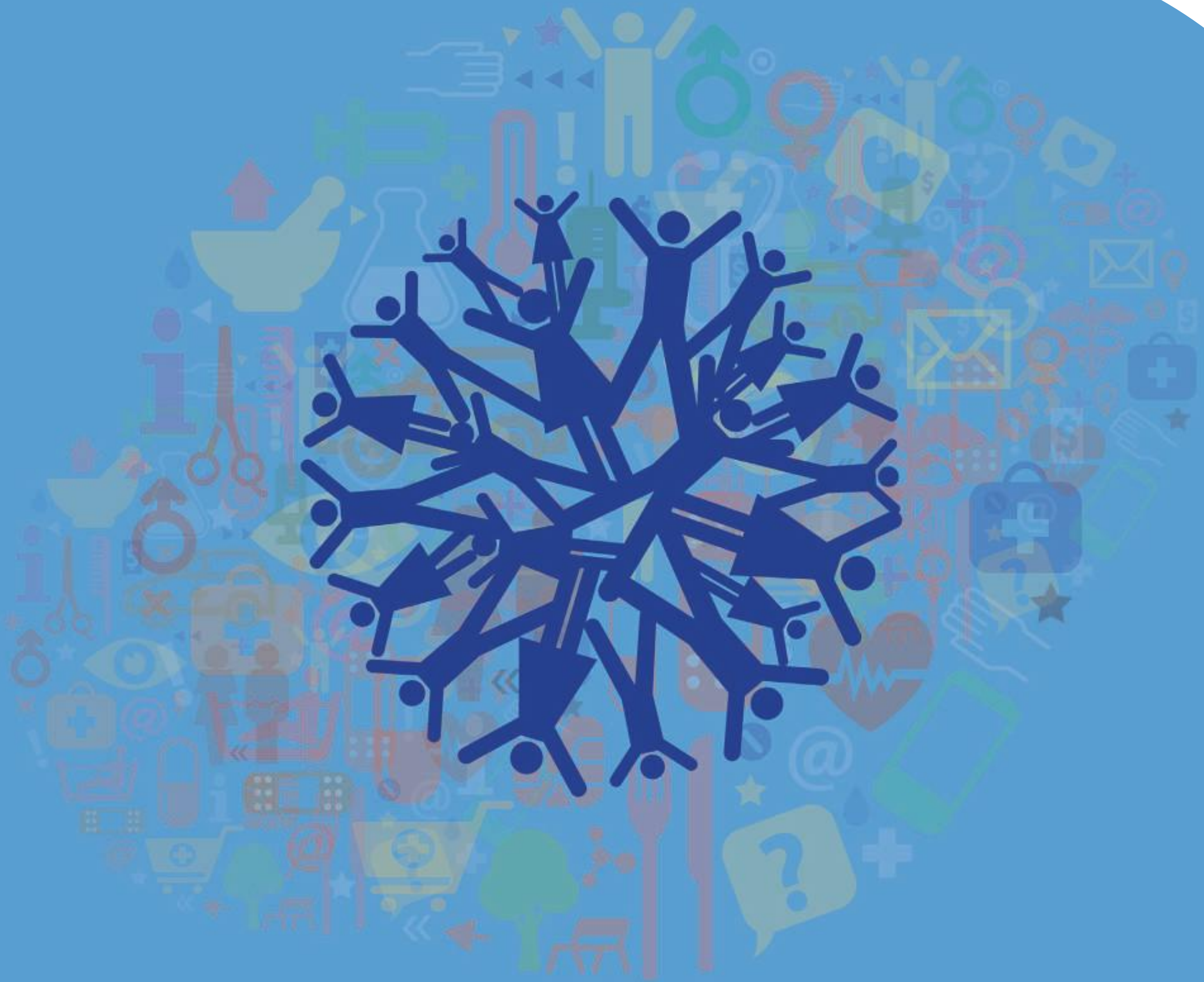
CHCPAL002
Plan for and provide care services using a palliative approach

Release 2



Learner guide

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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. Updated broken URL links.
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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CHCPAL002 Plan for and provide 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 *CHCPAL002 Plan for and provide 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 Plan a palliative approach to individual care	1A Assist with care planning using a palliative approach to maximise the person's quality of life and comfort	☐ Confident ☐ Basic understanding ☐ Not confident
	1B Identify care requirements based on the condition or illness of the person	☐ Confident ☐ Basic understanding ☐ Not confident
	1C Identify current specialist palliative care requirements	☐ Confident ☐ Basic understanding ☐ Not confident
	1D Ensure planning involves and supports the person, family members, carers and/or significant others	☐ Confident ☐ Basic understanding ☐ Not confident
	1E Ensure care plan addresses the person's ongoing needs holistically	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 2 Support individuals to identify their preferences for quality of life choices	2A Consult to identify and share information regarding current and changing needs and preferences	☐ Confident ☐ Basic understanding ☐ Not confident
	2B Respect the person's lifestyle, social, cultural and spiritual choices and needs in developing the care plan	☐ Confident ☐ Basic understanding ☐ Not confident
	2C Ensure the planning process supports discussion of spiritual and cultural issues in an open and non-judgmental way	☐ Confident ☐ Basic understanding ☐ Not confident

