about their own lives.

CDC

Consumer-directed care (CDC) enables people to make decisions about their own care. In the past, service providers often made these decisions.

Non-discriminatory

Discrimination means unfairly making decisions based on your own ideas about groups of people. This type of treatment is disempowering. Services and workers cannot discriminate against people in receipt of services. They must treat everyone fairly and equally.

Listen

When you communicate with an individual, one of the most important skills to possess is that of active listening. This will build trust and empathy with the person and their family. Try to ensure the environment has minimal distractions and that you both have time to talk. As a support worker, you must learn to listen not just with your ears but also with your eyes and with your heart. Remember, people with care needs have a long history of not being heard. To hear what they are saying, you need to put your own opinions aside and see things through their eyes.

Here are some strategies to keep in mind when listening to others.

Listening strategies

- Face the person you are listening to, if it is culturally acceptable.
- Observe their body language.
- Be patient and don't interrupt.
- Don't finish their sentences for them.
- Don't 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 don't understand.
- Give information based on fact. Don't give opinions.

Example

Use effective communication skills

Jay's mother lives in a residential facility and is dying. Jay lives 40 kilometres away. He has a young family, a supportive wife and works full time. Since Jay's mother has lived in the residential facility, Jay's frail father, Sam, has had to live with Jay and his family. Jay is worried about his wife taking on the additional responsibility of caring for his father. Jay visits his mother daily and the burden of caring for his mother and father is becoming difficult for him to manage. Jay is also struggling to keep up with the heavy demands of his job. Jay confides in Lydia, the palliative care worker, that his father is very demanding and difficult to care for and that his mother has always done everything for him.

Lydia acknowledges the emotional and physical burden on Jay of caring for his dying mother and frail father by listening and responding in a sensitive manner.

Lydia offers Jay help by suggesting that she arrange a meeting with a home care nurse to advise him on how to care for his father, including considering home care.

Lydia also suggests that Jay meets with a counsellor from the hospital to discuss strategies to keep up with the heavy demands of his job, his concerns about his wife being left with his frail father at home and looking after his dying mother.

Practice task 3

1. What does SOLER stand for?

2. State three actions that assist with effective listening.

Click to complete Practice task 3

1D

Demonstrate respect and include the family and carer as an integral part of the care team

It is likely that the person accessing palliative care will also be receiving support from others. This can include service providers, family members, neighbours, church groups and people in the person's networks. It is important that supports are well coordinated and that all of those providing support, work together to ensure the person receives the best care possible. The person's personal care support plan or assessment information will have the information about the level of support required. You need to be clear about your responsibilities and who is responsible for additional support and services.

Here is further information explaining a coordinated approach.

Family or neighbours

The person may have a spouse, family member or a primary carer who lives with them, or visits and provides some support. They may have lived in the area for many years and have a relationship with a neighbour who also pops in to assist where they can.

Service providers

Other services may provide a range of support. For example, district nursing might attend to dress wounds; home support services might come once a week to do some house work; delivered meals might come from Monday to Friday.

Networks

The person may have people who pop in to assist them from time to time, who have been a part of their network for many years. For example, RSL members, people from the same church, ex-sporting or service groups.

Community programs

Some people might attend or participate in a range of activities in the community. They may have either an informal support person such as a friend or a formal support person who is paid to attend with them.

The family and carer: an integral part of the care team

When a person is receiving palliative care there must be a coordinated team effort between healthcare professionals, palliative care workers, the person, family members and carers. In many instances, the palliative care worker spends as much time with the carer as they do with the person.

How respect for the relationship between the person and carer can be demonstrated is explained below.

Respect the carer

Carers are the people who often know the person best. The relationship between a person and their carer is very important and must be respected and may be even closer if the carer is a family member. Therefore, any suggestions they make about the person's preferences and needs are valuable insights. Remember to always address both the person and the carer when speaking – it's rude to exclude the person, even if their understanding is limited. Also, make sure the carer knows that you recognise their role and position.

Support the carer

A palliative care worker's job is to provide support, answer questions, provide information and make the often-difficult situation easier for everyone. You must never do anything that may cause a disagreement between the person and their carer. Coping with end-of-life issues is very emotional for everyone and each person must be allowed to show and share their grief, anger and sadness. You should also appreciate that the carer may be physically and emotionally exhausted due to the bond they share with the person, so be sensitive to their needs. You should also respect that both the carer and the person have the right to privacy.

Provide time alone

There may be times when the carer and person want to be together without you. Show respect and sensitivity by giving them time alone. The relationship between the person and the carer may vary in different cultures. Make sure you understand the various relationships. For example, for a person of Hindu faith, medical information is usually communicated to the head of the family first (Palliative Care Australia 1999).

Example

Demonstrate respect for family members

Martha always appears distant and withdrawn on the infrequent visits to her husband Stephen, who is dying. The palliative care team wants to involve Martha by encouraging her to visit more often and to assist with his care. Martha feels there is an expectation placed upon her. She explains the situation to Jo, the palliative care worker, because she trusts her. 'I know I may seem uncaring but I'm exhausted from looking after him 24 hours a day at home. I just can't do it anymore. I haven't been close with Stephen for many years and I find it such a relief to have some life of my own at last. I appreciate all the care you are giving him.'

Martha feels supported by her husband's care team and Jo respects that this is how Martha is feeling. When this explanation is conveyed to other members of the palliative care team, it reinforces the importance of communicating with family members.

Practice task 4

1. How can the personal care worker support the carer?

2. Explain the role of other services in providing palliative care support.

Click to complete Practice task 4

Summary

1. Palliative care can be described as the specialised care of people who are dying.
2. Palliative care provides people with relief and comfort when there is no cure for their illness, and measures to extend the person's life are discontinued.
3. A person receiving palliative care has an active, progressive and far-advanced disease with no prospect of cure.
4. Palliative care enhances the person's quality of life and may also positively influence the course of illness, by treating pain and physical, psychological, social and spiritual problems in a holistic manner.
5. The pattern of care for individual persons may differ. Factors that influence a person's pattern of care include where the person lives, the services in their area, their specific needs, beliefs, values, spirituality and culture and the needs and desires of their family members and friends.
6. Care plans are written documents developed by the palliative care team, the person, their family and carers that outline the care needs of the person.
7. Communication between all members of the team is essential for providing support, pain relief and comfort to persons accessing the service.
8. The family and carer are essential parts of the care team and require accurate information and support.

Learning checkpoint 1

Apply principles and aims of a palliative approach when supporting individuals

This learning checkpoint allows you to review your skills and knowledge in applying the principles and aims of a palliative approach when supporting individuals.

Part A

1. What are the aims of palliative care?

2. What are the principles of palliative care?

3. What are the needs of people accessing palliative care services?

4. What are the philosophies of palliative care?

5. When should palliative care services be accessed by a person?

6. What does holistic care mean?

7. Why is communication important between all members of the palliative care team?

8. What people comprise the palliative care team?

9. What is the difference between curative and palliative approaches to care?

Part B

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

Case study

Martha always appears distant and withdrawn on the infrequent visits to her husband Stephen, who is dying. The palliative care team wants to involve Martha by encouraging her to visit more often and to assist with his care. Martha feels there is an expectation placed upon her. She explains the situation to Jo, the palliative care worker, because she trusts her. ‘I know I may seem uncaring but I’m exhausted from looking after him 24 hours a day at home. I just can’t do it anymore. I haven’t been close with Stephen for many years and I find it such a relief to have some life of my own at last. I appreciate all the care you are giving him.’

Martha feels supported by her husband’s care team and Jo respects that this is how Martha is feeling. When this explanation is conveyed to other members of the palliative care team, it reinforces the importance of communicating with family members.

1. How does communication assist in the care planning approach in this example?

2. Where should the personal support worker document this information?

Topic 2

In this topic you will learn how to:

- **2A** **Encourage the person, carers and family members and/or significant others to share information**
- **2B** **Use a non-judgmental approach to support the person's lifestyle, social, spiritual and cultural needs**
- **2C** **Support a person's rights to openly discuss spiritual and cultural issues**
- **2D** **Identify needs and issues outside your scope and refer to supervisor when necessary**
- **2E** **Use effective communication skills to provide emotional support and empathy**

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

A person's care plan gives them the opportunity to maintain control over their lives. In the plan they communicate their wishes for their care and support, as well as their spiritual, cultural and social needs. It also gives them the opportunity to indicate how they want to involve their family and carers.

As a palliative care worker, you must follow the care plan the team has implemented, seek the person's views regarding their care decisions and listen to and respect their values, goals and beliefs. It is important not to judge the person or family or carer's views and behaviour, but instead be approachable and caring. To provide holistic care, it is necessary to encourage others to share information, respect the person's needs and cultural choices and support the person's right to discuss spiritual and cultural issues.

2A Encourage the person, carers and family members and/or significant others to share information

The person accessing the service and the people who are closest to them are the ones who best understand the person's needs and preferences. They should be encouraged to share all the information they have to ensure the person's care plan remains current.

Having a supportive network of family and friends is an important part of coping with a life-limiting illness. However, family members and carers may also require support as they deal with their grief and understanding of the situation. It is your job to provide the support they need.

Share information

A key responsibility for a palliative care worker is to build a good working relationship with a person accessing the service's unit of care, so information is willingly shared when the person's needs, preferences or condition changes. This ensures the best and most appropriate care is provided. To do this, the palliative care worker should establish and maintain a supportive environment that is comfortable and non-threatening, and where people are willing to listen and share ideas.

People are more likely to share information if they know they will be listened to and their opinions acted upon. It may be difficult having conversations about prognosis and end-of-life decisions with people who have life-limiting illnesses and their families. Some families may be unable or unwilling to share information and provide support; it may be against their culture or there may be family disputes that have not been settled. Ask your supervisor for guidance when communicating with these people.

Effective communication about end-of-life issues is a vital skill for healthcare professionals caring for people with progressive life-limiting illnesses and when dealing with their families and carers. Some of the valued qualities of communication are honesty, empathy and a willingness to talk about end-of-life concerns. Honest and open communication between the palliative care team and the person can calm the person, increase the person's satisfaction and assist them to make decisions and plan for the future.

Examples of organisational mechanisms for encouraging sharing of information include:

- making sure family members know they can telephone a team member whenever they need to
- organising a family conference to facilitate support and information exchange and to help reduce loneliness, loss and social isolation
- working with an advocate if a family is unwilling to share information and provide supports.

Encourage a supportive environment

All members of the palliative care team should monitor the emotional wellbeing and health of family members and carers and provide support when necessary. Support may include providing a comfortable, non-threatening environment, listening, showing empathy and allowing family members and carers to share ideas with you and other members of the palliative care team.

You should be able to provide family members with advice and information about the progression of the person's illness and the dying process, including social, emotional, cultural, spiritual and physical issues. This may be in the form of leaflets or brochures, which are valuable communication tools that can help to ease fears felt by the family members and carers, and generate questions and discussion.

Below are some key strategies for providing emotional support.

Providing emotional support
Acknowledge the emotional and physical burden on individual family members caring for a dying person.
Recognise and allow for different methods of coping between individual family members and carers.
Allow family members the opportunity and privacy to express their concerns and the difficulties they are experiencing.
Provide reassurance if family members are feeling guilty about issues that may include relationship issues such as wanting it to be all over; not wanting to be at the person's bedside all the time.

Empowerment

As a professional in the community services sector, you will work using an empowerment approach to support people. Empowerment refers to a state that people arrive at, which sees them take control of their own lives. A large number of people in receipt of support services are often vulnerable because of their care needs and the myths and stereotyping that occurs.

If your focus is to provide information, resources and support to assist people to build capacity, gain confidence and take control of their lives, then you will always be working to uphold people's rights through an empowerment approach.

The care worker can use this empowerment approach by utilising empathy and support in their communication with carers, families and the person accessing palliative care. When communicating with others, ensure that you show empathy through using terms such as 'I can see' or 'it sounds like..' and reflecting back the content of the message. Listen without interrupting and have the conversation in an area free from interruptions and distractions and allow adequate time for the conversation.

Reflect on your practice

- If you are the person making all the decisions, you will need to check your approach to your work.

Empathise

- Think about how you would want to be treated if you were in a role reversal with the person you support. Would you want people providing support in ways that stripped you of your dignity and personal control over your own life? If you answer 'no' then think about how you can change your practice. You can demonstrate empathy by listening without interrupting, being supportive and being available.

Find a mentor

- Talk to your supervisor and ask them to mentor you to build the skills to work from an empowerment model. Make a meeting time to meet regularly with your supervisor to discuss how you handled situations. Be honest – especially with yourself.

Supportive communication

- Use empathy to show you understand how the person is feeling. Give feedback and clarify the information to the person to show you are trying to understand their problems.

Gather information from the person accessing the service

People accessing the service may reside in their own homes or in a hospital setting; they may be frail older people residing in their own homes or in residential care. Or they may be adults with a disability, mental illness or chronic condition. The people you provide support to will have their own likes, dislikes, preferences and needs regarding their end-of-life care. They have the legal right to be offered appropriate and accurate information so they can make their own choices, accept or refuse treatment and/or appoint someone to speak on their behalf.

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 a person to respond. To assist, ask questions, give them time to answer and record what they tell you. Make sure the person is not in any pain or discomfort when you are speaking with them. Let them know that what they say will remain private.

The person's needs may change, so it is important their preferences are regularly reviewed. If the person is unable to express their feelings or finds it too emotional, information may be sourced from family members, carers and significant others.

Here is information the care team needs to know.

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 is accessing the Victorian voluntary assisted dying process
- The type of funeral they want

Record information

When you record information, you should:

- be factual
- be accurate
- be clear
- be brief but be complete
- follow organisational requirements
- check what you have written.

You will also need to store information, either manually or on a computer system.

Information must be kept safe and you are bound by law to keep client information private and confidential.

Always read, understand and follow your procedures, particularly OHS and emergency procedures. Ask for help if there is anything you don't understand. If you are working in a person's home, you should call your supervisor.

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Gather information from carers

People who provide care and support to those with life-limiting illnesses are referred to as carers. They may be parents, partners, grandparents, siblings, friends, neighbours or children. They may also be a person with no family connection to the client, who is appointed by an agency.

Carers play a significant role in palliative care and are an important link between the person accessing the service they are caring for and the palliative care team.

Carers are an important source of current information. They can tell when the person's mood changes, if they dislike a new treatment or if their condition deteriorates.

It is important for a palliative care worker to build a good relationship with the carer. Let them know you understand the importance of their role and the care they are providing. Use your communication skills and body language to provide support, encouragement and assistance when necessary.

Information the carer is likely to know:

- How the person may respond, think and feel in certain situations
- The person's emotional status
- The person's allergies and reactions to certain medications or foods
- The person's preferences regarding personal comfort, pain relief and treatment options
- The person's wishes about options of care at home, hospital or hospice
- The nature and type of support required

Gather information from family members

A family member is any person who is part of the central support network of a person requiring palliative care. A support network provides emotional, psychological and practical care needs. This description extends the boundaries beyond biological and legal relationships; therefore, a person considered as family by a person accessing palliative care may not be a relation by birth or marriage.

Family includes:

- the biological family; for example, parents, sons, daughters, uncles, aunts, grandparents
- the family people acquire through marriage or a contract; for example, a husband or wife (spouse), de facto partners, parents-in-law, brothers-in-law, and so on
- the family of choice and friends who are not related biologically or by marriage; for example; close friends, neighbours, carers
- the palliative care team; for example, when a person has no immediate family.

Information family members can provide

Each family member is able to provide important information about the person's changing needs and preferences. In a palliative approach, family members should be actively involved in all aspects of the person's care.

Family members appreciate good communication and knowing their input is valued. Family conferences provide emotional support to family members and carers and also an opportunity to discuss concerns about the person's life-limiting illness. Such organised meetings benefit the family and carers in that any information gained may be used to significantly improve the person's quality of life.

You can develop trust and build partnerships by:

- asking family members to let you know whenever the person's needs or preferences change
- listening and acting on family members' opinions, complaints and suggestions
- encouraging family members to speak about how they feel so you can help prepare them for the person's death
- providing privacy so they can speak to you in confidence.

Gather information from enduring powers of attorney

When a person is appointed an enduring power of attorney, the person gives them the power to make decisions on their behalf regarding financial, medical treatment or guardianship matters. The term 'enduring' means the power continues even when the person is no longer able to make decisions on their own behalf. A person can only appoint an attorney if they are over 18 years of age and able to demonstrate capacity to make the appointment.

In Australia, medical service cannot be provided without the consent of the person concerned. Below is an explanation of what informed consent is and what occurs when a person's capacity to consent is impaired.

Informed consent

Consent is considered informed consent when the person agrees to a treatment:

- without duress
- voluntarily provides their consent after a reasonable time
- has been provided with adequate information to give consent.

Capacity impaired

A person's capacity to consent may be impaired, for example, by a serious illness. If a family member has been granted a legal right to make decisions for the person, then the legal document stating this must be sighted by a member of the palliative care team and its powers and limitations noted on the client's record. The palliative care team is then directed by this document. As legislation regarding the responsibilities of those authorised by the person to make decisions on their behalf may vary, it is the responsibility of each palliative care team to check legal requirements.

Gather information from guardians

A guardian is a person appointed to make personal, lifestyle and healthcare decisions for someone with impaired capacity.

A person who is providing the person with professional care, treatment or accommodation cannot be appointed the role of the guardian.

The role of the guardian should be interpreted according to individual state and territory legislation or guidelines on the definition of a guardian, as they differ between states. For example, in Victoria the relevant legislation is the *Guardianship and Administration Act 1986* (Vic) and, in South Australia, the *Guardianship and Administration Act 1993* (SA). Your supervisor will explain your responsibilities when working with a guardian.

When making decisions on behalf of a person, a guardian must:

- take into account any wishes the person has expressed
- act in the person's best interests
- make the same decision the person would have made, where possible.

Gather information from advocates

An advocate is a person who speaks, argues or stands up for the needs, rights and opinions of another. An advocate may be a family member or someone appointed by an advocacy service when a person is no longer able to make informed decisions. Enduring powers of attorney, guardians and advocates should be able to provide the care team with information on behalf of the person. As part of your role, you may be present at meetings they attend or have access to documents that describe their legal powers. Make sure you know which persons you are providing care for have a power of attorney, guardian or advocate. Ask your supervisor if you are unsure.

Example

Provide emotional support and understanding to a family member

The nursing home is holding a dance for residents and family members. Doreen and Alice are sitting together with their husbands who are too ill and frail to join in the dancing. The women sit away from the dancing, both with sad looks on their faces. It is obvious to Aldo, one of the palliative care workers, why the women are sad. They're both in their early 70s, they visit their husbands every day and return to their empty homes late every afternoon. They are both experiencing the emotional impact of pre-widowhood. Aldo sits down next to Doreen and asks her about dancing and her favourite music. He encourages her to talk about how she feels. Doreen tells him she has not been to a social outing, especially a dance, since her husband was admitted to the nursing home six months ago. She tells Aldo she really misses dancing with her husband and the opportunity of dressing up and going out together.

Aldo links his arms with Doreen and they begin to dance. At first Doreen feels quite nervous and keeps looking over to her husband because she feels guilty. Aldo reassures her that it is all right and gestures to her husband who is watching them both and clapping. Doreen, flushed with excitement and stimulated by her memories, says to Aldo, 'Do you know, Albert and I used to go dancing every Saturday night. Since my husband's stroke, we haven't even been able to embrace. I think this is the first time anyone has put their arms around me for a very long time. Thank you so much.'