Topic	**Key outcomes**	**Rate your confidence in each section**
	2D Demonstrate respect for the roles of the person and carer in planning and decision-making	☐ Confident ☐ Basic understanding ☐ Not confident
	2E Refer issues outside scope of own role to appropriate member of the care team	☐ Confident ☐ Basic understanding ☐ Not confident
	2F Communicate to show empathy and provide emotional support	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 3 Assist with advance care planning	3A Assist with determining advance care directives	☐ Confident ☐ Basic understanding ☐ Not confident
	3B Assist with documenting advance care directives and ensure communication about them respects confidentiality requirements	☐ Confident ☐ Basic understanding ☐ Not confident
	3C Actively support the person's ethical end-of-life decisions in line with organisational policy and care plan directives	☐ Confident ☐ Basic understanding ☐ Not confident
	3D Identify and document the person's ongoing decisions, preferences, needs and issues in relation to end-of-life care	☐ Confident ☐ Basic understanding ☐ Not confident
	3E Observe the impact of the person's end-of-life decisions, needs and issues and provide support	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 4 Take action to alleviate pain and other end-of-life symptoms	4A Collaborate with others to plan and document strategies to maximise comfort	☐ Confident ☐ Basic understanding ☐ Not confident
	4B Assess and report the person's need for pain relief in line with care plan	☐ Confident ☐ Basic understanding ☐ Not confident
	4C Provide pain and symptom relief in line with role and requirements	☐ Confident ☐ Basic understanding ☐ Not confident
	4D Provide appropriate information about the use of pain-relieving medication and treatments in consultation	☐ Confident ☐ Basic understanding ☐ Not confident

Topic	**Key outcomes**	**Rate your confidence in each section**
	4E Observe, report, communicate and document effectiveness of interventions for pain and symptom relief	☐ Confident ☐ Basic understanding ☐ Not confident
	4F Communicate and document the ineffectiveness of interventions	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 5 Contribute to the development and implementation of end-of-life care strategies	5A Respect the person's preferences including cultural and spiritual wishes	☐ Confident ☐ Basic understanding ☐ Not confident
	5B Maintain the dignity of the person when planning end-of-life care and immediately following death	☐ Confident ☐ Basic understanding ☐ Not confident
	5C Observe and report signs of a person's imminent death and/or deterioration	☐ Confident ☐ Basic understanding ☐ Not confident
	5D Provide a supportive environment for the person and their family and/or carers involved at end-of-life	☐ Confident ☐ Basic understanding ☐ Not confident
	5E Ensure that decisions are reviewed regularly, communicated and recorded	☐ Confident ☐ Basic understanding ☐ Not confident
	5F Identify the emotional needs of people affected when a death occurs and provide necessary support or referrals	☐ Confident ☐ Basic understanding ☐ Not confident
	5G Prepare the person, family, other staff and self for any distressing end-of-life events	☐ Confident ☐ Basic understanding ☐ Not confident
Topic 6 Identify and manage emotional responses in self and others	6A Identify and reflect on your own emotional responses to death and dying	☐ Confident ☐ Basic understanding ☐ Not confident
	6B Identify and manage impact of emotional responses on yourself and others	☐ Confident ☐ Basic understanding ☐ Not confident
	6C Inform others about available support systems and bereavement care	☐ Confident ☐ Basic understanding ☐ Not confident
	6D Follow organisational policies and procedures in relation to emotional welfare of self and others	☐ Confident ☐ Basic understanding ☐ Not confident

Topic	**Key outcomes**	**Rate your confidence in each section**
	6E Assist colleagues to debrief and discuss bereavement care	☐ Confident ☐ Basic understanding ☐ Not confident
	6F Identify other strategies and resources available for debriefing	☐ Confident ☐ Basic understanding ☐ Not confident
	6G Evaluate effectiveness of emotional response strategies	☐ Confident ☐ Basic understanding ☐ Not confident

Topic 1

In this topic you will learn how to:

- **1A** **Assist with care planning using a palliative approach to maximise the person's quality of life and comfort**
- **1B** **Identify care requirements based on the condition or illness of the person**
- **1C** **Identify current specialist palliative care requirements**
- **1D** **Ensure planning involves and supports the person, family members, carers and/or significant others**
- **1E** **Ensure care plan addresses the person's ongoing needs holistically**

Plan a palliative approach to individual care

Palliative care specifically addresses the needs of people who have life-limiting illnesses or are in the final stages of their lives. It is when care moves from treating symptoms to providing care and comfort when a cure is no longer possible. Palliative care focuses on the person and their family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates) and/or carer.

Health care providers and health care professionals have a responsibility to ensure that people experience the best possible quality of life until their death.

People in the last stages of their lives may be residents or patients of a facility, or be receiving in-home support. Standards for providing palliative care have been developed by Palliative Care Australia and must be applied appropriately and sensitively.

1A Assist with care planning using a palliative approach to maximise the person's quality of life and comfort

Palliative care focuses on the care and support of people who suffer from a terminal condition. It also provides care and support to their family and/or carer. People with terminal conditions may be cared for in hospices, aged care residential facilities or at home. Specialised care can be accessed if required to overcome severe or complex problems. Changes to the care environment may also be necessary to support the person and their family and/or carer as the illness progresses.

A holistic approach to planning care is undertaken to provide the person with the best quality of life possible. This means the physical, emotional, social, cultural and spiritual needs of all people and family, carers and/or significant others are considered. Bereavement care is also planned to support the family and/or carer after the death of the person.

To be effective in planning care, clear communication is vital for the person and their family and/or carer, and the health team. As a person receiving care, the patient is an important partner in planning their care and managing their condition. Family and carers also have an important role in this area. When people are well informed, participate in treatment decisions and communicate openly with their doctors and other health professionals, they help make their care as effective as possible.

Care planning is an important process in ensuring the patient's wishes in relation to their care are met. Patients should speak to their doctor about anticipating their changing needs through advance care planning. Discussions about appointing a substitute decision-maker may also be important. In this topic you will learn about:

- the difference between curative and palliative approaches in palliative care planning
- addressing the individual's needs holistically in their care plan over time
- applying the principles and aims of a palliative approach when developing a care plan.

Understand the difference between curative and palliative approaches

Health care providers who work with people with life-limiting illnesses or people who are at the end of their lives must understand the various terms that are used in this area of health care. In particular, you should understand the difference between curative and palliative care approaches and take these differences into account when developing a person's care plan. It may be your role to explain these differences to the person and their family members, so they understand the way care is provided in these different contexts.

Curative care actively treats an illness and promotes recovery.

Palliative care provides the person with relief and comfort when there is no cure for their illness and measures to extend their life have been discontinued.

Maslow's hierarchy of needs

Abraham Maslow, an American psychologist, developed a hierarchy of needs that attempts to explain the needs of people and which needs may have priority over others.

People have many needs, including survival-related needs (such as food and safety) and the need to be the best person they can be. The hierarchy is not necessarily a continuum – people often attempt to satisfy needs in a number of categories at the same time. However, when a basic need is not being met, people may abandon more complex needs; for example, for someone who has not eaten in a number of days, the need to eat will be more important than their physical safety. Similarly, a person who is homeless may seek shelter before attempting to satisfy the need for respect from others.

Maslow's hierarchy is a useful tool for prioritising a person's needs. You can then use this knowledge to suggest support services and implement the appropriate care for the person. In palliative care the same needs for the person and the family still have to be addressed.

Physiological needs

These are the most basic and instinctive needs for survival, including the need for water, air, food and sleep. All other needs are secondary until these basic needs are met.

Security needs

Safety and security needs are important for survival, but they are not as critical as physiological needs. For adults, security needs can include a stable job, personal and financial security, health, wellbeing and shelter. For children, shelter, safety, security and knowing the limits for behaviour are important.

Social needs

Social needs include the need for belonging, love and affection. Although these are considered less basic than physiological and security needs, everyone has some need for companionship, love and acceptance.

Esteem needs

After the first three sets of needs have been satisfied, esteem and self-esteem needs (recognition, accomplishment, respect, acceptance and being valued) become increasingly important.

Self-actualising needs

Self-actualisation is the highest level of Maslow's hierarchy of needs. People who have all their other needs met are able to be self-aware, concerned with personal growth, less concerned with the opinions of others and more interested in fulfilling their potential.

Palliative care

Palliative care not only affirms life, but also regards death as a normal process. A person receiving palliative care will have an active, progressive and far-advanced disease such as chronic heart disease, end-stage renal disease, cancer, dementia or Alzheimer's disease, with no prospect of cure. A palliative care approach embraces eight philosophies. All of the following philosophies are equally important.

The eight philosophies of palliative care

1. **Taking a positive approach**
   It is important to take a positive approach to relieve symptoms and maximise the person's quality of life by treating their pain and attending to their physical, psychological, social and spiritual needs from diagnosis through to the final stages of the illness. Care plans should focus on enabling the person to live each day with quality care
2. **Not delaying palliative care**
   Always ensure that palliative care is not delayed until the end stages of a person's illness, but provided as soon as it is recognised that a cure is not an option. A comfort-focused, positive approach to reducing suffering and promoting understanding of loss and bereavement should be taken.
3. **Being proactive about suffering**
   Anticipate, prevent and treat suffering. The team's aim is to ensure the person's death is as comfortable as possible when it occurs.
4. **Working as a team**
   Use a team approach to address the needs of the person, their families and carers as they face the problems associated with a life-limiting illness. Provide information, emotional support and bereavement counselling.
5. **Providing holistic care**
   Provide holistic care for the person, their family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates), carers and other support networks before and after the person's death.
6. **Empowering people**
   This means assisting people to be independent and providing access to information and choice.
7. **Being positive and open**
   Have a positive and open attitude towards dying and death. Palliative care services respect dying as a shared and unavoidable consequence of life, and aim to reduce the personal distress and fear associated with dying.
8. **Being flexible**
   Be flexible so the care provided will continue to meet the needs of people with life-limiting illnesses, their family members and carers as conditions change.

Aims of palliative care

Palliative care is active care that anticipates and manages a person's symptoms, with a focus on identifying what is important to the person. Palliative care can raise many issues for individuals and their families when confronted with the inevitability of death. Conversations with the person about their hopes, fears and wishes allow the person and the palliative care team to plan ahead. Realistic care plans identify the person's wishes and preferences regarding their physical, psychological, social, cultural and spiritual needs.

All members of the palliative care team must understand the transition from a curative to a palliative approach, and the person's care plan should be reviewed and adjusted to provide tailored support for the person, their family members and carers.

Palliative care aims to:

- control and provide relief from pain and other distressing symptoms
- neither hasten nor postpone death
- bring together the psychological and spiritual aspects of the person's care
- offer a support system to help individuals live as actively as possible until death
- offer a support system to help the family cope during the person's illness and in their own bereavement
- regard dying as a part of life.

Goals of palliative care teams

Palliative care differs for each person due to factors such as geography, services available in their area and the needs of the person, their carer and family.