Practice task 5

1. List four different types of family structure or support for the person accessing services.

2. What information is a carer likely to know about a person accessing services?

Click to complete Practice task 5

2B Use a non-judgmental approach to support the person's lifestyle, social, spiritual and cultural needs

Everyone has a right to the best quality care. This means a person's needs, likes, dislikes and preferences in regard to their lifestyle social activities, as well as their spiritual and cultural needs, are taken into account when planning their treatment. These aspects should be discussed during the person's initial assessment and outlined in their care plan. It is important that all members of the healthcare team follow these directives and respect the person's preferences.

Everyone has the expectation that they will be respected and is able to contribute to their decisions that affect their care and level or type of support as required. It is a responsibility of the healthcare worker to assist a person to know their rights and assist them to exercise them if required. It is a legal requirement that people are not discriminated against according to their health and they should understand they have the right to complain if they are not satisfied with the support they receive or any other matter that they feel is discriminatory.

Understand people's rights

Palliative care services support people with end-of-life care. The person accessing palliative care is the best person to tell you what services they need and want. If they are unable to do this themselves, they may have a guardian or advocate protecting their rights and ensuring services best meet their needs.

People accessing palliative care services have the right to participate in and give their opinions on their care. Organisational policies and procedures should promote empowerment and involvement. Organisational guidelines should state that the person must be consulted and involved in service provision. Their opinions can influence the services that they use. Their ability to take responsibility for and control of their life is also central to their quality of life; there are many rights that all people, including people with end-of-life illnesses, have.

Some of these rights include the right to:

- receive accurate and easy-to-understand information
- make decisions when possible
- access relevant services
- be free from discrimination
- be treated as an equal and with respect
- participate in their own care
- confidentiality
- to make a complaint and appeal decisions.

Human rights of people in palliative care

People who access the services of palliative care hold the same rights as any other individual in society. These rights extend through the end-of-life experience and also after death.

Human rights recognise the value of every person, regardless of background, where we live, what we look like, what we think or what we believe. They are based on principles of equality and respect, shared across cultures, religions and philosophies. They are about being treated fairly, treating others fairly and having the ability to make genuine choices in our daily lives. Respect for human rights underpins the values and principles of the palliative care sector and should be applied by all workers when supporting people with end-of-life illnesses. It allows all people to contribute to society and feel included.

In Victoria, the *Voluntary Assisted Dying Act 2017* provides a legal framework for people who face an inevitable, imminent death as a result of an incurable disease, illness or medical condition. The law allows medical practitioners to administer medication to end the person's life at a time of their choosing. The process ensures the person's decision is voluntary and enduring, and provides clear guidance for how medical practitioners can lawfully support the person in their choice.

The Australian Government supports and respects many of the Universal Declaration of Human Rights developed after World War by the United Nations. These include the following.

Human rights treaties supported by Australia
International Covenant on Civil and Political Rights
International Covenant on Economic, Social and Cultural Rights
Convention on the Elimination of All Forms of Racial Discrimination
Convention on the Elimination of All Forms of Discrimination against Women
Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
Convention on the Rights of the Child
Convention on the Rights of Persons with Disabilities

Understand different needs

Each person accessing the service has different needs relating to:

- lifestyle
- social activities
- spiritual needs.

The way a person wants to live must be respected and their preferences considered when delivering their care. A person's lifestyle includes personal supports and relationships, sexuality and intimacy supports, emotional supports, and legal and financial supports.

Personal supports and relationship needs

A palliative approach takes into account the person's social needs. This includes the personal supports required and how the person's relationships with others can be maintained. The care and support needs of the person's family are best identified after you have developed an idea of the type of family, the relationships and patterns of relationships within the family unit. For example, society today is made up of:

- families consisting of husband, wife and children
- de facto families
- families with a same-sex couple
- families with different belief and value systems
- culturally diverse families
- mixed families.

Social interaction, continuing personal contact and having a strong support network is essential. A lack of social support may lead to depression, social isolation, loneliness and diminished (decreased) functional health. Therefore, the healthcare team needs to assess the person's social network and the contacts the person wants to continue. New social relationships should be established if this is in the best interests of the person accessing the service. A social worker, pastoral care worker or a volunteer may help to ensure the person's social support needs are addressed.

Personal and relationship needs

The person's care plan details the lifestyle the person accessing the service follows, the closest family member and the friends and social networks that have been established over the years. It should also describe the most appropriate way of communicating with the person and their family.

Communicating with a person's family about their relationships may help you identify a key family member through whom you can communicate with the extended family. For example, within some Indigenous communities, the identified next of kin may not be the person who makes the decisions regarding their care; this may be the role of an elder. Another example may be a family situation where one family member has medical or nursing experience and recognised expertise by the family; for example, the daughter may be a doctor or the daughter-in-law a nurse. Families may rely on a family member for information, direction, interpretation of medical information and support in decision-making.

Some people accessing the service may have withdrawn from social contact. To provide appropriate care, the team may need to work through the reasons why this has occurred.

Here are some factors that may influence a person's social contact, and strategies the care team can use to ensure the person's lifestyle is maintained and their dignity respected.

Factors that influence a person's social contact

- Their appearance, which may be caused by symptoms or medication
- Their condition/s seeming socially unacceptable, such as incontinence
- Their behaviour being affected by their condition, such as dementia
- Their location; for example, they may be too far away for friends to visit
- Communication barriers, which may be a result of their condition or if English is their second language
- Losses they have recently suffered, such as the death of a spouse

Strategies the care team can use to maintain a person's lifestyle

- Discuss the situation in a non-judgmental manner with the family and gain their support.
- Talk to the person's friends in a non-judgmental manner so they understand the person's feelings.
- Prepare a plan to help the person maintain their social contacts.
- Ensure access to family members and friends is maintained and supported.
- Respect and not judge the person's choice of friends.
- Respect and not judge the person's decision not to see people.
- Arrange for volunteer visits if the person is isolated from friends through distance.
- Organise social workers and others to develop social contacts.

Support the person's sexuality and intimacy needs

Intimacy and sexuality issues may be neglected in discussions about the wellbeing of people receiving a palliative approach. It is important that a person's sexuality is still considered as they age. A person's ability to express their sexuality and have this need recognised with understanding and care is an important factor in enhancing their wellbeing. Palliative care workers must be non-judgmental and able to acknowledge and discuss the person's sexuality issues.

Understanding the significance of touch (personal body contact) is important for both workers and the person. Often the person accessing the service may experience touch through routine procedures connected with their medical treatment; therefore, they may perceive touch in a negative way, especially when associated with pain or discomfort.

The use of comfort touch, such as massages and hand-holding, may enhance a person's sense of wellbeing and self-regard, improve communication between the worker and the person and decrease the person's levels of pain.

Access to massage therapists may also help to meet a person's need for caring and gentle touch, and family members and carers may also be able to fulfil this role.

Support the person's emotional needs

Supporting emotional needs is also important. Family members and carers often struggle to deal with their emotions when caring for a person with a life-limiting illness.

Members of the palliative care team may help a family's emotional needs by following these guidelines.

How to support a family's emotional needs

- Treat each family member and carer with respect; acknowledge their feelings and their approach to the situation in a non-judgmental manner.
- Provide clear, simple and honest information.
- Provide reassurance about the care and practical issues.
- Provide family members with the opportunity to be involved in care and to share their ideas.
- Ensure family members and carers have a clear understanding of the client's condition.
- Identify family members who may need support; for example, from support-group meetings.
- Provide pamphlets about grief and bereavement counselling.

Financial and legal supports

A person's financial situation often plays a major part in their ability to maintain their lifestyle. One responsibility of the care team is to advise the person accessing the service and their family to organise the person's financial affairs, ensure a will is prepared and arrange for a power of attorney if necessary.

Support the social needs of the person

People may have hobbies, interests and activities they have pursued during their lives, either within a social group or individually. People accessing the service should be encouraged to continue these social activities as long as possible, as this may help them maintain their quality of life and contribute to their emotional and physical wellbeing.

A person's ability to participate in social activities may be affected by the physical effects of their symptoms, the treatment provided for pain relief and the loss of some functions. Some people may not want to participate in what they consider activities of their previous life (when they were well).

Activities may be particularly beneficial to a new resident who is having trouble adjusting to their new environment or to someone who is experiencing difficulty getting along with people they don't know. If a person is living at home, their family should be encouraged to help them continue with any activities, hobbies and social activities they feel comfortable with.

Social activities may include:

- physical activities such as carpet bowls or handball
- group activities such as singing, drawing, beauty therapy sessions, bingo nights or walking
- special events such as music recitals, food events and visiting-expert programs
- chores such as simple housekeeping tasks including gardening, sweeping, vacuuming, folding clothes
- other activities to assist the person (especially those with dementia) to feel useful
- outings such as visiting shopping centres, a restaurant or an attraction such as a museum, zoo or art exhibition.

Support spiritual needs of the person and family

Spirituality relates to an inner sense of something greater than oneself, which may be met through faith or religion. When working with a person facing a life-limiting illness and their family, you must understand the role spirituality and religion plays in their life. For many cultural groups, it is the foundation of their existence. Some people may refuse treatment based on their religion. A person's spiritual beliefs often become very important when they have a life-limiting illness.

For example, when facing a life-limiting illness or the possible death of a family member or friend, religious practices, rituals and beliefs may become very important to the person, their family members and carers. Turning to spirituality is a common coping mechanism that can have a positive effect. It may help a person come to terms with their condition, feel content with their life, be able to close their affairs, feel they have control over their life or to regain a positive outlook.

Provide spiritual care

Spiritual care involves sensitive listening rather than providing answers. Spiritual care involves being aware of the feelings the client may experience at the end of their life, listening to the client and providing a healing and peaceful atmosphere. You may want to ask questions to learn more about the person you are supporting and their beliefs. Palliative care workers must never impose their own views.

A person's spiritual needs must also be documented in their care plan and not left to the end-of-life period. All team members should be familiar with the person's beliefs and requirements and understand their level of responsibility and the tasks they must carry out to meet the person's spiritual needs.

Palliative care workers should have an understanding of the rituals that are important in cultures other than their own. Here are some ways that you can support a person's spiritual needs.

Supporting a person's spiritual needs

- Allow the person to guide all spiritual interventions.
- Provide a supportive presence and avoid judgment.
- Coordinate spiritual services and people; for example, arrange access to chaplains or pastoral care workers, family, carers and friends as requested by the person.
- Ensure access to spiritual activities such as prayer times, Bible study and worship ceremonies.
- Obtain requested items for spiritual practice such as books, rosaries, statues.
- Avoid interrupting a person during spiritual activities.
- Help people accessing the service to celebrate specific religious events such as Ramadan, Good Friday or Rosh Hashanah.
- Encourage any pre-death rituals the client may wish to follow.
- Follow spiritual beliefs in regard to medical treatment; for example, some beliefs may forbid a blood transfusion.

Learn about other cultures

Understanding other cultures, what culture means to a dying person and how cultural issues impact palliative care are essential skills of a palliative care worker.

Many people have limited knowledge of other cultures and customs. If this is the case, a worker should acknowledge this and seek to learn more. This ensures workers respect the cultural beliefs of the people they are supporting and don't cause offence. Palliative care workers must be sensitive of the language and words they use when dealing with culturally diverse people.

Information about other cultures may be available from family members and from pamphlets and brochures published by cultural groups. Remember, these are general guidelines and everyone is different, so ensure the specific needs of each person and their family are understood.

Respect cultural choices

Australia is made up of many cultural groups; the diversity of customs, rituals and values from other cultures adds richness to our community. Palliative care workers must ensure they are sensitive to, and respect, customs that are different from their own. They must understand the concept of death and dying in other cultures and know how these cultures deal with this process. The concept of family may also mean different things to different cultures.

Cultural beliefs provide a structured pattern of behaviour and may also provide comfort. These beliefs are very important at the time of death, when people must cope with strong feelings of loss and confront their own mortality (death). At their initial assessment, the person may make choices for their care and treatment based on their cultural beliefs. These are recorded in their care plan, which is assessed by all members of the palliative care team.

Examples of how a person's culture may influence their choices and care are provided below.

Clothing

A person may need to wear:

- a headscarf to cover parts of their face
- black clothing if a family member has died
- a yarmulke (a skullcap worn by Jewish males)

Food and drink

- Hindus must not eat beef.
- Muslims fast during daylight hours during the month of Ramadan.
- Some cultures forbid alcohol consumption.

Language, body language and forms of address

- A person wants to speak in their first language and asks for the services of an interpreter.
- An interpreter may need to be a certain gender or age.
- In some cultures, it is disrespectful to look a person in the eye; in other cultures the opposite is true and it is polite to maintain eye contact when you are having a conversation.
- In some cultures, people must not stand too close to another person.
- A person may want you to call them by their surname and their title; for example, Mr Gates.

Rituals

- The person may ask to:
  - read religious texts
  - meditate
  - pray at specific times
  - receive a blessing
  - celebrate a religious or cultural festival.

Personal grooming

- Muslim women must only receive personal care assistance from female workers.

Treatment of deceased people

- Indigenous Australians do not speak the name of the deceased person for a certain period of time.
- Islam forbids autopsy and cremation.

Record observations

The *Guidelines for a palliative approach in residential aged care* (NHMRC 2006) recommends that all steps regarding a person's preferences for their care or treatment must be documented. These preferences should be regularly assessed to ensure they are still current. For example, a person may no longer want to participate in a social activity or decide that they do want to undergo a specific treatment after all. Care plans should be reviewed in accordance with the organisation's policy or when:

- the person experiences a change in their health condition; for example, an acute (brief and severe) episode of illness or a change to their chronic condition
- the family and/or carers request a case conference to review the person's care plan
- there is a change in the person's situation, such as the death of a spouse
- the person is transferred either into or from a palliative care environment.

Record case notes

Case notes can be recorded manually or electronically.

Case notes should:

- include on each page the name and DOB or other identifying information of the client. This can be handwritten, typed or constitute an electronic tag where an electronic case recording program is utilised.
- be dated
- be recorded as soon as possible after an interaction or event
- be typed or clearly readable if handwritten
- include the name, signature and profession/role of the author
- include the time of contact, particularly where there is a high volume of interactions in a day.

Guidelines for case notes

Here are some things to keep in mind when recording case notes.

Standards for documentation

- Be clear and accurate.
- Ensure notes are legible and in English.
- Use approved abbreviations and symbols.
- Time of entry (using a 24-hour clock – hhmm) and Date of entry (using ddmmyy or ddmmyyyy).

Recording material

Write in dark ink that is readily reproducible, legible, and difficult to erase and write over for paper-based records.

Signing of notes

- Make sure notes are signed by the author, and include their printed name and designation. In a computerised system, this will require the use of an appropriate identification system; for example, electronic signature
- Entries by students involved in the care and treatment of a patient/client must be co-signed by the student's supervising clinician.
- Entries by different professional groups are integrated; that is, there are not separate sections for each professional group.

Inclusion in notes

Be accurate statements of clinical interactions between the patient/client and their significant others, and the health service relating to assessment; diagnosis; care planning; management/care/treatment/services provided and response/outcomes; professional advice sought and provided; observation/s taken and results.

Format of notes

- Distinguish between what was observed or performed, what was reported by others as happening and/or professional opinion.
- Ensure that notes are made at the time of an event or as soon as possible afterwards. The time of writing must be distinguished from the time of an incident, event or observation being reported.
- Ensure that notes are sequential – where lines are left between entries, they must be ruled across to indicate they are not left for later entries and to reflect the sequential and contemporaneous nature of all entries.

Relevance of notes

- Be sufficiently clear, structured and detailed to enable other members of the healthcare team to assume care of the patient/client or to provide ongoing service at any time.
- Write in an objective way and do not include demeaning or derogatory remarks.
- Be relevant to that patient/client.
- Only include personal information about other people when relevant and necessary for the care and treatment of the patient/client.

Addendum

If an entry omits details, any additional details must be documented next to the heading 'Addendum', including the date and time of the omitted event and the date and time of the addendum. For hard-copy records, addendums must be appropriately integrated within the record and not documented on additional papers and/or attached to existing forms.

Written in error

No alteration and correction of records is to render information in the records illegible. An original incorrect entry must remain readable. Do not overwrite incorrect entries and do not use correction fluid. An accepted method of correction is to draw a line through the incorrect entry or 'strikethrough' text in electronic records; document 'written in error', followed by the author's printed name, signature, designation and date/time of correction. For electronic records the history of audited changes must be retained and the replacement note linked to the note flagged as 'written in error'. This provides the viewer with both the erroneous record and the corrected record.

Example

Consider culture when caring for a person accessing palliative care services

Greek culture

- Family, friends and relatives play a very important role in the care of a dying person within the Greek culture. Therefore, the home is preferred to the hospital as the place of treatment.
- The wife of a dying husband should be directly involved in the care of her husband, as this fulfils her sense of duty and obligation.
- Many Greek families, relatives and friends may wish to protect the dying person by preventing them from knowing their diagnosis and prognosis. They believe the person dying may give up hope and lose the will to fight.

- Terms such as 'that terrible illness' or the 'situation' may be used to avoid directly speaking about specific conditions.
- In the Greek culture, it is acceptable to display strong emotional reactions.
- For some people there is a strong fear of using morphine as it is associated with death.
- The role of the church is very important. The Greek Orthodox Church guides the behaviour of people in bereavement and certain 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 attire
  - holding a vigil in the funeral parlour where the body is 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.

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

Practice task 6

1. Explain the concept of spirituality.

2. List three rights of a person accessing services.

3. When should a care plan be reviewed? Give two examples.

Click to complete Practice task 6

2C Support a person's rights to openly discuss spiritual and cultural issues

The issues of spirituality and culture may be very important to a person with a life-limiting illness or those who are at the end of their life. One of the responsibilities of a palliative care worker is to encourage people to talk openly about their spiritual and cultural needs. This must be done in a sensitive, non-judgmental way. It is also important that it occurs within the level of the worker's authority and skills.

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 turned His back on them
- wanting to know how to make amends for things they have done in their life
- wanting to know if there is life after death
- wanting to know what will happen to their body after death.

A palliative care worker's responsibilities

A palliative care worker must be approachable and comfortable with talking to the people accessing the service and their families about their spiritual and cultural needs. This is often a very sensitive area. Some workers may find it difficult if they don't know the person well or if they don't hold the same beliefs and values. With understanding and good communication skills, workers can learn to handle this part of their job role well.

Here are some tips about communicating.

Tips for communicating about spiritual and cultural needs

- Encourage the person or family member to speak to you. Respect their fears and anxiety. Let them know you are willing to listen.
- Always respond to the person's questions regarding spiritual needs in an open, non-judgmental manner.
- Learn about the person's current or desired practices, attitudes, experiences and beliefs.
- Arrange for the person to see a pastoral care worker with experience and knowledge of spiritual issues.
- Ask the person about any personal items in their room that identify their culture.
- Help the person talk about what they have done in their life.
- Ensure that the person knows that everything they say will remain confidential.

Example

Care note for a client’s communication about spiritual and cultural issues

Care note

Name: Marjory Clements

DOB: 27/07/1938

Date: 23 October 2016

Time: 11.00 am

Comments:
When asked about religion, Marjory has always responded nil. She has said, ‘I’ve never been interested and it’s too late to change now!’ However, Marjory recently visited the chapel in the hospital for her room-mate’s funeral and was very comforted by the way the chaplain acknowledged her room-mate’s life and her place in the facility. Marjory told her family that she has changed her mind. She has now requested the chaplain visit her – she said, ‘He does a good funeral and I’d like him to do mine!’