All the people in palliative care teams work together to provide comfort, support and care for the person. As a member of the palliative care team, you should be aware of all the factors contributing to a person's situation. When delivering their care plan, you need to take into account their hopes, fears and wishes, and share the decision-making with family members and carers. You need to understand the needs of the person and those around them as the person approaches their end of life. The overall goals for the palliative care team are outlined below.

Support

To support people accessing the service by treating and managing symptoms to ensure the best possible quality of life

Help

To help the person self-manage their condition and make their own decisions relating to their care

Education

To educate the person's families and carers about death, dying, bereavement and loss

Palliative care services

In the course of their illness, some people will receive palliative care in community settings, hospices and palliative care beds, depending on their needs. A significant proportion of anticipated deaths occur in hospitals, and individuals are often identified as needing palliative care while in hospital. However, in many cases people prefer to return home in the final stages of their lives, to die with dignity in familiar surroundings.

The person's quality of life and comfort in the last days of their life are the main goals for palliative care. The setting will depend on the person's preference, their needs and the support required to meet these needs. These settings are described below.

The three settings in which palliative care may be required
Community settings Community settings; for example, an aged or supported care facility or the person's private home
Hospices Designated facilities; for example, a hospice delivering care in a hospital-like setting with a range of health professionals
Palliative care beds Designated palliative care beds in hospitals; for example, in a rural community hospital or a teaching hospital

Prepare a care plan

To comply with standards, organisations take a holistic view of a person's needs when developing their care plan. Holistic care emphasises an interdisciplinary team approach. It also places importance on building respectful and trusting relationships with the person's family and carers. A detailed assessment of the family unit including their strengths, weaknesses, dynamics, and short- and long-term needs is crucial to effective palliative care. By involving family members, you can identify the person's social, spiritual and cultural needs, their thoughts and preferences, and any issues they may not have told you in an assessment.

Beyond the palliative care team, a number of other services may provide support to people, their family and carers; for example, financial planning, legal advice and funeral arrangements.

Holistic care

Holistic care ensures that all aspects of the person are considered. For example, a person's social needs may be just as important as their physical needs. Or towards the end of their life a person's spiritual needs may take on a greater meaning and need to be further addressed.

The three key areas of holistic care are:

- assessment and control of pain and symptoms
- provision of psycho-emotional, social, cultural and family support and care
- assessment and referral to specialist services when appropriate.

Plan holistic care

There are a number of ways to plan holistic care. All relevant members of the team should contribute to the person's initial assessment. This will save time and ensure that all the person's needs are addressed. The person's physical, social, spiritual and cultural needs need to be identified and considered. For example, you may arrange social outings or for friends to visit to maintain social contacts and raise morale, or encourage the person to talk about spiritual issues and/or arrange pastoral care.

Encourage the person and their family to participate in the planning process. They need to know what a holistic palliative approach means for the person. All information gathered from the person and their family must be documented in the care plan. Give the person and their family as much information as they need to make informed decisions about issues such as treatment options or social support.

Prepare a framework for reviewing and evaluating the care plan, so everyone can see how it will be continually adjusted as the person's needs change. Assist the person and their family to decide whether they wish to prepare an advance care plan for when the person is no longer able to make these kinds of decisions themselves.

Holistic care planning

When completed, a holistic care plan may include the person's care needs from the initial assessment and the treatment decisions they have made. Advance care planning decisions will also be documented. The person and the family and/or carer will have set goals for care that will address the physical, psychosocial, spiritual and cultural needs for the person. Respite care details will also be documented in the care plan.

There are a number of ways to plan holistic care.

1. **Initial assessment**
   All relevant members of the team should contribute to the person's initial assessment. This will save time and ensure that all the person's needs are addressed.
2. **The person's physical, social, spiritual and cultural needs**
   Address the person's physical, social, spiritual and cultural needs. For example, you may arrange social outings or friends to visit to maintain social contacts and raise morale, or encourage the person to talk about spiritual issues or arrange pastoral care.
3. **The person and family participation**
   Encourage the person and their family to participate in the planning process. They need to know what a holistic palliative approach means for the person. All information gathered from the person and their family must be documented in the care plan.
4. **Informed decisions**
   Give the person and their families as much information as they need to make informed decisions about issues such as treatment options or social support.
5. **Evaluation**
   Prepare a framework for reviewing and evaluating the care plan, so everyone can see how it will be continually adjusted as the person's needs change.
6. **Advance care planning**
   Assist the person and their family to decide whether they wish to prepare an advance care plan for when the person is no longer able to make these kinds of decisions themselves.

Your role in care planning

Your principal role in contributing to a person's holistic care plan is to help the person assess their physical, emotional and spiritual needs; to support and encourage the care provided by primary and specialist healthcare services; and to contribute to comprehensive and practical suggestions for care.

To work well together in a holistic environment, each person must understand the role and responsibilities of all team members, communicate effectively, cooperate and collaborate well, attend regular meetings and plan their time efficiently.

Your duties and responsibilities

1. **Initial assessment**

   Contributing to the person's care plan by assessing them, interviewing their family members, making amendments to the care plan when necessary and ensuring the plan is current and accurate

2. **Referrals**

   Liaising with health professionals and the palliative care team and assisting with referrals

3. **Communicating with family**

   Speaking with family members to keep them informed of the person's progress, or to seek further information

4. **Information**

   Providing a range of information to the person, family members and carers

5. **Emotional support**

   Providing emotional support and counselling family members and carers

6. **Pain relief**

   Recognising the signs and symptoms of pain and providing pain relief

7. **Cultural support**

   Providing cultural support, such as interpreters

8. **Alleviating distress**

   Evaluating and alleviating a person's physical and psychological distress

9. **Respect**

   Respecting the person's cultural, spiritual and social beliefs and values

10. **Volunteers**

    Coordinating and training volunteers

11. **Policy and procedures**

    Following organisational policies and procedures

12. **Palliative care approach**

    Applying the principles and values of a palliative care approach in day-to-day tasks

Apply the principles and aims of a palliative approach when developing a care plan

It is important to understand the beliefs, values, philosophies and aims of a palliative care approach so the care and activities you carry out and document in a person's care plan are consistent with these principles.

The main philosophy of palliative care is to maximise the person's quality of life by anticipating, preventing and treating suffering and making their death as comfortable as possible when it occurs. When developing a care plan, keep in mind the aims of a palliative approach described earlier. All palliative care health professionals must support these aims, principles and values so they can be consistently applied when working with people with life-limiting illnesses or people approaching death.

Palliative care standards

Palliative Care Australia has developed a set of standards for providing specialist palliative care. The Standards aim to ensure a person's comfort and dignity are maintained, and encompass the physical, spiritual, psychological, social and cultural support required. These standards are based on the core values, assumptions and beliefs that underpin the work of health care services and health care professionals. They provide the framework for palliative care service providers to plan and deliver quality end-of-life care.

Palliative Care Standards can be accessed at: http://aspirelr.link/palliative-care-standards-qld

The Aged Care Quality Standards refer to the quality of care in aged care services.

Further information can be found at the Australian Aged Care Quality Agency website at: http://aspirelr.link/aged-care-accreditation

Quality of end-of-life care

Palliative care aims to give quality of end-of-life care to the person accessing the service. There are a number of ways the health care worker can contribute in a positive manner to assist with achievement of this aim. The framework for palliative care services is based on core values, assumptions and beliefs. Access the Standards for Providing Quality Palliative Care for all Australians, via the Palliative Care Australia website, at: http://aspirelr.link/pca-national-standards

The core values for palliative care are outlined here.

Core values necessary to ensure quality end-of-life care

1 **Dignity of the person**
Endeavour to maintain the dignity of the person, their family and carers.

2 **Collaborative approach**
Work with the strengths and limitations of the person and their family and/or carers to empower them to manage their own situation.

3 **Compassion**
Act with compassion towards the person, their family and carers.

4. **Equity**
   Consider equity in the accessibility of services and in the allocation of resources.
5. **Respect**
   Demonstrate respect for the person, their family and carers.
6. **Advocate**
   Advocate on behalf of the person and their family, carers and community.
7. **Excellence**
   Commit to the pursuit of excellence in the provision of care and support.
8. **Accountability**
   Be accountable to the person and their family, carers and community.
9. **Standards of care**
   Follow established practice standards and requirements for quality management such as leadership and governance, human resource management, safe practice, information management and continuous quality improvement.
10. **Codes of practice and ethics**
    Adhere to professional and organisational codes of practice and ethics.
11. **Current practice**
    Reflect on and evaluate current practice, and incorporate new evidence into protocols, policies and procedures.
12. **Professional development**
    Participate in continuing professional development in the knowledge, attitudes and skills required to deliver quality palliative care as this relates to the Standards.

Apply palliative care principles

When contributing to the development of a care plan you should keep in mind the following palliative care principles.

Person- and family-focused

- As the person is part of a family, when care is provided the person and their family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates) and carers should be treated as a unit.
- All aspects of care must be addressed and provided in a manner that is sensitive to the person and their family's personal, cultural and religious values, as well as their beliefs and practices, developmental state and preparedness to deal with the dying process.

Ethical

All palliative care activities must be guided by:

- the ethical principles of autonomy, justice, honesty and confidentiality
- the person's legal right to be offered appropriate and accurate information, to make their own choices, to accept or refuse treatment, and to appoint someone to speak on their behalf
- standards of practice that are based on nationally accepted principles and norms of practice
- standards of professional conduct
- policies and procedures that are based on the best available evidence or practice guidelines
- data collection/documentation guidelines that are based on validated measurement tools.

High quality

All palliative care activities must use the most appropriate strategy and the best resources to address the person's needs.

Safe and effective

All palliative care activities must be conducted in a manner that:

- is collaborative
- ensures confidentiality and privacy
- is without coercion, discrimination, harassment or prejudice
- ensures safety and security for all participants
- ensures continuity and accountability of care
- aims to minimise unnecessary duplication
- complies with laws, regulations and policies of palliative care organisations.

Accessible

All individuals, their family members and carers should have equal access to palliative care services:

- wherever they live
- at home, or in a palliative care setting within a reasonable distance from their home
- in a timely manner.

Adequately resourced

The person's care plan must ensure that sufficient resources are allocated to each of the activities and services selected so they are sustainable and benefit the person.

Collaborative

The needs for palliative care are assessed and addressed through the collaborative efforts of available organisations and services in partnership

Knowledge-based
All policy and advocacy should be based on the Palliative Care Association's work with the Commonwealth Department of Health and Ageing; the department consults with the association when developing policies and strategies underpinning the National Palliative Care Strategy program. Ensure there is regular interaction with appointed advocates when preparing the person's care plan.
Research-based
All activities should be based on the best available evidence for quality care.