Action: Notified supervisor immediately (10.45 am) to inform him that Marjory would now like the chaplain to visit her.

Worker’s name: Natasha Lever

Signature: *Natasha Lever*

Practice task 7

1. List three things a person may want to discuss about spirituality.

2. What is a personal carer’s role in supporting a person’s spirituality and culture?

Click to complete Practice task 7

2D Identify needs and issues outside your scope and refer to supervisor when necessary

People working in palliative care should know their level of authority and responsibility, and who to refer issues and problems to if they don't have the skills and knowledge. Job descriptions (also called position descriptions) outline people's roles, responsibilities and who they report to. 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.

At your induction you will be given an overview of your job role, the tasks you have to perform and the equipment you will use. You will be shown the procedures manual, which describes how to carry out specific procedures and operate equipment and machinery. Ensure you know where the manual is located so you can refer to it when necessary. You may also be paired with a mentor, whose job is to guide you through your role and answer any questions when you first start a new job. It is a care worker's responsibility to ensure they have the necessary knowledge and skills to complete their tasks and also to maintain their knowledge and skills through in-service and professional development activities.

Here is a list of tasks the personal care worker should carry out.

Personal care worker tasks

- Assist with the assessment of people accessing the service.
- Provide direct care for people according to their care plan.
- Provide emotional support to the person, family members and carers.
- Provide information about services to the person, family members and carers.
- Help the person to remain as independent as possible.
- Help the person maintain their social, cultural and spiritual needs.
- Keep accurate and up-to-date observations in care notes.
- Follow duty of care, ethical, privacy and confidentiality guidelines.
- Liaise with other healthcare services.
- Work cooperatively with healthcare professionals, services and volunteers.
- Follow the organisation's policies and procedures.
- Uphold the person's rights to be listened to, respected and have their dignity maintained.

Understand the extent of your role

It is a good idea to explain your role to the person accessing the service, their family members and carers so they understand the extent of a palliative care worker's job.

You need to be aware of when you have reached the limits of your knowledge and competence and to know when to seek advice. In your day-to-day work, you may encounter issues and concerns that are outside your job description and level of authority. At these times, you must follow the organisation's procedures. You need to know who to refer particular issues to. It is a good idea to keep a list of members of the care team, their roles, responsibilities and contact details handy. For example, if you are unable to cope with a situation, contact your supervisor or manager, a registered nurse or doctor immediately, and remember to always document your observations and actions.

The table below lists some situations where you may require help or need to refer the matter to someone more senior or experienced.

Need or issue	Appropriate personnel
A person accessing the service asks you how long they have to live	Doctor
A person requests communion as their condition worsens	Pastoral care worker
A person tells you they don't want any more morphine because they will become addicted to it	Registered nurse
A person tells you they want to die	Care team leader or supervisor
A person appears to be suffering severe depression and anxiety	Doctor and/or social worker
A person wants to prepare their will	Care team leader or supervisor

Example

Recognise and refer issues outside the role of the palliative care worker

Derek, a client James works with, is experiencing pain that is causing restlessness and irritability. James has been caring for Derek for a number of weeks and is aware that these behaviours are not routine and that Derek must be experiencing more pain than usual. Derek is becoming quite distressed, so James keeps him as calm as possible and stays with Derek. James calls the supervisor and advises her what is happening. The supervisor checks Derek's care plan and medication chart to see if there is any information regarding Derek's pain management plan. There is no documentation regarding further pain management so the supervisor notifies Derek's doctor, who provides a telephone order for pain relieving medication and arranges to come in to review Derek.

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Practice task 8

1. If a person accessing the service asks for Morphine to ease their pain, what member of the palliative care team should they be referred to?

2. If a person accessing the service tells you that they want to die, who should you refer them to?

3. If a person accessing the service tells you that they are starting to doubt their faith in God, who would you refer them to?

Click to complete Practice task 8

2E Use effective communication skills to provide emotional support and empathy

Providing emotional support and empathy to people accessing the service, their families and carers is a key responsibility for those working with people who are at the end of their lives or have life-limiting illnesses. This means you must listen to what the person, their family members and carers say, acknowledge the impact the illness is having on those involved and provide the appropriate support. In some cases, you may only need to be there to listen; at other times you may need to provide information.

Below are the things you need to consider when supporting family members and carers who care for a person who is dying.

Respect feelings

It is important to remember that as well as providing support to the person who is facing death, the needs and feelings of family members and carers are crucial. These people play an important part in the overall care of the person and 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 like being on an emotional rollercoaster. Many and varied emotions may be experienced. The anticipated loss of a loved one may lead to feelings of guilt, anger, frustration, distress or family conflict. Do not assume that a person's family is always supportive. There may be conflicts within the family; for example, regarding care.

Identify needs

People in a palliative environment have a range of emotional needs including the need to:

- grieve
- hope
- express their feelings freely
- maintain their self-esteem and dignity
- come to terms with fear, uncertainty and impending loss.

Listen to feelings

An important part of a palliative care worker's job is to listen.

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'. It is important to come to terms with your own beliefs and attitudes regarding death and dying so you are able to provide calm and rational support.

Effective communication strategies

Effective communication with people accessing the service and other members of the palliative care team is essential. The team should conduct regular meetings to ensure everyone is aware of the person's current situation and the care provided. This helps reduce any misunderstandings and disagreements. These meetings should also involve the person, their family members and carers, where possible, to allow them to receive current information about the person's status and an opportunity to voice their concerns.

Here are eight strategies that can help you develop effective communication skills.

Effective communication skills

Identify decision-makers
Clarify who the decision-makers are within the family and who you should share information with; for example, the person, family members or a community representative such as a community elder or religious leader.

Understand communication styles
Understand the communication styles and patterns of interaction within the family and communicate in ways that are appropriate. For example, avoid the use of jargon; speak clearly and in plain English. It is easy to misinterpret information even if a person speaks English fluently.

Use language skills
Do not assume the person, family members or carers understand English, as it may not be their first language. Provide information to culturally and linguistically diverse (CALD) clients, their families and carers in their own language by using an interpreter. Do not presume people have low literacy levels or levels of understanding, as making these assumptions may result in a person feeling patronised.

Respect cultures
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.

Known values
Be aware of your own values, beliefs, expectations and cultural practices and consider how these may affect how you communicate with people from cultures different from your own.

Develop networks
Develop communication networks with cultural representatives who can support the palliative care team to identify ways to assist grieving families and to access bereavement support while respecting beliefs and attitudes. Different people and cultures may have different reactions towards death.

Use two-way communication
Ensure everyone understands what you are saying. A one-way conversation where you talk at people, rather than with them, may result in miscommunication or misunderstandings. Rephrase sentences if you think someone may not understand and ask if you can clarify anything for them.

Consider involvement
Ask the person who they want involved in their support and the level of involvement. Be sensitive to who is considered to be immediate family and next of kin, as friends may play the role of relatives for some people you provide support.

Practice task 9

1. What are two things you could do to support a person's personal and relationship needs?

2. Explain three things a guardian must do when making decisions on behalf of a person.

Click to complete Practice task 9

Summary

1. The client and the people who are closest to them are the ones who best understand the client's needs and preferences. They should be encouraged to share all the information they have to ensure the client's care plan remains current.
2. Having a supportive network of family and friends is an important part of coping with a life-limiting illness.
3. Clients have different needs relating to lifestyle, social activities and spiritual needs.
4. Palliative care workers must ensure they are sensitive to, and respect, customs that are different from their own.
5. Palliative care workers must understand the concept of death and dying in other cultures and know how these cultures deal with this process.
6. Palliative care workers must encourage people to talk openly about their spiritual and cultural needs. This must be done in a sensitive, non-judgmental way and within the level of the worker's authority and skills.
7. 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 who to refer particular issues to.
8. You must listen to what the client, their family members and carers say, acknowledge the impact the illness is having on those involved and provide the appropriate support.
9. The relationship between a client and their carer is very important and must be respected and may be even closer if the carer is a family member.

Learning checkpoint 2

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

This learning checkpoint allows you to review your skills and knowledge in respecting people's preferences for quality-of-life choices.

Part A

1. What communication strategies can be utilised by the support worker to demonstrate an empowerment approach for people accessing palliative care services?

2. What communication strategies can be utilised by the support worker to demonstrate support?

3. What legal and ethical considerations regarding human rights need to be upheld in palliative care? Give two examples of rights people held by who access palliative care services.

4. Why should a personal care worker support religious practices for a person accessing palliative care services?

5. Provide two ways a personal support worker can support a person's spiritual needs.

6. Why is it important for the personal support worker to obtain information regarding the culture of a person accessing palliative care services?

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. 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. The nurse on duty makes an assessment that Narla is in pain and requires more morphine to relieve the pain. Casey, the palliative care worker, informs the nurse that she doesn't 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 Casey, decide to reduce the dosage of morphine to see if this would allow Narla to communicate with her family. Casey 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 is it important to use a non-judgmental approach to ensure the person's lifestyle, social, spiritual and cultural needs are supported and documented in the care plan?

2. Provide an example of a legal and ethical consideration regarding work role boundaries, responsibilities and limitations.

Topic 3

In this topic you will learn how to:

- **3A** **Interpret and follow advance care directives**
- **3B** **Comply with end-of-life decisions and legal requirements**
- **3C** **Report the person's changing needs and issues to appropriate personnel**
- **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**

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

Quality end-of-life and post-death care relies on good planning. Instructions for meeting these care needs are outlined in the care plan. A person may determine in advance if they are capable of making decisions for themselves. These include details about medical treatment, their care preferences and how to deal with any issues that arise. Palliative care workers must also be aware of the legal and ethical regulations that may influence end-of-life care.

3A Interpret and follow advance care directives

Ethics are the values, principles and standards that guide our view of what is good or bad, right or wrong. The ethics of care in a palliative environment mean that you must respect the person's wishes, maintain confidentiality of information, provide quality care and follow the instructions recorded in the person's care plan.

Behaving ethically often requires a delicate balance between the standard practice of providing quality palliative care and respecting the wishes of the person. For example, a person may request assistance to end their life; however, this is only available in the state of Victoria through the *Voluntary Assisted Dying Act 2017*. Everyone is different and has different end-of-life preferences. In many states, specific legislation is in place to protect the person's right to refuse treatment and the support worker's duty of care to provide treatment.

Here are some ethical principles relating to palliative care and health.

Ethical principles related to palliative care and health

- Respect for individuals and their dignity: every individual has inherent worth, dignity and basic human rights
- Autonomy: every individual has the moral and legal right to decide what will be done with him or her
- Privacy: every individual has a right to be secluded or isolated from the view of others and to confidentiality
- Truthfulness: every individual has the right to be told the truth
- Do no harm; do good: every individual has the right to be treated well and not unnecessarily harmed or pained

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Dignity of risk

The rights of people to dignity and choice, upheld in legislation and service standards, also require that duty of care or safety is not used as a reason to limit a person's freedom or personal choice. A support worker's adherence to duty of care and safety must be coupled with the concept of dignity of risk, which means that a person has the right to make their own choices and to take risks.

Dignity of risk acknowledges that life experiences come with risk, and that we must support people in experiencing success and failure throughout their lives. However, it can be a challenge to support decisions that we feel are risky or with which we don't agree, without considering safety and viewing decisions through our safety-oriented healthcare culture.

Dignity of risk needs to be considered in terms of capacity and decision-making. It is necessary to find a balance between the need for duty of care and the right and capacity of people to decide what level of risk they are comfortable with themselves.

Duty of care, negligence and dignity of risk

Community services organisations and workers have a responsibility to provide a duty of care to ensure the safety and wellbeing of people in receipt of their services. Legislative and regulatory obligations underpin an organisation's policies, which determine the procedures to guide service delivery that promotes and enhances the safety and wellbeing of people.

Here is more information about duty of care.

Duty of care

- Duty of care is the obligation a person has to act in a way that would not cause harm.

Negligence

- Negligence occurs when duty of care has been breached and harm to either person or property ensues. It is the legal and ethical obligation of any community worker, supervisor or organisation to ensure that people using services are not exposed to unnecessary or unreasonable risk.

Dignity of risk

- The rights of people to dignity and choice, upheld in legislation and service standards, also require that duty of care or safety is not used as a reason to limit a person's freedom or personal choice. A support worker's adherence to duty of care and safety must be coupled with the concept of dignity of risk, which means that a person has the right to make their own choices and to take risks.

Privacy, confidentiality and disclosure

When discussing a person's situation, always be aware of maintaining their privacy. You must protect confidential details. You always need the person's consent if you wish to talk about their situation. Often people are happy to give their consent because they know you want to help.

Maintaining confidentiality is part of respecting a person's privacy and individual rights. In practice, confidentiality means not discussing an individual's personal information unless they have given their consent for this to happen. There are exceptional circumstances that do enable you to disclose private information, but this is generally only when you become aware that someone may be harmed.

You can read more about privacy, confidentiality and disclosure at the following sites:

- http://aspirelr.link/aacqa-privacy-policy
- http://aspirelr.link/law-handbook-privacy-confidentiality

Collection, use and storage of information

On 12 March 2014, the Australian Privacy Principles (APPs) replaced the National Privacy Principles and Information Privacy Principles and apply to organisations, and Australian Government agencies.

For more information, visit: http://aspirelr.link/privacyfactsheet

There are now 13 National Privacy Principles that apply to the collection, use and storage of people's information. Here is further information about how to handle personal information.

Collection, use and storage of personal information

1. **Open and transparent management of personal information**
   Ensures that organisations manage personal information in an open and transparent way.
2. **Anonymity and pseudonymity**
   Requires organisations to give individuals the option of not identifying themselves, or of using a pseudonym. Some exceptions apply.
3. **Collection of solicited personal information**
   Outlines when an organisation can collect personal information that is solicited. It applies higher standards to the collection of 'sensitive' information.
4. **Dealing with unsolicited personal information**
   Outlines how organisations must deal with unsolicited personal information.
5. **Notification of the collection of personal information**
   Outlines when and in what circumstances an organisation that collects personal information must notify an individual of certain matters.
6. **Use or disclosure of personal information**
   Outlines the circumstances in which an organisation may use or disclose personal information that it holds.
7. **Direct marketing**
   An organisation may only use or disclose personal information for direct marketing purposes if certain conditions are met.
8. **Cross-border disclosure of personal information**
   Outlines the steps an organisation must take to protect personal information before it is disclosed overseas.
9. **Adoption, use or disclosure of government-related identifiers**
   Outlines the limited circumstances when an organisation may adopt a government-related identifier of an individual as its own identifier, or use or disclose a government-related identifier of an individual.
10. **Quality of personal information**
    An organisation must take reasonable steps to ensure the personal information it collects is accurate, up to date and complete.

11 **Security of personal information**
An organisation must take reasonable steps to protect personal information it holds from misuse, interference and loss, and from unauthorised access, modification or disclosure. An entity has obligations to destroy or de-identify personal information in certain circumstances.

12 **Access to personal information**
Outlines an organisation's obligations when an individual requests to be given access to personal information held about them by the organisation.

13 **Correction of personal information**
Outlines an organisation's obligations in relation to correcting the personal information it holds about individuals.

Advance care directives

One of the most important areas of legal and ethical concern involves the person's advance care directives in their care plan. Advance care directives outline the person's wishes for their end-of-life medical treatment and post-death treatment. They are called advance care directives because they give the person the opportunity to record their wishes and preferences in advance – while they are still capable of doing so. If this is not done and the person is later unable to express their choices for treatment, the palliative care team and the person's family and carers may not know what the person would want. Advance care directives provide the person, their family members and carers with reassurance that the person's wishes will be respected by the palliative care team when the person is no longer able to make these decisions.

Here is some additional information about advance care directives.

General points

- Formal, legally endorsed documents signed by the person accessing the service and are also referred to as living wills
- They only come into effect if the person is no longer considered legally capable of making their own decisions about medical treatment
- It is the role and responsibility of all members of the healthcare team to follow the instructions in the advance care directives in the person's care plan
- Adhere to state and territory legislation or guidelines regarding advance care directives)

Information included

- An information sheet describing the directives (instructions)
- The name of the person nominated to make decisions for the person accessing services about their medical treatment, when they are no longer able
- A contact sheet for details of those who have a copy of the plan

Example

Uphold a person's privacy

Jane is a personal support worker who has been employed at the facility for only three weeks. The facility is in a small regional area and is the only facility available to people living in this region. One of the people Jane supports, Jack, is showing signs of imminent death. Jane has known the family, and Jack's daughter, Susan, is a friend with whom Jane socialises as they live in the same town. Jack's family is very distressed and have been staying with Jack for the last two days.

Jane is aware that Jack disclosed that he had another son from a previous relationship, before his condition worsened. Jack informed staff that this child was living in an aged care facility as he had severe mental and physical disabilities present from birth. Jack had advised that provisions had been made to ensure this child would be well looked-after financially and that he had not told his current family about his existence. Jane is unsure of what her obligations are towards the family and asks her supervisor for advice. Jane's supervisor advises that Jack is entitled to his privacy and that the information should not be disclosed to the family by Jane. The supervisor refers the matter to a social worker.

Practice task 10

1. What information can advance care directives include for a person accessing services?

2. Explain what dignity of risk means?

Click to complete Practice task 10

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

Advance care directives take effect when the person is unable to make their own decisions. When this occurs, the healthcare team has a discussion with the substitute decision-maker. The palliative care worker must make sure they know who the decision-maker is. Remember, you must also sight the advance care plan in the person's file and understand the directives it outlines. It is important that an advance care directive is current and to understand that an advance care directive is only a small component of the whole process of advance care planning.

Advance care planning documents usually include a variety of legal documents as well as less-formal documents for determining a person's end-of-life wishes; for example, addressing issues such as pain control and comfort care.

Make a decision on behalf of a person

When a person is no longer able to make decisions for themselves, a substitute decision-maker is used. This is the person the person has nominated to be responsible for making decisions for them about their medical treatment. It may be a family member, a carer or an appointed advocate.

Substitute decision-making only comes into effect when the person loses the capacity to make decisions or is unable to understand the nature and complexity of the treatment.

If a family member has been granted a legal right to make decisions on behalf of a person, then an enduring power of attorney (medical treatment) must be sighted by a member of the palliative care team, and its powers and limitations noted in the person's record.

Any disagreement about the person's prior wishes is usually resolved by further discussion and support by social workers, pastoral care workers or others.

Common advance care directives and ways to comply with legal and ethical considerations are explained below.

Medical treatments

- Ensure medical treatments meet the person's preferences.
- Ensure you are honest if treatment goals have not been met.

Maintain the person accessing the service's wishes

- Respect the person's wishes.
- Encourage ongoing discussion with the person, their family, doctor and guardian to ensure that the person's and/or family's wishes are current.
- Maintain the person's personal goals.

When the person can no longer make decisions

- Follow the person's advance care plan.
- Work effectively together with the substitute decision-maker.

Life-sustaining treatment

- Ensure life-sustaining treatment meets the person's needs and preferences.
- Ensure treatments enhance comfort and quality of life, and no specific therapy is excluded.
- Maintain the person's treatment goals.

Important aspects of care during dying phase

- Maintain privacy and confidentiality.
- Promote a sense of dignity.
- Respect the person's end-of-life decisions.
- Allow for the goals of care to be reset at all stages of the person's life-limiting illness.