Apply palliative care values

As a member of the palliative care team you should also act with compassion and maintain the dignity of the person, their family and/or carers, and, where necessary, advocate on behalf of the person, their family and/or carers.

People working in palliative care must be aware of the values underlying the palliative approach.

Palliative care values include:

- the intrinsic value of each person as an autonomous and unique individual
- the value of life, natural processes of death and the fact that both provide a worker with opportunities for personal growth and self-actualisation
- the need to address the person's suffering, expectations, needs, hopes and fears, as well as those of their family and/or carers
- care that is provided only when the person, their family and the carers are prepared to accept it
- care that is guided by quality of life defined by the individual person
- the need to respect the person's lifestyle, social contact cultural choices and spiritual needs
- care where professionals enter into a therapeutic relationship with the person, their family and carers based on dignity and integrity.

Address changing needs

The person accessing the service, their families and/or carers need help during the transition from therapy aimed at altering the course of the disease, to coping with the palliative phase of illness. When first developing a care plan for people receiving palliative care, you need to assess the following areas so the care plan addresses current needs:

- Symptom management
- Psychosocial issues
- Pharmacological and non-pharmacological options
- Medical equipment to promote a person's quality of life

Support and healing

Many people work through their grief with the support of friends and family, and do not require additional formal support. Some people, especially those who have few pre-existing supports or are experiencing difficulties coming to terms with their loss, may benefit from additional help.

You must be able to work with grieving people to help them identify the kinds of support they need. This might be drawing on informal support within their family and community, or using formal services, such as doctors and counsellors, to address specific needs. If newly diagnosed, he grieving process may commence on the transition to palliative care; if they have had a chronic illness for a period of time, the person and their family and/or carer will have had time to work through some of the stages of grief. When people are made aware that life is ending, some people will have made a conscious decision to cease active treatments to prolong life. For others, there is no further treatment available. They have transitioned to a palliative stage in their life, and will still undergo a grieving process for this new stage of their life and the loss they are facing.

Sources of support for people who are grieving include bereavement support groups, counsellors and psychologists who specialise in grief and trauma, palliative care services, ethnicity-specific services, telephone support services, doctors and other health care professionals.

Recognise negative impacts on health and wellbeing after a loss

Loss, grief and bereavement are highly stressful experiences that can have a range of impacts on an individual's health and wellbeing. You need to be able to recognise the elevated risk of negative impacts associated with loss and assist grieving individuals to obtain appropriate support.

Health and wellbeing are based on a balance within a person's mental, physical, emotional and spiritual life. Negative life events, such as the experience of loss and grief, disrupt and unbalance an individual's sense of wellbeing and may drain them of energy.

The person and their family and/or carers will need support from the palliative care team to support them through this stage. For some, support will be having a person to talk to and accept their feelings. For others, referral to other supports in the community will be necessary.

Assist the grieving process

Supervisors can assist the grieving process by supporting family members and carers in a number of ways:

- Encourage them to express their feelings to help them cope with uncertainty, denial, anger, depression and feeling like they have lost control.
- Acknowledge the emotional and physical burden on individual family members of caring for someone who is dying.
- Recognise and allow for different coping styles between individual family members and carers.

- Provide family members with privacy to express their concerns and the difficulties they are experiencing.
- Provide reassurance if they feel guilty about issues; for example, relationship issues, wanting it to be all over, not wanting to be at the person's side all the time.
- Offer interventions such as pastoral care.

Example

Assist with care planning using a palliative approach to maximise the person's quality of life and comfort

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 the person is experiencing.

An education session is held for all of the staff on the need to reassess people who are living in the facility with pain. Mr Cane was used as the example. On admission to the facility Mr Cane's pain was managed with a regime of Panadol Osteo and at night sedation was ordered to assist him with sleeping. Over the last six months, Mr Cane had become bed bound and had also developed contractures of his limbs. This required regular position changes and Mr Crane, in addition to being known as a 'whinger', had become very aggressive to staff. Mr Crane had withdrawn from social activities in the facility and spent all the time in his room in bed. Mr Crane was reluctant to take stronger pain medication as he thought once he was given morphine he would die within a couple of days.

The doctor reassured him regarding the use of medication and Mr Crane agreed to wearing a patch with an opioid medication, after hearing that it was slowly absorbed and that he would be closely monitored to assess for overmedication effects. Mr Crane gained immediate relief and was much happier in himself and towards staff in the facility. Mr Crane was then able to sit out of bed in a recliner chair and enjoyed taking part in the music therapy sessions.

Practice task 1

1. List two aims of palliative care.

2. Identify three values that a palliative approach employs to increase a person's quality of life and comfort.

3. List two aspects of care management that a care plan needs to address.

Click to complete Practice task 1

1B Identify care requirements based on the condition or illness of the person

Treatment is given to people to halt the progression of disease and to manage symptoms experienced in the curative stage of treatment. As the disease progresses the person may transition to the palliative care focus that aims to maximise the person's quality of life. There are a number of illnesses that people may present with either after many years of illness, or after acquiring a disease that has progressed rapidly and will require palliative care.

Along with symptom management the focus is on maintaining the quality of life for the person through the end stages of life. This will require management of psychological issues, pharmacological and non-pharmacological options and the provision of medical equipment to assist the person maintain quality of life.