Deal with conflict

- Respect the person's preferences and decisions.
- Ensure the person, their family and carers are provided sensitive support and assistance in any possible way.

Advance care plans and end-of-life strategies

Advance care planning documents usually include a variety of legal documents as well as less-formal documents for determining a person's end-of-life wishes. End-of-life care strategies focus on supporting the person and their families. It encompasses both the physical, psychological and spiritual concerns of the person and their family. Physical problems are also a priority for end-of-life care of a person, to promote their comfort. The problems that can occur are pain, delirium/agitation, dyspnoea, respiratory secretions, mouth and skin care, bladder and bowel care and nausea and vomiting.

Here is the information and documents that may be found in an advance care plan.

Documents and information in an advance care plan

- The names of family members and staff members who have been involved in discussions regarding the person's condition and future care plan
- A description of the person's health condition and likely prognosis
- Information identifying whether the person is competent; that is, able to make decisions regarding their medical care
- The person's wishes, preferences and chosen options regarding their future medical care
- Information identifying how long the person wishes the advance care plan to be current and when they believe it should be reviewed
- The date the document was completed, the person's signature and their name clearly printed

- The person's privacy and confidentiality requirements (particularly relating to intimacy and sexuality needs)
- The signature of the medical practitioner and the care team
- An enduring power of attorney (medical treatment) form
- A completed witness certificate

Your responsibilities regarding advance care directives

If advance care directives have been completed, it is your responsibility to ensure they are followed so the person's right to dignity and choice are upheld. You must never try to persuade a person to do something they do not want to do even if you believe it is in their best health interests. Instead, you should report your concerns to your supervisor. For example, if a person makes a statement to you that reflects their desire for a hastened death, it is essential that you inform your supervisor or manager immediately.

Below is information that you may have to follow in an advance care directive.

Information included in advance care directives

- Medical treatment; for example, the person may ask not to have a specific treatment, such as a blood transfusion
- Conditions or states the person would find unacceptable
- How far treatment should go when the person's condition is terminal, incurable or irreversible
- Non-medical aspects; for example, information about complying with their cultural wishes

Comply with end-of-life decisions

End-of-life decisions relate to the actions taken when a person's death is imminent. These decisions may be documented in the client's care plan or in their advance care directives. Remember, it is a legal requirement under state and territory legislation that these decisions are complied with. End-of-life decisions cover a broad range of issues. In some cases, people residing in Victoria may choose to access the voluntary assisted dying laws that enables them to end their life in a manner and time of their choosing. It is part of your duty of care as a support worker that you follow the end-of-life decisions as requested by the person accessing services.

End-of-life decisions should be discussed with the person and their family members and all decisions documented and signed. They should be regularly reviewed with the person, their family members, doctor, other palliative care team members, carers and the substitute decision-maker (if appropriate) to ensure they are current.

Sometimes, a person living at home may not have an end-of-life plan. This may have consequences if they require urgent treatment and decisions have to be made quickly without knowing their wishes.

Below are some key end-of-life things people may consider.

Making a will

It may be your job to arrange the material or relevant expert to help a person prepare their will or update their current will. Ask your supervisor to explain any legal considerations when doing this.

Funeral arrangements

Many people provide instructions about the type of coffin they want and how they want their funeral to be conducted. Sometimes they will talk to you about this, as it may help to alleviate their fears and help them feel in control. Ensure their wishes are documented.

Treatment

The palliative approach is focused entirely on the person's preferences and aimed at enhancing their quality of life. Reaching decisions should ideally involve the person's family members or suitable people to act as the person's proxy in providing information to the palliative care team about the person's preferences, personal values and history.

Family arrangements

The person may have complex family matters that need to be resolved; for example, financial decisions or interpersonal or relationship matters. It may be your job to provide emotional support for the person at this time.

Example

Make decisions on behalf of a person

John supervises Sally, a personal care worker, who has a client called Louise. Louise is near the end of her life and is a very frail 83-year-old lady. Louise was an only child who never married or had children. Louise only has a distant cousin who lives overseas and whom she has never met. All of Louise's close friends have either died or are unable to provide assistance due to age or ill health. Up until recently, the palliative care team members have fulfilled the role of family for Louise. Sally notices that Louise's mental condition is deteriorating and is aware that this is a sign of imminent death. Louise reports this to her supervisor..

John contacts the palliative care team and Louise is referred to the court for a guardian to be appointed to uphold her advanced care directives and to make decisions on Louise's behalf if appropriate.

Practice task 11

1. List two items that might be found in the advance care plan.

....

....

2. Who can make a decision for a person when they are no longer capable of doing so themselves?

....

Click to complete Practice task 11

3C Report the person's changing needs and issues to appropriate personnel

Your role as a palliative care worker is to understand the person's wishes and preferences so you know how to provide the appropriate care. These are discussed in team meetings and are documented in the person's care plan. However, when you work closely with a person on a daily basis they may take the opportunity to talk about end-of-life issues that are on their mind. They may express wishes that are different from those documented, as their needs and circumstances change. For example, they may become anxious that they have not prepared a will; they may want you to help them resolve a family quarrel before they pass away; or they may change their mind and request to see a pastoral care worker.

Here is what must be done if a person's end-of-life needs or wishes change.

Respond to changes to end-of-life requests
Report to relevant person; for example, your supervisor, manager or the director of nursing.
Revise the person's care plan to reflect changes.
Consult family members so they are aware of any new needs or issues and have time to consider the decisions made by the person.
Document the issue or change in the person's care notes to inform other team members to take appropriate action.
Follow up so you know your comments have been read and acted upon.

Example

When a client reveals new information

Surani supervises Ruth, a personal care worker, who has a client called Jacob. Jacob is near the end of his life. He has not spoken to his family for many years after a falling out over money, although he knows where they are living. It is starting to worry him as he is a religious man and doesn't want to die without saying goodbye to his family. His carers notice Jacob has recently become very stressed and seems to be in more pain than usual. Their care notes indicate that Jacob finds it difficult to sleep and is often uncomfortable and withdrawn.

Ruth speaks with him and eventually finds out the reason for his behaviour. She notes the situation in the care notes and informs her supervisor Surani, who is also the team's coordinator.

Example

Surani speaks with Jacob and repeats his request so she knows she understands exactly what he wants. She explains the procedure for contacting family members in these instances and says she will call them to arrange a family meeting. She immediately calls a meeting of Jacob's healthcare team to advise them of the developments.

Although all end-of-life decisions must be documented and all members of the team informed, the specific situation dictates who needs to be consulted first. For example, you may be able to deal with the situation yourself or you may need to refer it to a health specialist such as a doctor, nurse, physiotherapist or another specialist, such as a lawyer, financial expert, funeral director or advocate.

Practice task 12

What should you do if a person changes their end-of-life requests?

Click to complete Practice task 12

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

The role of the primary carer is a special one, especially if the carer is a family member. Providing care is often physically tiring and emotionally exhausting and a carer may have to put their own life on hold while they are caring for the person. Part of your role is to provide support to carers as well as the person with the life-limiting illness; carers are your responsibility as well.

Palliative care workers must understand the role of the carer including their relationship with the person, the tasks they undertake and the impact their care-giving has on them emotionally, psychologically and physically. It is also important to understand the carer's cultural and spiritual beliefs and values, as these may influence their feelings and how they behave.

Carers often experience as many emotions as the person receiving their care, including anger, frustration and sadness. The carer's role may also change as the person's condition progresses. Carers who look after a number of people may experience multiple losses over a short period of time. They must learn to deal with these losses so they are able to continue providing appropriate care and support for their other people.

Provide support for carers

As emotions and changing circumstances may be very stressful, it is the responsibility of the palliative care worker to recognise the impact of these end-of-life issues on carers and to support them. It may be your job to assist the carer with their day-to-day support of the person. Your supervisor will explain the tasks that fall within your job description. This may involve showing workers how to assist with activities of daily living or demonstrating the use of aids and equipment. It may also involve liaising with allied health professionals, such as occupational therapists or counsellors, for advice and information. If you are ever unsure about something or are asked to do something beyond your level of authority, always refer to your supervisor for advice.

How the palliative care worker can provide support to the carer is explained below.

Providing support to carers

- Provide as much information as possible to the carer so they understand the person's situation.
- Provide pamphlets or brochures about grief to help them understand their own feelings.
- Ask the carer what help they require and put them in touch with carer organisations or other support services and networks.

- Make themselves available to talk to the carer and answer their questions; talking to someone else is often beneficial as it helps people come to terms with their emotions.
- Look out for signs that the carer is stressed, so you can step in and provide support.
- Arrange respite care so the carer has a break from their role.
- Encourage the carer to look after their own needs by eating well, getting plenty of rest and exercising.
- Remind them that if they become ill, they won't be able to continue their role.

Inform the carer

You need to keep carers informed by providing as much information as you can to the carer about their role and answering their questions so they understand the person's situation. You should also explain the client's progress and what is likely to happen to the client in their end-of-life stage – remember, everyone is different, and some carers may prefer more-detailed information than others about the dying process, potential complications and immediate post-death arrangements, than others. Some carers may need to have unfamiliar terminology explained.

Carers may require access to organisations that can provide practical assistance, support and counselling and educate them about the client's conditions; for example, the Cancer Council Helpline. Information in the form of pamphlets or brochures about grief may be useful to help them understand their own feelings.

Practice task 13

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

Case study

Teresa, a palliative care worker, is visiting Huong, a Vietnamese lady, who has been sent home to die with dignity, surrounded by her family. Her son Tran is her primary carer. 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 to Teresa. She notices that every now and again his head drops and he closes his eyes. It seems that Tran is quite exhausted. Tran eventually admits that he hasn't slept for two or three days. Teresa 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 respite worker to look after Huong so Tran can recuperate. She also speaks to Tran's sister who visits and asks if she can take over Tran's task of providing personal care for their mother for a day or so.

1. What action could you take to support Tran and give Tran a rest?

2. What signs is Tran displaying that indicate he is feeling stressed?

Click to complete Practice task 13

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

As a palliative care worker, your responsibility is to ensure care services are delivered in accordance with the person's wishes. One of the most important wishes a person may have is to choose the location of their end-of-life care. This may be in their own home, a hospice, a residential facility or an institutional setting, such as a palliative care unit in a hospital.

Many people choose to die in the familiar setting of their own home surrounded by their family. In such cases, they are supplied with nursing or hospice services in their home so quality care is maintained. The person's preference is listed in their care plan or in their advance care directives and it is essential that the person's right to choose is upheld. This forms part of the legal and ethical guidelines regarding people accessing palliative care services.

Workers are informed of the person's wishes at team briefings. As with all decisions, the person's preference of location for care must be regularly reviewed and documented as circumstances may change; for example, the person may decide they would prefer to be in a hospice rather than their home at the end of their life.

Continue to deliver quality care regardless of the location

An important responsibility is to monitor the standard of care from your perspective. For example, are items available when required? Are providers contactable when needed? Is information readily available? Is appropriate support being maintained?

Your role is to continue to provide quality care regardless of the location. Follow the instructions of your supervisor or team leader.

Your primary tasks are to:

- ensure the person is physically comfortable
- provide emotional support to the person and carer
- be available to listen, support and provide information
- treat the dying person with respect
- provide information and emotional support to family members
- document your observations as well as verbally pass on information you receive from the person, their family members and carers
- communicate with other members of the healthcare team.

Example

Respect the person's decision for end-of-life location

Doris lives at home with her older husband who has Alzheimer's disease. They have a son who has an intellectual disability and is cared for in a hostel. Her eldest son lives in another state. Doris has a history of severe cardiac disease and one day she requires surgery. Following the surgery and after a long, complicated admission to the intensive care unit she is transferred to a long-term ventilation unit for a slow-weaning process. Each day, Doris finds it increasingly difficult to wean from the ventilator. Although her condition appears to be improving, she is weak and reluctant to be removed from the ventilator. Cara, the palliative care worker, speaks to Doris about her feelings, beliefs, values and goals in life. Doris clearly understands the condition of her heart and is clear about her wishes if her heart ever stops. She firmly says that she does not want to be resuscitated. As the conversation continues, she explains what is important to her at this time. She wants:

- to be allowed thick drinks
- to be always kept clean
- to not have to wean off the ventilator anymore or be treated for any more acute episodes
- to receive pain medication when she requires it
- to be cremated.

Cara knows that Doris is the most appropriate person to make her own decisions. Doris also tells Cara that under no circumstances should her husband be bothered by having to make any decisions, as he also has a bad heart and she wants the medical team to make all decisions for her. A conference is called to discuss the impact of the wishes Doris has expressed about her treatment. As a result, she completes the statement of choices, to reflect her decisions, in the advance care directives in her care plan. Doris is grateful for the opportunity to express her wishes and she dies peacefully three days later with her family and carers by her side.

Practice task 14

1. List two locations where a person might request to die.

2. When a person who is accessing services informs you that they wish to die at home, what action should you take?

Click to complete Practice task 14

Summary

1. Ethics are the values, principles and standards that guide our view of what is good or bad, right or wrong.
2. Behaving ethically often requires a delicate balance between the standard practice of providing quality palliative care and the wishes of the person accessing the services.
3. When people are no longer able to make decisions for themselves, a substitute decision-maker is used.
4. If a family member has been granted a legal right to make decisions on behalf of a person, then an enduring power of attorney (medical treatment) must be sighted by a member of the palliative care team, and its powers and limitations noted in the person's record.
5. Advance care directives take effect when the person is unable to make their own decisions.
6. End-of-life decisions relate to the actions taken when a person's death is imminent. These decisions may be documented in the person's care plan or in their advance care directives.
7. As a palliative care worker, you need to understand the person's wishes and preferences so you know how to provide the appropriate care. These are discussed in team meetings and are documented in the person's care plan.
8. The persons you are caring for may express wishes that are different from those documented, as their needs and circumstances change.
9. All care services must be delivered in accordance with the person accessing the service's wishes.

Learning checkpoint 3

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

This learning checkpoint allows you to review your skills and knowledge in following the client's advance care directives in the care plan.

Part A

1. What is an advance care directive?

2. What information might advance care directives include?

3. Explain the term 'dignity of risk' in relation to caring for people accessing palliative care services.

4. Explain the legal and ethical considerations regarding privacy.

5. Explain the legal and ethical considerations regarding confidentiality and disclosure.

6. Explain the legal and ethical concepts of the term 'duty of care'.

7. Explain the responsibility of a personal care worker in upholding the rights of an individual to choose the location of their death.

Part B

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

Case study

Doris lives at home with her older husband who has Alzheimer's disease. They have a son who has an intellectual disability and is cared for in a hostel. Her eldest son lives in another state. Doris has a history of severe cardiac disease and one day she requires surgery. Following the surgery and after a long, complicated admission to the intensive care unit she is transferred to a long-term ventilation unit for a slow-weaning process. Each day, Doris finds it increasingly difficult to wean from the ventilator. Although her condition appears to be improving, she is weak and reluctant to be removed from the ventilator. Cara, the palliative care worker, speaks to Doris about her feelings, beliefs, values and goals in life. Doris clearly understands the condition of her heart and is clear about her wishes if her heart ever stops. She firmly says that she does not want to be resuscitated. As the conversation continues, she explains what is important to her at this time. She wants:

- to be allowed thick drinks
- to be always kept clean
- to not have to wean off the ventilator anymore or be treated for any more acute episodes
- to receive pain medication when she requires it
- to be cremated.

Cara knows that Doris is the most appropriate person to make her own decisions. Doris also tells Cara that under no circumstances should her husband be bothered by having to make any decisions, as he also has a bad heart and she wants the medical team to make all decisions for her. A conference is called to discuss the impact of the wishes Doris has expressed about her treatment. As a result, she completes the statement of choices, to reflect her decisions, in the advance care directives in her care plan. Doris is grateful for the opportunity to express her wishes and she dies peacefully three days later with her family and carers by her side.

1. Describe the changing needs that Doris communicates to Cara. Where should this information be documented?

2. Who should Cara report Doris's decisions to?

Topic 4

In this topic you will learn how to:

- **4A** **Observe and document a person's pain**
- **4B** **Implement strategies to manage pain and promote comfort**
- **4C** **Evaluate and document the effectiveness of pain management strategies**
- **4D** **Understand how to address misconceptions surrounding the use of pain-relieving medication**

Respond to signs of pain and other symptoms

Experiencing pain may lead to distress and a reduced quality of life. It may also have a psychological and physical impact. One of the aims of a palliative approach is to provide relief and comfort when a cure is no longer possible. Palliative care workers have a responsibility to understand and follow the strategies that healthcare professionals have identified as a response to pain.

4A Observe and document a person's pain

A major part of providing palliative care is to ensure that the person's pain is controlled and they are comfortable. Pain may be either acute (brief and severe) or chronic (long lasting). In palliative care, a person's pain is usually chronic and may be due to a combination of their disease, their treatment, the ageing process and emotional pain caused by fear and distress. Not all people accessing palliative care suffer pain; however, pain and pain management are major factors for many people with life-limiting illnesses. The person's care plan identifies the type of pain they may have and the care directives for managing it.

Pain can be acute or chronic, as detailed below.

Acute pain	**Chronic pain**
▶ Pain is due to acute injury or illness. ▶ Pain may last days or weeks but has a predictable and limited duration. ▶ Clinical signs are obvious; for example, increased blood pressure, increased heart rate, sweating and pale skin. ▶ Pain makes the person anxious and distressed. ▶ Pain causes the person to be inactive until they recover. ▶ Pain causes the person to temporarily use analgesics.	▶ Pain is related to a number of different medical conditions including (but not limited to) diabetes, arthritis and cancer. ▶ Pain has a gradual onset and becomes progressively worse. ▶ Pain usually has no characteristic signs or indications of the disorder or disease. ▶ Pain may cause the person to appear depressed, withdrawn and lethargic; they may also be distressed and call out. ▶ Pain requires the person's underlying disease to be treated with the regular use of analgesics.

Identify pain

Palliative care workers must monitor the person closely to identify whether they are experiencing pain or other symptoms. Because they see the person on a daily basis, workers are in a good position to regularly observe, assess and monitor the person's levels of pain. Always be familiar with a person's care plan so you know the type of pain they may experience, the symptoms they may display, and whether their pain is likely to increase.

Below are the steps to follow if you identify symptoms of pain.

Recognise the type of pain a person may experience

- Information relating to person's pain is detailed in the care plan and through the instructions you receive from your supervisor. It is important for you to understand the meanings of any medical words used in the care plan or by the supervisor.
- This will assist you to be prepared for the pain you may observe.

Monitor and identify the symptoms a person is experiencing

- Sometimes it is easy to make your own observations regarding a person's pain; for example, you may see the person holding a part of their body tightly, groaning or constantly changing position in an effort to become comfortable. A person may experience pain only at the end of the day or after they have taken medication.
- Always record these observations, especially as person may not always tell you if they are in pain.

Ask the person to describe the pain

- Ask the person to describe the pain. To better understand the pain a person is experiencing, 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. For example, ask the following:
  - 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?
- If the person has difficulty communicating, use pictures or a scale where one indicates slight pain and 10 indicates severe pain. You can use a line with numbers or words attached, where the person moves a slide to the number or area matching the severity of their pain. You may require the services of an interpreter.
- Some workplaces have brochures you can give to people, written in a variety of languages, which describe the pain and what may be done to manage it. Be familiar with the types of resources available to you.

Listen to what the person says about their pain

- Always listen carefully to how a person describes their pain. They may use words such as intolerable, unbearable or annoying. Some people may deny they are in pain and use words such as discomfort or uncomfortable. You must follow up immediately if a person says they are in pain, by notifying your supervisor or another member of the care team.

Identify any changes in a person's pain

- Constantly monitor the person's behaviour and what they tell you, so you can determine if there are any changes in the type, location and severity of pain they are experiencing.
- Ensure you document any changes and inform others as soon as there is a change.

Talk to family members and carers

- Talk with the person's family and other carers. They can tell you whether they think the person is in pain or if the person has spoken to them about being in pain. People often talk more freely with their family as they think they are being a nuisance if they tell staff about their pain.
- The more people involved in monitoring and talking to the person, the better the information that can be gained to manage their pain.

Check the care plan

Palliative care workers must follow the care plan and any instructions they have been given regarding a person's care. An important responsibility is to be up to date with the person's instructions to determine whether any changes have been made to the service delivery.

Here are examples of why there may need to be changes to the service delivery and how you can ensure the care you provide is in line with the person's wishes.

Reasons for change to service delivery

A person may:

- change their mind about the type of treatment they want
- be in pain and request more pain relief
- decide they don't want visitors anymore
- decide they want to go home to die
- request to regularly see a pastoral care worker
- want to change their will.

Supporting changes

You can support changes in line with the person's wishes by:

- reading the care plan on a weekly basis
- confirming the person's situation at team briefing sessions
- reading the care notes left by workers on the previous shift
- asking your supervisor or the case manager.

Document and report observations of pain and other symptoms

Providing accurate, current and clear information about a person's pain is essential and an important part of working in a palliative care environment. Always follow your organisation's procedures regarding documentation; for example, you usually record observations in the person's progress notes. Or you may write comments in the communication book, if appropriate. You may also have to notify your supervisor or the appropriate person immediately – either verbally or by phone.

When documenting pain observations, you must write down exactly what you observe and what the person tells you. Be brief and concise when you write, and use simple sentences.

You must record your observations after every encounter with the person, so their information is kept up to date. Always record the date and time of your comments. This information must be available for each member of the care team to refer to, so it must be written in clear and plain English. Ensure your writing is legible and easily understood.

Most records should include the following information:

- Date and time of observations
- Person's behaviour
- Level of pain
- Location of pain
- Intensity of pain
- How you observed the pain
- What you did to relieve the pain

Example

Document a palliative care worker's observations

Care note

Name: Graham West

DOB: 12/07/1944

Date: 5 March 2016

Time: 10.45 am

Observations:
Mr West, who has rheumatoid arthritis, complained of considerable stinging pain in his left hand and wrist whenever he moved them. Mr West also complained this morning of stiffness.

Action: Notified the care team leader at 10.40 am

Worker's name: Aaron Wisley

Signature: *A Wisley*

Delirium

Delirium is a syndrome that can present as a disturbance in the person's consciousness, cognition or perception. Delirium fluctuates throughout the day, with episodes of the patient being confused to varying degrees. It usually develops over a short time, often over hours to days.

Some reasons a palliative care person can develop delirium are as follows.

Delirium development

- Medicines
- Urinary tract infection or a chest infection
- Low oxygen levels
- Dehydration
- Constipation
- Drug withdrawal

Symptoms of delirium

- Appearing confused
- Difficulty focusing or paying attention
- Sleep disturbance; being awake overnight and sleeping in the daytime
- Being very physically restless
- Being quiet and withdrawn
- Having no concept of time or place
- Seeing, hearing or feeling things that are not there

(*Clinical Practice Guidelines for the Management of Delirium in Older People*, 2006)

Dry mouth

Dry mouth (xerostomia) can occur for a variety of reasons. It can occur as a result of the disease itself or from medication ordered to treat the disease or symptoms experienced by the person as a result of the disease.

It can be a decrease of saliva or a feeling of dryness in the mouth by the person.

Dry mouth can be treated by a review of the person's medication, frequent mouth care and artificial saliva.

Here are some symptoms of xerostomia.

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.

Fatigue

Fatigue is physical and/or mental exhaustion that can be caused by stress, medication, overworking, or mental or physical illness or disease. The person accessing the service may have more than one reason for fatigue to occur and the appropriate team member needs to assess and implement care strategies to address any reversible causes. It is important that the personal care worker reports symptoms of fatigue to the supervisor and documents this in the case files.

Anorexia

Anorexia is the loss of appetite that results in weight loss. This can be distressing for personal care workers, families and carers. It can be an indication that the person is approaching the end of life. The personal care worker should report anorexia to the supervisor or relevant palliative care team member for assessment. Some causes of anorexia are reversible.

Cachexia is a wasting syndrome and is caused by loss of muscle and fat, often due to chronic illness. People accessing the services may develop this and simultaneously experience loss of function, requiring full assistance with activities of daily living.

Reasons a person may become anorexic include:

- increased disease
- side effect of treatment
- side effect of medicines
- nausea
- constipation
- depression
- fatigue
- dry mouth.

Shortness of breath

Shortness of breath is often referred to as dyspnoea. Dyspnoea can be a result of both physical and psychological causes. If a person accessing the services has shortness of breath, the personal care worker should immediately report this to the supervisor and document the episode in the case files. The person may be ordered medication or oxygen by the doctor to treat dyspnoea. Other measures that can be taken by the personal care worker is to support the person with activities of daily living to avoid exertion, assist in positioning the person to provide comfort and monitoring oxygen delivery as per orders.

Dyspnoea can occur in a person due to:

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

Nausea and vomiting

Nausea and vomiting can be a distressing symptom for a person at end of life. It can occur for a variety of reasons but needs to be referred to the doctor or registered nurse for assessment. Treatment can vary. The doctor can order medication to treat the cause or alleviate the symptom for the person. Other care can include small frequent meals, appropriate positioning, or discussing issues that are causing anxiety for the person. These care strategies should be included on the care plan and documented in the case file.

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.

Constipation

Constipation is when bowel motions become less frequent or are difficult to pass. It can be due to lack of fibre, exercise, fluids or medication. In some cases it could be caused by an obstruction in the bowel, a tumour or a result of the bowel becoming twisted.

Symptoms of constipation include:

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

The personal care worker needs to refer the person to the appropriate team member for assessment, report to supervisor and document in the case file. The person should have a special chart commenced for monitoring their bowel movements called a bowel chart.

Nutrition and hydration requirements

All people are entitled to food and drink of adequate quantity and quality and to the help they need to eat and drink. Malnutrition and dehydration can be both a cause and consequence of ill health, so maintaining a healthy level of nutrition and hydration can help to prevent or treat illness and symptoms, and improve quality of life. You must keep the nutrition and hydration status of the people you are supporting under review. You should be satisfied that nutrition and hydration are being provided in a way that meets the person's needs, and that, if necessary, the people are being given adequate help to enable them to eat and drink. The person will sometimes require specialised charting, such as a food or fluid chart to monitor their intake.

If a person refuses food or drink, or has problems eating or drinking, you should first assess and address any underlying physical or psychological causes that could be improved with treatment or care. It is important that the person is assessed for any health problems that may be reversible and also assessed for any swallowing difficulties. It may be necessary for the support worker to physically feed the person. This information should be documented in the person's care plan and reported to the supervisor.

Some health problems that may be addressed are:

- advanced dementia
- apathy
- fatigue
- metabolic disorders
- oral health factors
- therapeutic diets
- vitamin deficiencies.

Example

Assess pain

Mr Cane, an 87-year-old man with a history of arthritis, has been living in a residential aged care facility for the past three years. Some of the nurses and palliative care workers on night shift describe him as a whinger and say that he always goes on about his pain. They say he never looks like he's in pain and that he only wants their attention, so they avoid him. It is not until a new nurse, Georgie, starts at the facility and performs a comprehensive pain assessment, that the doctor prescribes the appropriate medication. Mr Cane's pain is reduced from severe to mild and he becomes more interactive with other residents. Georgie reminds other staff members that they should never presume to know what a person is experiencing.

Practice task 15

1. What are two things you should document when a person is reporting that they have pain?

2. List four actions a personal care worker can do to support a person in care delivery, including pain management.

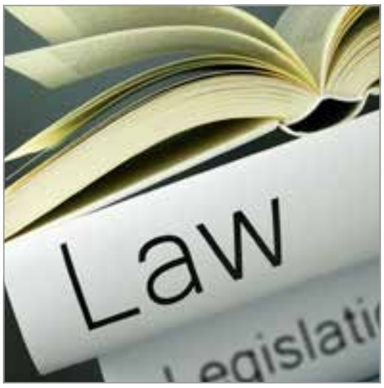
Click to complete Practice task 15

4B Implement strategies to manage pain and promote comfort

Palliative care aims to control the person's symptoms, relieve pain and remove discomfort. You must be aware of what you can and cannot do regarding pain relief. To make sure the person is comfortable, calm and free of pain you can provide emotional support and general care techniques. You must never administer medication. Pain-relief measures may only be administered by an authorised member of the palliative care team; for example, a registered nurse (Division 1) or doctor. You must always remember this if a person's pain relief involves administering an opioid medication (a medication that relieves pain), such as morphine. State and territory legislation requires that pain-relieving medications are only administered by qualified personnel. Other tasks that must be undertaken by qualified personnel include:

- treatments such as administering oxygen and sedatives
- interventions including giving the person non-opioids such as paracetamol and aspirin
- administering injections and/or rectal swabs.

You must always follow the organisation's pain-management policy and procedures that dictate your role and responsibilities.



General care techniques

Apart from conventional medical treatments, there are other ways to relieve a person's pain and promote comfort. Below are seven different approaches to pain management.

Approaches to pain management

1

Massage
The sensation of touch is often very important for a person with a life-limiting illness as it is soothing and provides reassurance. A massage is also an excellent way of providing relief. Massaging helps manipulate muscles to ease muscle tension, relieve headaches, decrease anxiety and calm a person. You can massage a person's hands, feet, neck or back. It requires a gentle, rhythmic touch and you don't have to be a professional masseur to give a massage. A physiotherapist can show you how.

Massage is not suitable for all people. Massage may even pose a health risk to people with certain medical conditions such as some cancers, deep vein thrombosis, skin conditions and certain forms of arthritis. Always check the person's care plan and speak to your supervisor or a health professional before giving a massage.

2

Diversional therapy
As the name implies, diversional therapy is used to divert a person's attention from their pain. Diversional therapy activities may include physical activities, relaxation, massage, meditation and social interaction. These may all help a person overcome their emotional and physical pain.

3

Distraction

Listening to music or using imagery techniques can be helpful during brief episodes of pain or painful procedures. Music therapy is used to reduce disruptive behaviour such as aggression in people with dementia.

4

Hot and cold applications

Applying heat and ice packs can reduce the pain caused by muscle spasms. Make sure you know when it is appropriate to apply them and how they should be applied. Your supervisor can instruct you or you should follow the instructions in the person’s care plan.

5

Aromatherapy

Aromatherapy uses plant and essential oils to provide therapeutic relief from pain. Oils may be added to an oil burner and inhaled or mixed with a carrier substance, such as a sorbolene-based cream, and gently massaged into specific areas of the person’s body. Aromatherapy may show positive results in people with various symptoms.

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

6

Complementary and alternative therapies

There is an increasing use of complementary and alternative therapies for palliative care people and older people. People who are unable to tolerate or who refuse pain medications as part of a palliative approach may benefit from appropriate complementary therapies. These therapies may also fit better with a person’s cultural preferences and may enhance their sense of control. Complementary and alternative therapies should be administered by trained professionals.

It is important to ask the person if they are already using any complementary and alternative therapies, as some may interact with traditional medications.

7

Support groups

Support groups consist of people with similar problems or illnesses. A trained professional may lead these groups, which discuss members’ situations and problems and provide a supportive environment in which to do so. Your supervisor will let you know if the person is receiving this type of support. Remember, it is the person’s right to seek the treatment they prefer.

Follow the care plan

It is important to be familiar with a person’s pain-relief directives in their care plan and to understand how to follow them. The instructions will describe what pain relief is to be provided, 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.

You must have a clear understanding of your level of authority in terms of the pain relief requirements of your person. Support workers should not administer medications. If you are unclear of your responsibilities in this regard, ask your supervisor for advice or strictly follow the directives outlined in your person’s care plan.

Here is an explanation of what a person’s pain management may involve and the people responsible for each aspect.

Pain management

A person's pain management may involve:

- non-opioids, such as paracetamol or aspirin, which are delivered orally (by mouth), unless this causes ongoing nausea and vomiting or the person has difficulty swallowing
- opioids, such as Panadeine Forte, orally for moderate high-level pain
- opioids, such as codeine or morphine, orally for high-level pain
- regular analgesic medication (for example, every four hours) to prevent pain returning
- drugs, such as anti-depressants, to help the client remain calm or steroids to reduce any swelling.

Person responsible

- A registered nurse (division 1) must administer morphine regularly via a drip bag at the appropriate rate, give prescribed anti-depressant medication to the client in the morning and administer sedatives for swelling.
- Carers/support workers may apply hot and cold packs and/or aromatherapy (the carer's role in administering alternative therapies will vary depending on the training requirements of the therapy).
- A physiotherapist may assess and treat musculoskeletal disorders; however, clients may be assisted with ongoing exercises by carers/support workers.
- Carers/support workers may use music therapy; that is, play the client's favourite music as a means to calm them.
- Carers/support workers may give clients a daily hand massage with essential oils.
- A diversional therapist may run a daily meditation session for clients.

Example

Pain-relief directives in the care plan

Care plan

Client name: Mr Roy McDougall

Birth date: 03/09/1934

Room: 3B

Worker name: Julie Rinaldi

Assessment date: 04/08/2016

Diagnosis:
Early stage dementia, significant hearing loss, reduced blood supply to the heart caused by coronary artery disease, prone to deep-vein thrombosis (DVT) in legs, uses a four-wheeled walking frame following surgery for fractured hip. Has developed a pressure area post-surgery, with necrotic tissue, on right leg. The foot is also heavily infected.

Example

Personal details:
Male, 82 years old, Roman Catholic, likes listening to country and western music, enjoys the outdoors, cars and football.

The client's environment:
Single room in a residential aged care nursing home. The room has photos of his favourite football team. He has a collection of CDs and the family have transferred them to an iPod so he can listen to music whenever he wants.

The client's condition:
Often in pain, has balance issues and is often shaky, at risk of falling in the shower, experiences breathlessness, shows signs of mental confusion, is often frustrated and angry. The client has mild cognitive decline associated with the dementia and wears a hearing aid but forgets to switch it on.

How to meet the client's physical needs:
The client is assessed regularly for pain and discomfort and the appropriate intervention is taken. Medication is provided for side effects such as vomiting and diarrhoea. Anti-thrombotic stockings are required to prevent DVT. Shower chair is provided and carer is to supervise personal grooming. Specific dressing management routine is undertaken for infected foot that attends to the pain and the smell. Alternative therapies are used, such as massaging legs and feet with essential oils. Oxygen is provided when appropriate. Opioids are to be administered regularly via a drip bag at the appropriate rate. St John's Wort is also used for depression and to help Roy remain calm. Rest time has been allocated during the day.

Practice task 16

1. Who is legally allowed to administer an opioid medication to a person?

2. List two other methods that could be used to treat pain other than medication.

Click to complete Practice task 16

4C Evaluate and document the effectiveness of pain management strategies

One of your roles in pain management is to observe the person to monitor whether the pain-management strategies used are effective. This means regularly reviewing the person's appearance and comfort, and documenting when pain occurs and how severe it is. Members of the healthcare team can then take your observations into consideration when making decisions about the person's treatment.

You are in the perfect position to monitor a person's pain, especially if you have built an effective relationship with the person in which they talk openly and honestly about how they feel. In addition to asking the person about the location, quality and severity of the pain, you can also provide other information to the team. This information may show that:

- the pain relief delivered is effective and the person is no longer in pain
- the client is still experiencing pain at the same level
- pain appears to be increasing.

Evaluate pain strategies

There may be side effects from the medication a person is given to manage their pain, such as vomiting, drowsiness, confusion and constipation. It is important to note that different people may have different reactions to the same medication.

People should be regularly monitored to evaluate their pain-management strategies. Your supervisor will explain what you should look for.

You must accurately document all observations as soon as you see them. In some cases, you may need to notify your supervisor either by phone or in person, especially if you believe the person's condition has worsened. It is important to note that a person's appearance and behaviour may be the result of their condition and not the treatment. However, you should document everything you notice and the healthcare professionals will make a judgment about the reasons.

Here is what you should be monitoring.

What to monitor

- The person's appearance; for example, whether they look pale, if their face shows signs of pain, such as their eyes being screwed up or they're biting their lips
- The person's posture; for example, whether they are curled up, slumped over, clutching a specific part of their body or if they look relaxed and comfortable
- The feel of their skin; for example, whether the person's skin is hot, cold, dry, clammy or normal for their condition
- Their behaviour; for example, if the person is moaning, crying or calm; if they are not sleeping; if they are refusing to eat or drink; difficulties communicating or confusion
- Any smells; for example, unusual smells in their urine, faeces, vomit, body, breath or coming from bandages
- How the person feels; for example, if they say their pain seems worse or has moved to another area or if they have a temperature
- How long the pain relief is effective; for example, whether the person asks for more pain relief before the next dose is due

Example

Pain management interventions

Care notes

Client name: Joe Ricardo	**Date of birth:** 4 October 1930
Date: 25 September 2016	**Time:** 11.30 pm

Observations:

Client behaviour – Client looks pale and has hot skin. Client is also anxious and unsettled. Has identified is annoyed because of burning pain.

Level of pain – Moderate

Location of pain – Upper body, stomach area

Intensity of pain – 8/10

Assessment type – Question-based/verbal rating

Action:

Care worker – Notified the nurse on night duty at 11.20 pm and stayed with the client until the nurse arrived. Care worker applied cold packs to the temples and massaged arms and hands with essential oils. Dimmed lights and played client's favourite music and sat with the client until he had fallen asleep.

Nurse – Nurse to administer opioid medication (morphine) regularly via drip at the appropriate rate and 1 x sleeping tablet (temazepam) to help the client sleep.

Worker name: Bruno Agulera	**Signature:** *Bruno Agulera*

Practice task 17

Explain three observations that you would make to see if the pain relief is effective or not effective

Click to complete Practice task 17

4D Understand how to address misconceptions surrounding the use of pain-relieving medication

There are often misconceptions about pain treatment, which may cause family members, carers and other staff to be concerned about the treatment being administered. For example, they may think the person will become addicted to the medication or fear adverse effects of the medication. Language differences and cultural issues may also impact the way people think about pain-relieving medication. Everyone should feel confident that they can ask questions and seek clarification about analgesics and additional therapies that are given to the person. They should be able to provide feedback; for example, if they feel the medication is having a negative affect such as making the person drowsy or nauseous.

Clarify common misconceptions

Palliative care workers should be aware of the types of queries they may receive about treatment in general and about specific treatments. If they can't answer a particular query, they should refer it to their supervisor or the most appropriate person such as a registered nurse, doctor, physiotherapist or diversional therapist. Misconceptions should be dealt with as quickly as possible to ensure everyone understands why the treatment is being given and the impact of any side effects. Staff members understand the reason for the treatment and can provide the person and their family members with accurate information so they can make informed decisions about maintaining or discontinuing medication or treatment.