A curative approach

Curative care actively treats an illness and promotes recovery. An illness that is curable and therefore does not get progressively worse is referred to as a non-malignant illness. These illnesses may be controlled by medical treatments, medications or complementary or alternative therapies. Curative treatment relies on an accurate diagnosis of the person's condition by means of imaging technology such as ultrasound, endoscopy, radiography and pathology. For example, a non-malignant illness such as a benign tumour may be controlled by surgery, chemotherapy and radiation therapy.

Curative care aims to:

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

When a curative approach is no longer appropriate

When a curative approach is no longer appropriate (for example, when treatments are no longer effective and the person is approaching the end of their life), patient care is transferred to a palliative approach. You must be aware of when this occurs so the person's care plan can be updated and the transition to palliative care implemented.

However, it is generally not an either/or case of curative versus palliative care; rather, it is a transition from a curative to a palliative approach, to promote the best possible care. It is often the person's wish to stop a curative approach when there is no hope of recovery, so they can be made comfortable in the final stages of their life.

When the decision has been made to transition to a palliative care model treatment, medical interventions are still accessed to ensure comfort and alleviate suffering.

Life-limiting illnesses

Life-limiting illnesses are progressive and it is expected that death will be a direct consequence. This includes malignant and non-malignant illnesses and illnesses that were once referred to as 'terminal' or 'incurable'. You should understand the differences between the following types of life-limiting illnesses, as you may have to discuss them with your co-workers.

Malignant illness

A malignant illness usually becomes progressively worse and may cause death; for example, a cancerous tumour. Cancerous tumours comprise malignant cells and have certain characteristics. They:

- are invasive
- usually grow rapidly
- may recur after removal
- cause death if growth is not controlled and stopped.

Terminal illness

A terminal illness is one expected to result in the person's death. Terminal (end-of-life) care is a form of palliative care appropriate when the person is in their final weeks or days of life. End-of-life care requires that the person's care decisions are reviewed more frequently; that the care goals are more sharply focused on the person's physical, emotional and spiritual comfort needs; and that adequate support is provided for family members and carers.

Incurable illness

An incurable illness 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.

Some examples of incurable illnesses are:

- Ebola
- lupus erythematosus (lupus)
- Creutzfeldt-Jakob disease

Irreversible illness

An irreversible illness is one where a person's usual health cannot be regained and is of such severity that recovery is impossible; for example, motor neurone disease.

People with life-limiting illnesses may have their functional capacity, quality of life, communication abilities and psychosocial wellbeing severely compromised. The palliative care team can make significant contributions to the care of these people through appropriate, evidence-based assessments and interventions.

Common life-threatening illnesses

A number of people who will access palliative care services are people who have had a chronic illness usually for a number of years. A chronic illness is a disease or a group of diseases that are long lasting and have persistent effects. These diseases can be immediately life threatening, or they can last for a long period of time and require intensive management.

Individuals with chronic illness need to deal with the stressors of having these illnesses. The stressors can be the physical effects of the illness, treatments, communication with health professionals, negative feelings of self and self-image, and loss of confidence.

A person with a chronic illness needs to have trust and confidence in the health team, especially if recovery is not possible, and must maintain social relationships. A number of chronic diseases will cause the person to develop health problems related to the symptoms of the disease; for example, pneumonia can develop due to poor respiratory function.

Some of the most common diseases that lead to palliative care are:

- Parkinson's disease
- dementia
- stroke
- coronary artery disease
- multiple sclerosis
- motor neurone disease
- cancer.

Treatments are given to attempt to halt the progression of all chronic diseases and to manage symptoms for the person.

Immediate and future care requirements of people with life-threatening illnesses

Some common chronic diseases may require palliation of the person. In these cases, symptom management becomes the main focus and people will often require multiple approaches and interventions to manage the symptoms of the disease. New symptoms will emerge as the disease progresses that will require reassessment and treatment to alleviate pain and discomfort. Here are some examples of common chronic diseases that may require a palliative approach.

Coronary heart disease

Symptoms that require care and/or medical intervention:

- Angina – may become more frequent and occur at rest as the disease progresses
- Heart attack – may occur more, causing an increase in symptoms for the person as their heart condition worsens
- Heart failure – as a result of increase cardiac muscle death, the person will exhibit more system failures resulting in new and more advanced symptoms (for example, swelling progresses to pitting oedema)Arrhythmia – will progress to more frequent episodes for longer periods of time
- Shortness of breath – will worsen and require the administration of oxygen, initially after exertion til the person requires this at all times

Future care:
As the person's conditions progresses, symptoms may require more frequent interventions and new symptoms will arise that will need to be addressed. For example, a person's symptoms may initially be relieved by a period of rest, yet as the disease progresses the person may require administration of oxygen on an ongoing basis to treat breathlessness, confusion and pain. Skin will become more fragile as blood supply containing oxygen is diverted to critical organs of the body away from the periphery.

Stroke

Symptoms that require care and/or medical intervention:

- Weakness or numbness or paralysis of the face, arm or leg on either or both sides of the body
- Difficulty speaking or understanding
- Dizziness, loss of balance
- Loss of vision, blurring or decreased vision in one or both eyes
- Difficulty swallowing – may worsen, requiring the person to be reassessed and for dietary requirements to be modified (for example, the consistency of food may need to be adjusted to a vitamised formulation or the insertion of a PEG tube if the person is unable to swallow)

Future care:
As the person's conditions progresses, symptoms may require more frequent interventions and new symptoms that arise need to be addressed. For example, care requirements will increase as skin becomes more fragile and fluid builds up in the extremities or the affected limbs, leading to more skin tears or ulcer formation.