Following are some commonly expressed statements related to misconceptions about pain-relieving medication, the best response to these misconceptions and who you should refer to for further clarification.

Pain relief should only be given for pain currently present

Appropriate response

- I will seek clarification about this and get back to you with an answer.

Person to refer to for clarification

- Doctor

Doctors and nurses are the best judge of a person's pain

Appropriate response

- I will refer your comment to your doctor and the nurse on duty and one of them will come and see you as soon as they are free today.

Person to refer to for clarification

- Doctor, nurse

People should not receive pain relief until cause is determined

Appropriate response

- One of the aims of a palliative approach is to provide relief and comfort to the person when a cure is no longer possible. It is an important responsibility for the whole palliative care team to understand and implement strategies to promote comfort as a response to pain after an assessment of the person has been conducted.

Person to refer to for clarification

- Nurse, palliative care team leader or supervisor

The person may become addicted to pain-relief medication

Appropriate response

- Drug addiction is often associated with people misusing drugs. However, addiction is not an issue when opioids are used correctly to relieve pain. I will organise for the doctor to come to see you later today to discuss any concerns you may have.

Person to refer to for clarification

- Doctor

Strong analgesics may shorten a person’s life

Appropriate response

- I’ll explain your concerns about the safety and effectiveness of strong analgesics to your doctor and get back to you.

Person to refer to for clarification

- Doctor

Pain management alone is not palliative care

Appropriate response

- Yes, pain management alone is not palliative care. Palliative care enhances the person’s quality of life by treating pain and physical, psychological, social and spiritual problems in a holistic manner.

Person to refer to for clarification

- Nurse, palliative care team leader or supervisor

The person is too drowsy to communicate with family members

Appropriate response

- 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.

Person to refer to for clarification

- Nurse, palliative care team leader or supervisor

Common misconceptions specific to opioids

Ask your supervisor to explain anything you are unsure about so you can provide the person accessing the service and their families with accurate information regarding the use of pain-relieving medication. Find out what information you may pass on to the person and families and what information should be provided by a professional healthcare worker. For example, you may be allowed to explain that opioids are the safest and most effective pain medicine for moderate to severe pain in most people. Always refer to your organisation's policy and procedures or refer the query or issue to the appropriate person.

Below are some common misconceptions specific to the use of opioids.

There is a limit to the length of time a person can use morphine

- There is no limit to how long a person can use morphine. The physical and emotional experience of pain is different for everyone; therefore, the use and dose of morphine required varies from person to person. In palliative care, morphine is usually started at a low dose and is continued until the pain is relieved with minimal side effects. Additional medication may be required depending on the type of pain.

Using opioids now reduces effectiveness in the future

- This is not true, 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 use opioids, they should be used.

The person will become addicted

- Addiction is not an issue when opioids are prescribed and used under the supervision of qualified healthcare workers to relieve pain. Rather, drug addiction is associated with people who misuse drugs for their effects.

Morphine is only used when death is imminent

- 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 many months before they begin to deteriorate or are close to death and not everyone who is dying requires morphine.

Example

Case note

Case note

Name: Graham West

DOB: 12/07/1939

Date: 5 March 2016

Time: 10.45 am

Observations:
Mr West, who has rheumatoid arthritis, complained of pain that was not relieved by pain medication or heat packs and rest.

Action:
Notified the care team leader at 10.40 am.

Worker's name: Aaron Wisley

Signature: *A Wisley*

Practice task 18

1. Explain four common misconceptions regarding pain-relieving medications.

2. Explain why pain management alone is not palliative care.

Click to complete Practice task 18

Summary

1. Pain may be either acute (brief and severe) or chronic (long lasting).
2. In palliative care, a client's pain is usually chronic and may be due to a combination of their disease, their treatment, the ageing process and emotional pain caused by fear and distress.
3. The client's care plan identifies the type of pain they may have and the care directives for managing it.
4. Providing accurate, current and clear information about a client's pain is essential and an important part of working in a palliative care environment.
5. To make sure the client is comfortable, calm and free of pain you can provide emotional support and general care techniques. You must never administer medication.
6. Pain-relief measures may only be administered by an authorised member of the palliative care team; for example, a registered nurse (division 1) or doctor.
7. You must regularly review the client's appearance and comfort, and document when pain occurs and how severe it is.
8. Language differences and cultural issues may also impact the way people think about pain-relieving medication.
9. Always refer to your organisation's policy and procedures or refer the query or issue to the appropriate person.

Learning checkpoint 4

Respond to signs of pain and other symptoms

This learning checkpoint allows you to review your skills and knowledge in responding to signs of pain and other symptoms.

Part A

1. List and explain two common misconceptions regarding pain-relieving medication.

2. Who should the personal support worker report to when they observe a person they are supporting is in pain?

3. What actions should the personal support worker take if a person accessing services refuses food?

4. If a person who is at the end of their life is unable to take fluids orally, what care strategies should be implemented?

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 expresses her father's concern 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 and 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 the 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. List three care strategies that the personal care worker could implement for Katie to assist in managing her pain.

2. Explain three evaluations the personal care worker can undertake to assess the effectiveness of pain and comfort interventions.

Topic 5

In this topic you will learn how to:

- **5A** **Identify changes that have been made and reviewed in the care plan**
- **5B** **Provide a supportive environment for the person involved in end-of-life care, their family and carer**
- **5C** **Provide care in accordance with the person's preferences and culture**
- **5D** **Maintain dignity of the person at end of life and following death**
- **5E** **Recognise signs of imminent death or deterioration and report to appropriate person**
- **5F** **Provide emotional support to other people, carers and families when a death occurs**

Follow end-of-life care strategies

It is important to focus on the care of the person, their family and carers when the person's death appears imminent. End-of-life experiences may vary from person to person depending on their medical condition, treatment, beliefs, values, culture and spirituality. Regardless of a person's situation, each person is entitled to optimal end-of-life care. To do this, it's important to regularly check the care plan.

5A Identify changes that have been made and reviewed in the care plan

It is one of the main responsibilities for the personal care worker to review and update the person's care plan. The care plan needs to reflect any changes in care delivery, in line with changes in the person's condition and wishes.

In many facilities it is a requirement of the work role that care plans are updated on a regular basis. This generally occurs at the end of the shift in readiness for the next shift to review. The care plan is a dynamic document that reflects the person's condition and is a legal document.

By regularly checking the care plan, a personal care worker can be confident that the care delivered to a person is the most appropriate, respects the person's wishes and is responsive to the person's needs.

If a change has occurred in the care plan that the personal care worker is not confident in delivering or unsure whether this falls within their scope of practice, the matter should be referred to the supervisor for clarification. The care plan should be checked at the start of the shift and regularly checked over the progression of the shift.

Changes to the care plan and implementation of care

The care plan will change as the person's condition changes. When signs of imminent death are present there are often frequent changes to the care delivery to meet the changing needs of the person. The end-of-life care plans often have directions and planning that encourage good communication between all members of the palliative care team and family. The individualised care plan allows the person's care needs and those of their family to be met. It promotes co-ordination among the multi-disciplinary team to provide high-quality care. The person is able to decide on the setting of end-of-life care and delivery of care can occur in the setting chosen. The care plan will include details of services that are being used by the person and this can change depending on the person's care needs and those of the family/carer.

Example

Case note

Care notes

Client name: Marjory Bicknell	**Date of birth:** 3 July 1938
Date: 3 January 2016	**Time:** 10.30 am

Observations:
Marjory was conscious and able to talk and listen. She showed signs of mental anguish and frustration today. Her care plan says she is to be admitted to a nursing home as her condition has deteriorated; in end-of-life stage now. Spoke with her and she now says she wants to stay home. She told me:

‘This is where I want to spend my last days. I want to die where I have lived for the last 50 years with my husband and children. I miss my husband terribly and I want to feel close to him. My husband died in our house seven years ago. This is where I belong.’

Action:
Reassured Marjory that it is her decision and arrangements can be made to continue care in her home. Notified Aline (care team leader).

Worker name: Bradley Loak	**Signature:** *Bradley Loak*

Practice task 19

1. When should the care plan be reviewed and updated?

2. Why should the personal care worker regularly check the care plan?

Click to complete Practice task 19

5B Provide a supportive environment for the person involved in end-of-life care, their family and carer

A supportive environment is one that is comfortable and non-threatening, and where actions are taken to make conditions easier. A key responsibility for those involved in palliative care is to ensure that information is regularly shared between all team members, including the person accessing the service, their family members and carers; and that the person's concerns and fears are listened to and they are made to feel their contribution is valuable. The emphasis at this stage of a person's life is on ensuring their comfort; a palliative approach does not mean withdrawing care.

Family and carers play a particularly important role in assisting to manage symptoms, such as distress, by communicating with the person and helping them with their physical care needs. The person accessing the service must be supported both physically and emotionally. As the person's death nears, they may need additional support.

Support family and carers

Family members and carers may also require support. Watch this video for information about supporting families.

v0216

Family members may experience emotions such as anger, grief, denial, guilt and hopelessness. They may become depressed, anxious or confused, and may exhibit changes in mood such as becoming aggressive. These are common reactions to death. The care team should have strategies in place to support and manage these behaviours.

Help the family prepare

To help prepare the family for their relative's impending death and to help them cope with their loss, members of the care team should provide a holistic, team-based approach.

Here is a range of support strategies the team can use.

Support strategies

- Keep the family and carers informed of changes to the person's condition.
- Arrange regular meetings with the family.
- Ensure that treatment and care reinforces the idea of the person as a whole.

- Respond to any dissatisfaction expressed about the care given – this may reduce the complexity of the grief and guilt experienced by family members and carers.
- Recognise that family members and carers have already made a significant contribution to the person's wellbeing.
- Encourage family members to have an active and equal role in the care planning process.
- Provide information about grief and loss.
- Suggest counselling services or refer them to a pastoral care worker or social worker if appropriate.
- Provide support to make the family's access to the person easy, such as allowing 24-hour visitation.
- Give the person and their family privacy.
- Follow care directives for pain relief and comfort measures.

Emotional impact of diagnosis and death

Palliative care services are arranged for people when there is a diagnosis of a life-limiting illness. In some cases this diagnosis can occur early in the implementation of palliative care and the person, family and carers have time to work through the stages of grief before coming to acceptance. For some people, diagnosis and end-of-life occur very quickly in succession. The grief reaction can be heightened and people often have not accepted the imminent occurrence of death.

Sudden death is when death is unexpected; for example, following an accident, heart attack or when a person is expecting to die over a period of time suddenly dies.

Specialist members of the palliative care team need to be involved from the commencement of the services to enable best practice and outcomes for the person, family and carers and people involved in caring for the person.

Here are possible symptoms of grief that people may experience when someone they know and love dies – suddenly or over a period a time.

Symptoms of grief

- People may tire easily and be physically inactive.
- People may become manic and way-too-busy.
- They may tenaciously hang on to clothing or other belongings.
- They may have really poor concentration, be unable to think clearly, or have trouble making decisions.
- They may have no appetite at all, or eat too much.
- They may sleep too much or not get enough sleep.

A palliative care worker's responsibilities

Below are examples of a palliative care worker's responsibilities for providing support to the person, family members and carers.

Support the person, family members and carers

1 **Listen to issues**
If a family member, carer or person complains about another worker, listen carefully, record their views and tell them you will follow it up with your supervisor.

2 **Answer questions**
Answer questions such as, 'Can I see my friend outside of visiting hours?'

Questions such as, 'How long have I got to live?' should be referred to health professionals.

3 **Act on queries promptly**
If a family member asks for information about counselling services, follow up immediately. Provide brochures and contact details of relevant services.

4 **Encourage family members to continue their care-giving role**
Suggest ways family members can offer support to the person dying; for example, by listening to them or playing their favourite music.

5 **Give the person what they want**
Giving the person what they want in accordance with workplace policies and procedures and legal requirements. If a person prefers alternative therapies, arrange for these to be provided in consultation with your supervisor.

6 **Make arrangements with healthcare professionals**
Liaise with appropriate healthcare professionals, such as a therapist or counsellor, under instructions from your supervisor.

7 **Refer issues**
Referring issues to the appropriate person if you don't have the required skills or knowledge

If a family member asks you to increase the person's pain medication, record this in the care notes and notify your supervisor.

8 **Provide privacy**
Provide as much privacy as possible at this time; for example, offer a private room for taking visitors.

9 **Provide respite for carers**
Offer and arrange respite services if carers or family members appear overly stressed and fatigued.

10 **Make processes and procedures as simple as possible**
Assist family members and carers to complete any necessary paperwork.

11 **Arrange bereavement support**
Put family members in contact with the relevant bereavement services.

12 **Keep care notes up to date**
Document all observations and comments made by family members at this time.

Practice task 20

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

Case study

Rhonda is a care worker in an aged care facility. Penny, a client, is admitted there after being discharged from hospital. It was found on admission to the hospital that her breast tumour had not responded to treatment and that prognosis was only 2–3 months. Penny up until this point in time had resided at home independently but the tumour was aggressive despite all treatments. Penny was unable to undertake activities of daily living and her husband was not coping with Penny's health deterioration. Penny underwent a radical mastectomy three months ago and had undergone extensive chemotherapy, causing loss of hair. On admission to the facility, Penny was very depressed.

1. Describe four measures the palliative team can take to assist Penny's family prepare for end-of-life.

2. What key responsibility does the palliative care team hold for Penny and her husband?

Click to complete Practice task 20

5C Provide care in accordance with the person's preferences and culture

Meeting the person's wishes becomes even more important as they enter the end-of-life phase, even if they are incapable of knowing or understanding what is happening to them. Instructions in the care plan and advance care directives regarding the person's preferences must be understood and followed. These may include:

- who they want to see
- the need to be touched
- rituals they want to follow such as praying
- the need to be left alone
- the need to be surrounded by relatives and friends
- being spoken to in their own language
- how they want their funeral to be conducted.

Changes in views and preferences

The circumstances of a terminally ill person may change rapidly, so the team must review the care plan with family members, carers and others to identify the person's preferences and whether they are current. Services may need to be modified; for example, if a person has been taking part in social activities but is unable to anymore, the team should determine ways that social interaction can still take place. They may encourage friends to visit and bring books to talk about or music to play. They may be encouraged to talk about the football. As the person moves towards death, they may experience stronger spiritual, religious and cultural views. Any changes should be recorded in the person's care plan.

A person accessing the service may:

- request more visits from their religious representative
- change their mind about cremation and want a burial instead
- decide to refuse treatment in accordance with their religious beliefs
- decide to access voluntary assisted dying if they are located in Victoria
- want a different pain relief treatment
- want to return home.

Example

Support family members to be involved

Elizabeth consistently visits her sister, Bea, for several hours each day. She is usually asked to leave the bedside when the palliative care team is in attendance. One day, Annie, a palliative care worker, asks Elizabeth if she would like to assist with Bea's care and if there is anything she would like to do for Bea. Elizabeth says she would just like to help make Bea comfortable. 'I could even wash her. When I was about seven years old and Bea was 16, I was very ill with a high fever. I remember Bea sponging me and how it seemed at the time that she helped save my life. I know I can't do much for her now that she's dying but I'd like to repay her if I can.'

Example

Elizabeth is very pleased to be included in the palliative care team and massages Bea's limbs with fragrant oil and assists with other care when appropriate. When Bea dies, the team refers to a note in her care plan, which says that Elizabeth wants to assist by washing Bea's body and dressing her in her favourite nightgown.

Elizabeth expresses her appreciation for this involvement, stating how much it has assisted her with the closure of her relationship with her sister.

Practice task 21

1. List four preferences a person might express regarding their care at end-of-life.

2. What changes may a person make in their care plan in reference to end-of-life care?

Click to complete Practice task 21

5D Maintain dignity of the person at end of life and following death

Different people may have very different views about what dignity means. In the face of a progressive illness or the ageing process, the meaning of dignity may change over time. At first, most people like to retain a sense of privacy and dignity when it comes to their personal grooming. However, as an illness progresses and they are less capable of looking after themselves, these tasks may need to be carried out by a member of the healthcare team. For some people, this represents a loss of dignity. Your perception of dignity may differ from that of the person. Family members and carers may also define dignity differently. The notion of dignity may be influenced by the nature of the person's illness, as well as culture and ethnicity. You should always be alert to whose perspective of dignity is being considered.

The best way to understand what dignity means for an individual person is to ask them and their family what the most important factors are for them to enhance and maintain their dignity during end-of-life care.

Factors that may minimise a person's loss of dignity include:

- a sense of control
- strengthened relationships with loved ones
- the capacity to communicate
- recognising family members and friends
- being continent
- adequate pain and symptom management
- avoiding inappropriate prolonging of their life.

Strategies to maintain dignity

The person's dignity must be maintained during end-of-life care and immediately following death.

Here are strategies for maintaining dignity during these times.

During end-of-life care

When death is imminent, the person's comfort, dignity and quality of care are very important. Practical comfort measures to manage end-of-life symptoms are often more effective than other interventions. To maintain a person's dignity, consider:

- the most appropriate clothing for the person– day clothes or bed attire
- the person's preference to either remain in bed or be transferred to a chair
- massaging the person with lightly scented oil to remove hospital smells
- limiting the number of visitors to only those the person wants to see
- removing mirrors from the room.

Following death

It is crucial that a person's dignity is maintained immediately following their death. Each state and territory has legal requirements in relation to the death of a person, such as notification requirements and certification of death.

You must support the person sensitively and with respect, which may mean:

- following any cultural or religious rituals
- closing the person's eyes and placing their arms by their side
- placing a pillow under the person's head to prevent discolouration due to blood pooling, and a towel under their chin so their face does not sag
- maintaining the person's usual facial features; for example, replace dentures
- gently washing the body to remove soiled areas
- removing equipment, such as tubes, from the body
- providing the person's family and the palliative care team with the chance to say their farewells before the person's body is removed
- collecting the person's clothing and personal belongings.

Example

Maintain a person's dignity

Siobhan was admitted to the aged care facility following a long battle with colon cancer. Siobhan was immaculately groomed but due to the symptoms of the illness she was no longer able to independently manage her hygiene and grooming needs to the standard that she liked to maintain. Rebecca, her support worker, had seen the photographs of Siobhan before her illness made her unable to care independently for herself. Rebecca approached Siobhan's daughter who communicated that her mother was distressed by the fact that her makeup was not applied and her hair not coiffured to her usual grooming style. Rebecca reported the conversation to her supervisor, and documented in the case files. Siobhan's daughter brought in all of her mother's cosmetics and demonstrated to staff how to do her mother's hairstyle. Siobhan expressed her appreciation for their efforts and was noticeably more interactive with staff and visitors.

Practice task 22

1. List four factors that may help to maintain a person's dignity.

2. How can a personal care worker support a person sensitively and respectfully after death?

Click to complete Practice task 22

5E Recognise signs of imminent death or deterioration and report to appropriate person

End-of-life care refers to the phase where death is expected to occur within hours or days. An important aspect of a palliative care worker's role is to recognise when the terminal phase has commenced, along with the signs of deterioration and imminent death.

Here are some things to be aware of.

Changes to the person's body

- For some people, death may occur more quickly than expected, while for others the dying process may be longer than expected. However, immediately before death (hours to days), several of the following symptoms and signs may be present:
  - Loss of appetite
  - Profound weakness
  - Difficulty swallowing
  - Dry mouth
  - Weight loss
  - Irreversible daily deterioration
- In most cases the person will be bed-bound and their condition will require frequent intervention. Be alert and always notify your supervisor if you believe a person's condition is worsening. Make sure you know who you need to contact. All members of the palliative care team should be informed of the changes in the person.

Signs of deterioration and imminent death

- At some point, the severity and number of symptoms a person displays may increase as the person's condition rapidly deteriorates. Signs of deterioration and imminent death include:
  - shutdown of the person's external body functions
  - changes in breathing patterns, ranging from slow to irregular to rapid
  - a decrease in urinary output
  - drowsiness or a reduced level of response to verbal and/or physical stimuli
  - retained upper airway secretions
  - becoming semi-conscious, with lapses into unconsciousness
  - heart failure
  - uncharacteristic or recent restlessness and agitation
  - becoming detached and unresponsive
  - seeing visions of friends who have already died
  - letting go.

What to do if signs of imminent death are recognised

If you identify any signs or symptoms of impending death, you must follow your organisation's procedures. This may mean immediately informing the palliative care nurse, team leader or doctor, so they can conduct an assessment to determine whether the condition is reversible. If family members are present, you may need to ask them to leave the room so care can be administered. However, they have a right to remain present. When death is imminent and reversible causes have been excluded, the person's comfort must remain the ultimate goal. The family may also require more support at this time and you need to be able to provide this.

Example

Steps taken in response to signs of imminent death

Johan is admitted to a nursing home after he is discharged from hospital. His condition deteriorates rapidly and the staff contact the hospital palliative care service for support. As he has limited family support, Johan agrees that he would like Les, a volunteer from a local palliative care service, to sit with him. The palliative care worker arranges for this to happen. Two days later, Les finds that Johan is unresponsive, appears agitated and restless. He informs the palliative care worker who records the symptoms and immediately notifies Johan's doctor. Les sits with Johan for several hours, playing his guitar. Johan dies peacefully several hours later.

Practice task 23

1. List four signs of imminent death.

2. What should a palliative care worker do if they observe signs of imminent death for a person they are supporting?

Click to complete Practice task 23

5F Provide emotional support to other people, carers and families when a death occurs

When a person dies, everyone involved in their care may experience feelings of loss and grief. Different people will react in different ways. You need to recognise their emotional needs and provide support when a death has occurred.

After death has occurred, the bereaved individual typically feels much more than physical loss. The deceased person may have played many roles in their life; for example, a spouse may have been a person's lover, best friend, confidante, social partner, housemate, travelling companion, business associate, career supporter and housekeeper. With death, the bereaved individual loses someone who may have filled all these roles and who met those needs. In addition, they lose all the feelings, thoughts, hopes, wishes, dreams, assumptions, expectations and beliefs they shared with the loved one. In some cases, family members may not have resolved issues before the death.

Your role is to offer practical comfort measures to manage end-of-life symptoms and to know what to do when a person accessing the service dies.

Here is the normal range of responses to death.

Emotional reactions

- Shock
- Tearfulness
- Making no sense when they speak
- Fear
- Anger
- Guilt
- Detachment
- Helplessness
- Feeling free
- Relief

Physical reactions

- Hollowness in the stomach
- Tightness in the chest and throat
- Over-sensitivity to noise
- A dry mouth
- A sense of unreality
- Lack of breath
- Muscle weakness
- Fatigue or lack of energy

Mental reactions

- Disbelief
- Confusion
- Preoccupation
- A sense of the dead person's presence
- Hallucinations

Responses to grief

Responses to grief may occur together or one after the other; allow everyone to grieve and cope in their own way. Grief is the normal response to loss and may include physical, mental, emotional and spiritual responses. These are usually associated with unhappiness, anger, guilt, pain, and longing for the lost person or thing. Remember, grief is a continuing development – feelings of grief may change over time. It is also a natural reaction, and occurs in response to many types of loss, not just death. It also depends on the individual's unique perception of loss.

Grief may also be shaped by the worker's relationship with the person who has died, the nature of the person's death, gender, personality, culture, age, religion, availability and access to support and previous life and loss experiences. In some circumstances, a worker may experience a reaction so strong that it moves beyond normal grief to what is known as pathological (or complicated) grief, the symptoms of which are shown below.

The five stages of grief – denial, anger, bargaining, depression and acceptance – are a part of the framework that makes up our learning to live with the death of a person. The person who is dying and those close to them usually pass through these stages.

Stages of grief
Denial Denial is a conscious or unconscious refusal to accept facts, information, reality, etc., relating to the situation concerned. It's a defence mechanism. Of course, death is not particularly easy to avoid or evade indefinitely.
Anger Anger can manifest in different ways. People dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them.
Bargaining For some people, facing death can involve attempting to bargain with whatever God the person believes in.
Depression A preliminary level of acceptance with emotional attachment. It's natural to feel sadness and regret, fear, uncertainty, etc. It shows that the person has at least begun to accept the reality.
Acceptance There is some emotional detachment and objectivity. People dying can enter this stage a long time before the people they leave behind.

Support family and carers after the person's death

All of these reactions are part of the normal range of responses. Some people find it hard to communicate at this time. They may not be able to find the words to describe how they feel or they may fear they will break down when they speak. Some people may be ashamed to admit they are having difficulty coping or may not want to burden others with their feelings.

Here are ways you can support family and carers directly after and soon after a death.

Support directly after death	Support soon after death
▶ Wait patiently until they are ready to speak.	▶ Give the family the client's personal possessions.
▶ Listen to them; this helps validate their feelings of loss.	▶ Suggest bereavement counselling and support services.
▶ Calm them.	▶ Ensure family members understand how to meet the person's wishes.
▶ Just be with them.	▶ Provide any assistance you can in line with policy and procedures.
▶ Give them time to be with the deceased.	▶ Support carers displaying signs of extreme grief.
▶ Gently explain what the next steps are.	
▶ Wait patiently until they are ready to speak.	

Bereavement support for other clients

In a nursing home or hospice, death may be a regular occurrence. However, it may be very distressing for other people to learn of a death, witness the death of a person they shared a room with, or witness the reaction of family members. While witnessing a death can be very upsetting for other people, it gives them an understanding of how the palliative care team provides support to all those involved. This may give them comfort because they know that they too will receive this care when their time comes.

An important consideration is to allow families to grieve while making sure their grief doesn't impact others. This is especially the case for cultures that display emotions openly and loudly.

Here are ways you can support other people in line with your organisation's procedures

Supporting other people after a death

- Draw a curtain around the bed of the deceased.
- Explain what has happened to their roommate.
- Sensitively explain what is going to happen to the person's body.
- Explain that everyone reacts differently so they understand the family's reaction and are not frightened.
- Ask them if they would like any information about bereavement.
- Write a notice about the person's death in the facility's newsletter.
- Listen to the person accessing the service, their families and carers and discuss their thoughts and feelings towards death.
- Listen without interrupting while the person accessing the service is talking.
- Affirm and support the person accessing the service, their family members and carers when they share their feelings with you.
- Request more information to assist in providing support; for example, 'I'd like to know more about this'.
- Offer to follow up and suggest that you check in with them the following day; encourage them to let you know if they need to talk before then.

Example

Help to maintain dignity at end of life

Rukmani is a support worker at a day centre for people with dementia. She often sees family members when they visit their relative. One of Rukmani's clients is Rosa.

Today, Gina, Rosa's daughter, is upset when she visits her mother at the centre. Gina's mother has been deteriorating for the last three months and has now reached the end-of-life stage with a progressively deteriorating physical and mental condition. Rukmani takes Gina into a quiet office, makes her a cup of tea and talks to her about how she is feeling. Gina says that Rosa didn't know who she was this morning. Gina says that she is upset because she spends so much time caring for her mother and doesn't see anyone else. She feels very hurt when her mother doesn't know who she is. She also says that the children were quite frightened by their grandmother's confusion.

Rukmani explains to Gina that many family members of people at the end-of-life stage face this distressing time, when the person can no longer recognise their loved ones. She points out that if Rosa is talking to one of the children as if she is Gina, this shows that Rosa knows and remembers Gina, but has returned in her memories to the times when Gina was a child. She says the fact that she is talking to 'Gina' even though she is actually addressing the grandchild, shows her deep love for Gina.

Gina also states that she is finding it hard to accept that her mother is not acting or looking as she always did. Gina states that her mother had never let anyone see her without her full makeup and hair immaculately done. Rukmani asks Gina if she would like to do her mother's hair and makeup and will document this on Gina's care plan.

She suggests that Gina may like to attend the carer support group that runs from the centre. She also gives her some brochures and information sheets from Palliative Care Australia and gives her phone numbers for other support services in the local area.

Practice task 24

1. List and explain the five stages of grief that the person and/or families go through in palliative care.

2. How can a personal care worker support other people after a death has occurred in a facility?

Click to complete Practice task 24

Summary

1. Palliative care workers must follow the care plan and any instructions they have been given regarding a person's care.
2. It is very important to regularly review a person's care plan, making adjustments and ensuring all workers are aware of any changes.
3. A key responsibility for those involved in palliative care is to ensure that information is regularly shared between all members of the team, including the person, their family members and carers; and that people's concerns and fears are listened to and they are made to feel their contribution is valuable.
4. The circumstances of a terminally ill person may change rapidly, so the team must review the care plan with family members, carers and others to identify the person's preferences and whether they are current.
5. In the face of a progressive illness or the ageing process, the meaning of dignity may change over time.
6. It is important to understand that people, including carers, 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

This learning checkpoint allows you to review your skills and knowledge in following end-of-life care strategies.

Part A

1. Identify two common signs of grief a person, their family or carer might exhibit on diagnosis of a life-threatening or life-limiting illness.

2. Identify and explain the five stages of grief.

3. What actions can a personal support worker take to support a person's culture when providing end-of-life care?

4. List four care strategies a personal care worker can undertake to promote dignity for the person after death.

5. It is important to regularly check the care plan for any changes to the care delivery for a person accessing palliative care services. List two things that a person might change.

6. What does a supportive environment mean for people accessing palliative care services?

7. Identify two care strategies to support the family/carer after death has occurred.

Part B

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

Case study

Rhonda is a care worker in an aged care facility. Penny, a client, is admitted there after being discharged from hospital. An assessment prior to her discharge identified the following end-of-life symptoms:

- Loss of appetite
- Weight loss
- Profound weakness
- Changes in breathing patterns
- Hypertension
- Mental anguish
- Blood pooling along the skin
- Day-to-day deterioration

Penny is also bed-bound and over the coming weeks her condition deteriorates rapidly. She appears agitated and restless and begins to talk about her mother, who died many years before. Rhonda contacts the local hospital's palliative care service for support.

Two days later, on one of her care rounds, Rhonda finds that Penny is no longer responsive. Her breathing is irregular and, as Rhonda is watching, Penny lapses into unconsciousness. Penny's body temperature also appears cooler than the previous day. Rhonda immediately notifies Gemma, her team leader.

Gemma then informs the care nurse on duty and Penny's doctor. The nurse confirms that Penny is falling into a coma. Gemma asks Rhonda to sit with Penny, hold her hand and talk to her until she passes away. Gemma notifies Penny's family who live in the country and tells Rhonda she has done a good job. 'I don't know if it was any help but she seemed calmer while I was there,' Rhonda says.

1. List three signs of imminent death that Rhonda might have observed when caring for Penny.

2. Who should Rhonda report these signs to?

Topic 6

In this topic you will learn how to:

6A **Follow organisational policies and procedures when managing emotional responses and ethical issues**

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

6C **Discuss ethical issues or concerns with the appropriate person**

6D **Identify and implement self-care strategies to address the potential impact of your personal responses**

6E **Access bereavement care and support of other team members**

Manage your own emotional responses and ethical issues

Caring for people at the end of their lives can be exhausting because people working in palliative care constantly provide support to others, work in situations where suffering and distress are common and must deal with ethical issues. Palliative care workers need to know how to deal with their own reactions and responses to people accessing services who are receiving palliative care. They must be aware of the type of support available to them and strategies to help them cope with stress.

6A Follow organisational policies and procedures when managing emotional responses and ethical issues

All organisations have their own guidelines, policies and procedures that are based on legislation and industry standards. The policies of your organisation guide you as to what to do when making a decision or performing a task. The procedures are the step-by-step instructions for completing the task.

Policies and procedures must be made available to you. In some organisations, they are available on the organisation's intranet or in a hard-copy manual in the office or library.

You should be shown where the policy and procedures manual is located when you first start work. Your supervisor will also discuss your duties and obligations as outlined in your job description. It is your responsibility as a healthcare worker to be familiar with, and follow, these procedures. You have a duty of care to the people accessing services and co-workers to ensure that you uphold legislation and industry standards in the workplace at all times.

Included in palliative care policies and procedures is information about end-of-life issues, such as emotional support and related ethical dilemmas.

Understand your own beliefs

It is important that you understand the palliative approach to care, the philosophy behind it and your own feelings and beliefs.

Everyone has different values, ideas and thoughts regarding death and dying. These are formed by a person's background, upbringing, education and culture. However, when you work in palliative care, you must understand and follow the policies and procedures of the organisation you work for. These may be in conflict with your own beliefs and attitudes. If this is the case, you should discuss this with your supervisor.

Working in this area can be very rewarding and satisfying. However, discussing end-of-life issues with people suffering a life-limiting illness is not easy. Taking the person's, their family's and carers' emotional concerns into account and responding empathically can be very stressful and frustrating at times. You should acknowledge your own need for support and self-care as a palliative care professional.

Death and dying reactions

It is important to understand your own emotions about death and dying. The first thing to realise is that everyone is different. Some people remain cool and detached. Others may feel as emotional as the person's family members and carers. A person's culture and background may also affect the way they perceive death and dying.

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Understand your role and responsibilities

Ensure you understand your role and responsibilities regarding following policy and procedures when managing emotional responses and ethical issues. Remember, always ask your supervisor to clarify anything you don't understand – it's better to ask than do something incorrect or unethical. Workers may have legal action brought against them if they do something that is not in accordance with legislation and the organisation's policies and procedures.

Below are areas covered by policies and procedures for managing emotional responses and ethical issues.

Ensure confidentiality and privacy

- Never discuss a person's condition or comments they make to anyone except appropriate members of the care team.
- Make sure person's files are stored securely and are only accessible to the appropriate people.

Provide bereavement support

Refer and allow adequate support for family members and carers so they can cope better with the bereavement process. Support includes sensitive communication, allowing family members and carers to express their feelings and providing information about the organisation's bereavement care program.

Support the person's family

- Explain to the family what a palliative approach means.
- At all times, promote a caring attitude that is sensitive, empathetic, compassionate and demonstrates concern for the family.
- Provide information and emotional support to the family.
- Be sure that any decisions relating to the person are made with the family.
- Make sure all communication is open and clear to avoid conflict and confusion about palliative care goals.
- Let everyone know about their rights and responsibilities regarding decision-making.
- Build respectful and trusting relationships with all family members.

Maintain the person's dignity and quality of life

- Relieve suffering and discomfort as directed.
- Promote a person's sense of dignity by listening to their wishes and helping them remain as independent as possible.
- Remain sensitive to the values, social beliefs and spiritual and cultural differences of the person, their family members and carers.
- Provide the desired physical comfort and emotional support.
- Respect the person's wishes and preferences when making pain relief and treatment decisions.

Provide spiritual support when requested

- Encourage the person to continue their spiritual and cultural beliefs.
- Arrange for appropriate pastoral care.
- Understand the role spirituality and religion have in the lives of the person, their family members and carers.
- Listen to the person and provide a healing and peaceful atmosphere.

Follow care plans and the person's preferences

- Review the care plan regularly and encourage ongoing discussions with the person, their family members, doctors and palliative care team members.
- Implement strategies and actions (interventions) that are prescribed to help the person achieve or maintain their care goals.

Implement advance care directives

- Follow advance care directives recorded in the person's care plan.
- Understand that every individual has worth, dignity and basic human rights.
- Follow your state or territory's guidelines regarding advance care directives.

Understand and respect cultural issues

- Provide a supportive presence and avoid judgment.
- Be familiar with the person's beliefs and requirements.
- Allow the person to guide all spiritual interventions.

Remain sensitive to, and respect, customs that are different from your own. To do this, you should understand the meaning of death and dying in other cultures and how other cultures deal with this process.

Provide psychological support

- Encourage the person to discuss how they feel about their life-limiting illness and death, what they want and who they want to assist them.
- Be a good listener and build a supportive relationship based on effective communication and honesty.

Support social intimacy and sexuality issues

- Provide social interaction, continuing personal contact and a strong support network for the person.
- Understand family relationships to ensure you are non-judgmental and accept the family's situation.
- Understand the importance of touch for the person.

Example

Understand your role and responsibilities

Seth is a newly qualified personal care worker and commences his first shift in the aged care facility he is employed with. Seth has never seen anyone die before and is anxious when he learnt that he was to care for Joe who recently moved into the palliative care area. Seth reports his fear to the supervisor who arranges for a mentor for Seth and spends time going through the care plan and allows Seth to ask questions to clarify his responsibilities and duties. The supervisor informs Seth that Joe has requested a male nurse, if possible, to provide his care. Seth finds the responsibility of caring for Joe very rewarding and a close relationship grows between Seth and Joe over the last three months of Joe's life.

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Practice task 25

1. Explain your obligations in relation to confidentiality and privacy.

2. Explain how you can support the family/carer of the person accessing palliative care.

Click to complete Practice task 25

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

Palliative care means dealing with suffering, pain, distress, anger and grief. People accessing the service may suffer pain. People accessing the service will die. Family members and friends may be demanding or take their grief out on the worker. Dealing with ethical issues, such as ending a person's life by taking them off a life-support system or not providing further treatment, is very emotional. You must be adequately trained to cope with death and bereavement as palliative care is challenging.

Palliative care workers must maintain a steady, professional manner and display understanding, warmth and empathy towards others. They should also maintain their own health and fitness. There is often little time to grieve or talk about feelings with others. This may result in high stress levels for workers.

Recognise and deal with the potential impact of your personal responses on others

Different people will respond differently to a person's death. However, the way a palliative care worker responds to death and dying has an impact on others such as their co-workers, family members, carers and other people who access the service. The worker should provide a calming, supportive environment, which is not possible if they are crying and unable to cope. They may have experienced a loss of their own and be grieving or a death may be one of many recent deaths they have had to deal with. They may have formed a close bond with a person accessing the service in their final days. All these things may cause an emotional response in a worker.

You may experience a range of emotions such as sadness, confusion, fear and anger. Below are ways your reactions can have an impact.

How your reactions may affect your work and others

- Your work becomes affected by your feelings when you can't perform effectively anymore and are unable to provide the support necessary to family members and friends.
- If you withdraw as a result of emotions, people accessing the service in the future will be deprived of your high-quality care and effective support.
- You may develop a fear of death and dying.
- You may become frustrated and depressed as a result of the powerlessness of a person's situation and your inability to help.
- You may be personally affected and grieve as if the person accessing the service was your own family member.

- You may find yourself unable to talk to others about their grief.
- You may feel unable to cope with the physical and mental stress. When palliative care workers put the needs of the person who is accessing the service above their own, this is called compassion burnout.

Typical and complicated reactions

In some cultures, people may behave very emotionally when faced with death, while others regard it as an important part of life. There are also cultures where death is not often spoken about and people are embarrassed or ashamed to reveal how they feel. You may display a range of emotions as a response to experiencing loss and grief.

Typical reactions may occur altogether or one after the other. Everyone should be allowed to grieve and cope in their own way. In some circumstances, a worker may experience a reaction so strong that it moves beyond normal grief to what is known as pathological (or complicated) grief. Below are the typical reactions to death you may have when you first start working in palliative care, and indications of complicated grief.

Typical reactions

- Crying and sadness
- Poor concentration
- Confusion and fear
- Anger
- Silence
- Stress and feeling burnt out
- Feeling isolated
- Feeling uncomfortable or ill at ease with family members

Complicated grief

- Pangs of severe emotion
- Distressing yearnings
- Feeling incredibly alone and empty

Raise issues with appropriate people

You should talk through the issues you have about death, dying and grief with your supervisor or an appropriate person with expertise in bereavement. This may be a bereavement counsellor, psychologist or clergy. It is useful to keep a list of contacts for easy reference – you may need them yourself or for members of your team.

Learn to recognise when this type of support is needed and take action to receive it so you remain an effective team member. A worker should not continue to work when under extreme stress or when their behaviour negatively impacts others. While you may find it difficult to talk about personal emotions or clearly articulate the problem, the important thing is to recognise and acknowledge your feelings and seek help.

Example

Emotional responses

Sophie, a new palliative care worker, is caring for Joan, who has dementia. Joan is now also experiencing pain due to other conditions. Joan's daughter Marilyn can't bear to see her mother's discomfort and asks Sophie to make sure additional pain relief is provided. However, Joan has made advance care directives before dementia had set in, which state that she doesn't want any pain relief beyond the usual treatment. Marilyn demands that her mother's preferences be overridden.

Sophie becomes very angry with Marilyn and tries to avoid her. Marilyn puts in an informal complaint regarding the care Sophie is giving to her mother. Sophie asks her co-worker Gary for his advice about what she should tell Marilyn and what else she should do. Gary explains that workers must always uphold their client's wishes. He also tells Sophie that she should document the conversation she had with Marilyn and notify her supervisor immediately so the matter can be discussed. Joan's wishes are upheld and all members of the team and family agree on the course of action. After discussion with the supervisor, Sophie acknowledges that her anger towards Marilyn was an emotional reaction to Joan's condition. Sophie and Marilyn are then able to work together to care for Joan.

Practice task 26

1. What is not a typical reaction?

2. Describe three ways your reactions may affect your work and others.

Click to complete Practice task 26

6C Discuss ethical issues or concerns with the appropriate person

There are many ethical issues regarding death and dying. You should be familiar with the issues that may arise. These may be discussed at team meetings, family conferences or debriefing sessions. In some major hospitals there is an ethics committee, which guides the medical team in making appropriate decisions. Ask your supervisor if you are unsure about how these decisions impact your work.

When you first start work, your training includes becoming familiar with the types of concerns and issues that are part of caring for people with life-limiting illnesses or who are at the end of their lives. You will also be instructed on how to respond to these issues and concerns. In many circumstances, it may be easy to follow instructions you are given; however, there may be times when you need to refer an issue to your supervisor if it is beyond the level of your authority or skills.

In a palliative care environment, the rights of the person accessing the service and family members must always be upheld. If rights are not upheld, it may become an ethical issue. People accessing the service and families may complain or, in some cases, take legal action.

The rights of people and their families include the right to:

- privacy and confidentiality
- dignity
- choose or refuse treatment
- make their own decisions such as the type of care they want, including pain relief and whether or not they want their life to be prolonged
- have their preferences acknowledged
- be provided with information about their care and condition
- maintain their cultural and spiritual practices
- choose who they want to help them and manage their affairs when they are unable to do so.

Understand ethical issues

To ensure high-quality care is provided, the palliative care team should consider the person’s rights in line with their needs and preferences, and the best way to provide care.

This requires a delicate balance between the standard practices of palliative care and the person’s wishes. Ethical issues may arise between team members and the person accessing the service in relation to the person’s personal values and decisions or the balance between a person’s preferences and the reality of their situation.

Below are ethical issues you may be faced with in the palliative care environment.

Ethical issues that can arise in palliative care

Person accessing the service doesn't accept treatment
If a person doesn't accept treatment options offered, notify your supervisor immediately. A person has a right to refuse treatment; however, the team may be able to identify an alternative treatment that the person will accept. It is unethical to provide treatment against a person's wishes and it is within the person's rights to take action against the care team if this occurs. Some states, such as South Australia, Victoria and Western Australia, have legislation that protects health professionals when they follow a person's wishes to withhold treatment. This ensures they are not liable for the person's death if it occurs due to the lack of treatment.

Person accessing services requests euthanasia
There may be times when you are caring for a person who won't accept the treatment options prescribed for them. If this occurs, a person may request assistance to die (voluntary euthanasia). This process is only supported by law in Victoria through voluntary assisted dying legislation. It is deemed illegal in other states and territories.

Person accessing services requests no CPR
A person may request that no cardiopulmonary resuscitation (CPR) is given if the need arises. This should be documented in the person's advance care directives in their care plan. Be familiar with these directives.

Person accessing services chooses alternative therapy
A person's choice of pain-relief treatment must be respected even if the palliative care team believes another method may be more effective. For example, a person may decide to use contemporary alternative therapies rather than conventional treatment. In this case, your beliefs and values are irrelevant and withholding the preferred treatment is unethical.

Nutrition and hydration
Nutrition and hydration issues are important in the later stages of a person's life. Maintaining nutrition and hydration provides comfort and prolongs life. Make sure you follow care plan instructions; for example, it is unethical to provide food because you feel sorry for the person if the care plan says not to provide food.

Person accessing services can no longer make decisions
When a person can no longer make their own decisions, you should refer matters to family members, significant others or the person with enduring power of attorney (medical) if the person has not given advance care directives. Never make any decisions on your own, even if you believe the person would agree with you.

Full disclosure
All information regarding a person's condition, treatment and potential life expectancy must be provided to the person, their family members, carers and significant others. This is referred to as disclosure. These people must be able to make informed decisions based on the facts provided to them. This should include information about pain relief, alternative treatments available, nutrition and hydration issues that may arise, how long they are expected to live, visiting guidelines, support provided and the person's preferences.

The palliative care team has an ethical obligation to tell the truth and fully inform all people accessing the service regarding their observations and intervention recommendations. Once the person is fully informed and has been assessed as having the cognitive ability to make their own decisions, it is crucial that the palliative care team respect the person's needs and their right to choose their preferred intervention. You should be aware of your level of authority and refer any queries you are unable to answer to your supervisor or the appropriate member of the care team.

Person accessing services confidentiality
All information about a person and their condition must be treated in confidence. This is a crucial ethical issue. Ensure you know what (if any) personal information about a person can be released to their family and friends. Always be vigilant when dealing with a person's file and make sure it is returned to the appropriate place after it has been used – usually a lockable filing cabinet. Never talk about a person with friends or your own family.

Maintain the person accessing services' dignity
People must be treated with dignity and all efforts made for them to maintain this dignity. Never take shortcuts to make your own work easier if it means the person's dignity is compromised.

Person accessing services' right to change their mind
Respect the person's right to change their mind regarding their care over time and as their condition progresses. Regular opportunities to discuss the person's preferences should be provided.

Cause of death
There may be ethical dilemmas concerning a person's cause of death. This may occur if a person's family decides to take the person off life support, which results in their death.

Discuss ethical issues

It is your duty of care as a palliative care worker to make the person accessing the service comfortable and free from pain, and to carry out your duties safely so no-one is harmed or placed in a position of danger. It is a good idea to discuss any ethical issues or concerns you have with your supervisor and other team members providing care and support. You will learn more about ethics and what to do as you gain more experience. Don't ignore something that is worrying you, instead you may like to bring up a topic for discussion at a team meeting.

You can also watch how others deal with ethical issues.

Laws may vary from state to state, so make sure you know the legislation and ethical guidelines under which your organisation operates. For example, there are some legal differences regarding the scope of decisions or functions that a guardian and advocate may exercise and the law in Victoria allowing voluntary assisted dying.

Debrief

Most organisations have a bereavement program that includes formal and informal debriefings for palliative care staff. Formal opportunities may include meetings with the hospital social worker and/or regular palliative care team meetings.

A timely debriefing can assist in stabilising a workplace and ensure that anyone requiring specific bereavement support receives the assistance they need. Organisations may also provide one-on-one support by arranging professional counselling for colleagues.

An informal debriefing is one in which everyone is given the opportunity to talk about the death, express their emotions by talking about how they feel about the person and allowing time to cry. Everyone is then permitted to reminisce about the person by recalling funny, sad or tender moments and to talk about other difficult or stressful cases or incidents. Finally, a discussion of the person's funeral and ways to celebrate the person's life may be explored.

A supervisor's responsibilities

A supervisor is responsible for the emotional welfare of the people they care for and work with. People may require support in different ways. Follow organisational policy and procedure when managing others' emotional welfare.

The supervisor is often the first person that a personal care worker can access if they have any concerns. The supervisor is also able to observe the personal care worker and may pick up on signs of grief or anxiety that the personal care worker has not acknowledged formally. These reactions may be negated with increased support and training.

The World Health Organization (WHO) defines stress as 'the reaction people may have when presented with demands and pressures that are not matched to their knowledge and abilities and which challenge their ability to cope'. The WHO advises that 'stress occurs in a wide range of work circumstances but is often made worse when employees feel they have little support from supervisors and colleagues and where they have little control over work or how they can cope with its demands and pressures'.

Identify other strategies and resources available for debriefing

In addition to the debriefing strategies mentioned earlier, there are other support strategies a coordinator may use, described below.

Grief books

Encourage staff to contribute their thoughts, feelings and memories to a grief book. This provides them the opportunity to voice and reflect on their feelings and emotions. It also allows people the feeling of getting things off their chest and may help them move forward in the grieving process.

Acknowledge the loss

It is important to provide opportunities for people to acknowledge a loss. For example:

A personal service can be held to acknowledge the death of a client, to provide support to family members, carers, palliative care team members, other clients and volunteers.

A memorial ceremony can be held annually to acknowledge the clients who died in the last 12 months; this is a public recognition that each client's life and death has not passed unnoticed, but is recorded in the organisation's history.

You can arrange for an acknowledgment that meets the family's cultural needs; for example, a celebration at their local church.

Staff support

Staff support groups are another option for teams who have the time to meet. These groups generally work best when led by someone external to the team, who can provide the safety of structure and boundaries.

A coordinator can also provide support to staff by arranging debriefings to review and discuss an especially distressing incident or series of incidents. Discussion about how the incident was handled, how care could have been improved and how staff members were left feeling, promotes a supportive team culture in which emotions can be openly discussed.

Formal appraisals

Formal appraisals by managers are valuable opportunities to identify sources of stress, provide feedback and consider remedial action. Managers can use this opportunity to acknowledge and praise an individual's work while assisting to develop their range of skills through initiatives such as training, taking on different clinical roles, teaching, research and management.

Continuing professional development not only enables support workers to stay current with skills and academic knowledge, but also provides support for their emotional wellbeing.

Relaxation

It is important for staff to be aware of their stress levels. Suffering from stress can cause people to burn out, where they become emotionally exhausted, develop low morale, become withdrawn, unable to cope and have reduced job satisfaction. Learning to relax can release stored muscle tension and bring wide-ranging health benefits. Common relaxation techniques include massage, meditation, yoga and exercise.

Example

Debrief with supervisor

Amanda has been working in palliative care for 18 months. Recently Amanda has been caring for Lucy. Lucy is 6 years old and has been in a coma for 10 months following massive brain damage after a motor vehicle accident. Amanda has a daughter Lucy's age and finds it emotionally very stressful to care for Lucy. Amanda is having difficulty sleeping and is unable to stop thinking about Lucy on her days off. Amanda approaches the supervisor and discusses her anxiety and concerns. The supervisor is able to refer Amanda to a specialist counsellor and arrange a change in work duties to support Amanda.

Practice task 27

1. With whom should a palliative care worker discuss ethical issues?

2. How can timely debriefing assist in stabilising a workplace?

Click to complete Practice task 27

6D Identify and implement self-care strategies to address the potential impact of your personal responses

Learn to recognise your reactions and how to deal with your emotions. This may involve speaking with your supervisor or another experienced person, seeking bereavement support, discussing your feelings with family members and seeking external support from support groups.

Strategies to cope with specific emotions are detailed below.

Crying

Others (team members, people accessing the service, family members and carers) may be personally affected and it will impact on the calming, supportive environment that should be provided by the palliative care team.

Coping strategies:
Discuss your feelings with your supervisor or another experienced person. Seek support through your organisation, external organisations or support groups.

Poor concentration

You are unable to complete the tasks that your team members are relying on you to do.

Coping strategies:
Your team should allow you time to grieve. This includes permission to cry, allowing you to be angry, not expecting you to return to work immediately and offering time to discuss how you feel.

Fear

You are unable to provide the support necessary to other team members, the person accessing the service, their family members and carers.

Coping strategies:
Have a colleague or mentor assist other workers through difficult times. They should be available at all times, even after work hours, in case the worker needs to talk.

Anger

You may take out your anger on other people by swearing, crying or yelling, which creates an unpleasant and upsetting environment.

Coping strategies:
Access support from team members. Allow time to grieve. This includes permission to cry, allowing you to be angry, not expecting you to return to work immediately and offering time to discuss how you feel. A simple memorial ceremony held in the hospital or nursing home chapel or lounge may help to acknowledge a person’s life.

Silence

If you withdraw or isolate yourself as a result of emotions, people accessing the service in the future will be deprived of your high-quality care and effective support.

Coping strategies:
Seek support from your team and organisation; for example, bereavement training or debriefing sessions. Also seek support from counsellors, therapists, psychologists or social workers.

Stress/burnout

If you are overly stressed or burnt out, you are unable to complete the tasks that your team members are relying on you to do.

Coping strategies:
Draw on the expertise of health professionals within the organisation such as psychologists, social workers or therapists. They will suggest ways to cope such as maintaining your health, evaluating your priorities, giving yourself timeout and getting adequate rest and sleep. Draw on the expertise of external organisations to provide stress-management training and/or professional bereavement support.

Example

Support palliative care workers to manage their emotional reactions

Bruce has worked in a residential aged care facility in a small rural community for 10 years. Dianne has been a resident for seven years, before she died recently at age 102. Bruce was very close to Dianne, particularly because she reminded him of his mother, who died before he was able to say goodbye. Following Dianne's death, Bruce grieved openly for her. He cried a lot, kept apart from other staff members and had difficulty concentrating on his work. The care manager, Lorna, suggested that Bruce seek help from the facility's social worker and offered to make an appointment for him.

Practice task 28

1. Identify four emotional responses that a personal care worker can experience that could impact others.

2. If a personal care worker's emotional response is having an impact on others, describe a self-care strategy that they could do.

Click to complete Practice task 28

6E Access bereavement care and support of other team members

Palliative care work relies on a team approach and one in which everyone provides support to each other. Therefore, you and the team should be given opportunities to formally acknowledge a loss, and have access to adequate bereavement assistance and support when required. It is important to be able to recognise when you require this type of support and to take action to receive it, so you can remain an effective team member. Be aware that everyone is different and some people require more support than others, when grieving.

Be familiar with the type of bereavement support offered by your organisation and the wider community and what you have to do to access it. It is a good idea to accept help and support when it is offered. There is a range of support available to cater to different people's needs. Choose support that is appropriate to you and that makes you feel comfortable.

Support from your team

Your team should allow you time to grieve. This includes:

- permission to cry
- allowing you to be angry
- not expecting you to return to work immediately
- offering time to discuss how you feel.

External support and support from your organisation

There are a number of professional bereavement support services your organisation can suggest or you can approach yourself; for example, professional counsellors or religious ministers. These people can explain the grief process and the commonly encountered stages people go through when coping with death. Find out what services are in your area. Collect their brochures to see what services they offer. Palliative Care Australia provides a list of the type of support that these services should provide. Visit their website at: http://aspirelr.link/palliative-care.

Here are some of the things an organisation can do to support its staff.

Organisational support
▶ Arrange debriefing sessions in which everyone is encouraged to talk about the person
▶ Conduct stress-management or bereavement training to provide coping strategies.
▶ Encourage staff to write about their feelings in a grief book. This gives them the opportunity to voice their feelings.
▶ Provide workplace activities such as exercise classes, aromatherapy or yoga, which may help people to relax, become refreshed and move on.

- Provide an opportunity to acknowledge losses; for example, a service to acknowledge the death of a person
  - A service to acknowledge the death of a person may support family members, carers, palliative care team members, other persons accessing the service and volunteers.
  - A simple memorial ceremony, held annually at the organisation, provides an opportunity for palliative care team members to acknowledge the life and death of the person accessing the service who died in the last 12 months. This is a public acknowledgment that each person's life and death has not passed unnoticed but remains recorded in the organisation's history.
- Arrange for the palliative care worker to make follow-up visits to bereaved family members and carers so they have time to discuss their grief
- Draw on the expertise of health professionals within the organisation such as psychologists, social workers, therapists and pastoral workers. They can suggest coping strategies such as maintaining your health, evaluating your priorities, giving yourself time-out and getting adequate rest and sleep.
- Have a colleague act as a mentor or support person to help other workers through difficult times and to encourage them to recognise their emotions

Practice task 29

1. Does everyone grieve in the same way?

2. Explain two ways members of the team could support you.

Click to complete Practice task 29

Summary

1. Dealing with ethical issues, such as ending a person's life by taking them off a life-support system or not providing further treatment, is very emotional. You must be adequately trained to cope with death and bereavement, as palliative care is a challenging environment to work in.
2. In some circumstances, a worker may experience a reaction so strong that it moves beyond normal grief to what is known as pathological (or complicated) grief.
3. You may experience a range of emotions such as sadness, confusion, fear and anger. You must be able to recognise how your reactions affect your work and others.
4. Palliative care work relies on a team approach and one in which everyone provides support to each other. There are a number of professional bereavement support services your organisation can suggest or you can approach yourself.
5. When you first start work, your training includes becoming familiar with the types of concerns and issues that are part of caring for people with life-limiting illnesses or who are at the end of their lives.
6. It is your duty of care as a palliative care worker to make the person comfortable and free from pain, and to carry out your duties safely so no-one is harmed or placed in a position of danger.
7. All organisations have their own guidelines, policies and procedures that are based on legislation and industry standards.

Learning checkpoint 6

Manage your own emotional responses and ethical issues

This learning checkpoint allows you to review your skills and knowledge in managing your own emotional responses and ethical issues.

Part A

1. List and explain two areas that organisational policies and procedures cover to manage emotional responses and ethical issues a personal care worker may experience.

2. Identify two reactions a palliative care worker may have after the death of a person.

3. Explain what bereavement care involves.

Part B

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

Case study

Joan is in palliative care and her support worker is Sophie. Joan's condition deteriorates and her daughter Marilyn becomes increasingly anxious about her mother's impending death. Marilyn constantly asks Sophie if Joan is experiencing any pain and is worried as her mother is unable to take more than a few spoonfuls of soft food and sips of fluid. Marilyn stays at the facility with her mother for the last two days of Joan's life and is not sleeping or eating a great deal herself. Sophie becomes concerned for Marilyn and reports these concerns to the supervisor. The supervisor organises the pastoral care team worker to spend time with Marilyn and Marilyn reports that she finds comfort in these visits.

1. Identify an emotional issue or concern that Sophie is experiencing in caring for Joan.

2. Identify two self-care strategies that Sophie can implement to address the emotional impact of providing support.