Cancer

Cancer can cause any sign or symptom depending on where the cancer is, how large the tumour is and how it affects the organs or tissues.

It can spread to other parts of the body (metastasise) and can cause fever, fatigue or weight loss.

Future care:
As the cancer progresses new symptoms will emerge that require interventions which will depend on the growth of the tumour and the location of the tumour or metastases.

Dementia

Early signs of the disease:

- Memory loss that affects day-to-day function
- Difficulty performing familiar tasks
- Confusion about time and place
- Problems with language
- Problems with abstract thinking
- Poor or decreased judgment
- Problems misplacing things
- Changes in personality or behaviour
- A loss of initiative

End stages of the disease:

- Memory loss
- Problems with communication
- Loss of mobility
- Weight loss
- Problems with continence
- Unusual behaviour

Future care:
New therapies and interventions will be required to address changing conditions of the person. For example, the loss of mobility will require physiotherapy to prevent contractures of limbs, and occupational therapy to provide specialist equipment.

Multiple sclerosis

Early signs of the disease:

- Blurred or double vision
- Thinking problems
- Clumsiness or a lack of coordination
- Loss of balance
- Numbness
- Tingling
- Weakness in an arm or leg
- Fatigue
- Bowel and bladder disturbances

End stages of the disease

Multiple sclerosis (MS) is a progressive disease of the nervous system. It can cause a wide variety of symptoms, which may continue or worsen as the disease progresses.

Future care:

- Swallowing and eating – may require the insertion of a PEG or a modified diet to prevent aspiration.
- Communication – the speech therapist will provide therapy and communication aids for the person
- Pain – constantly needs assessment to ensure medication is effective for the person.

MS leads to a decline of the respiratory system. This can lead to shortness of breath and increased respiratory secretions and death from associated infections such as pneumonia. Future care needs may require suctioning and physical therapy to remove secretions, medications to dry up the respiratory secretions produced, and oxygen therapy to support the person's comfort.

Chronic obstructive pulmonary disease (COPD)

COPD is a progressive disease that affects your ability to breathe.

Early signs of the disease:

- An ongoing cough or a mucous-producing cough
- Shortness of breath
- Wheezing
- Chest tightness

Future care:

- Extreme weight loss will require modification to diet, such as a soft diet, progressing to a vitamised formulation to enable easier ingestion of food.
- The person may require insertion of a PEG to ensure adequate nutrition.
- Shortness of breath will require oxygen therapy.

Parkinson's disease

Early signs of the disease:

- Tremor
- Rigidity
- Bradykinesia (slowness of movement)Freezing
- Stooped posture
- Shuffling gait
- Micrographia (small, cramped handwriting)
- Lethargy

End stages of the disease:

- Progressive worsening of the symptoms until the person is unable to care for themselves and requires constant nursing care
- Complications associated with the symptoms of the disease, such as poor respiratory functioning, can lead to death.

Motor neurone disease

Early signs of the disease:

- Stumbling due to weakness of the leg muscles
- Difficulty holding objects due to weakness of the hand
- Slurring of speech or swallowing difficulties due to weakness of the tongue and throat muscles
- Cramps and muscle twitching

End stages of the disease:

The end stage is a progressive weakness and often a sudden deterioration in all systems of the body. The most common cause of death is due to respiratory failure.

Diabetes

There are two types of diabetes conditions:

- Type 1 diabetes is an autoimmune disease that destroys the cells of the pancreas.
- Type 2 diabetes that is a progressive disease that causes the body to become gradually more resistant to insulin. Insulin is the hormone responsible for the transfer of glucose from the blood to the cell.

Future care:

- Increase in skin ulcers – requires wound management and could eventually lead to amputation
- Peripheral vascular disease – leads to more fragile skin , that leads to ulceration and wounds
- Coronary heart disease – (see above)
- Kidney disease – leads to renal failure and can require dialysis to manage the symptoms

How the systems of the body interact

The body is a unified and complex assembly of functioning parts or body systems. Each of the body systems, and the organs and structures that make up these systems, are designed to perform specific complex functions. All systems work together to ensure the healthy survival of the human body. The interrelationship between body systems becomes more obvious when a disease or illness that affects one body system also affects other systems. All of the body's systems work together, as outlined below. In palliative care it is important to assess the needs of the person for all the systems of the body, as they will all be affected by the disease condition of the person.

Body system	Interaction with other body systems
Cardiovascular The cardiovascular system is responsible for transporting blood throughout the body. It works in conjunction with the respiratory system to help move oxygen throughout the body.	**Respiratory** – The cardiovascular system helps the respiratory system transport gases. **Musculoskeletal** – The cardiovascular system delivers and removes material to and from the musculoskeletal system. **Endocrine** – The cardiovascular system transports hormones for the endocrine system. **Nervous** – The cardiovascular system delivers oxygen and hormones to and from the brain and spinal cord. **Digestive** – The cardiovascular system transports nutrients for the digestive system. **Urinary** – The cardiovascular system helps maintain kidney function. **Reproductive** – The cardiovascular system helps with the blood flow needed to maintain and sustain an erection. **Integumentary** – The cardiovascular system controls sweat production. **Lymphatic** – The cardiovascular system provides the lymphocytes for the lymphatic system.
Respiratory The respiratory system is responsible for ensuring the body has sufficient oxygen intake to oxygenate the blood and that it expels carbon dioxide.	The respiratory system provides oxygen to the entire body and removes carbon dioxide from cells
Musculoskeletal The musculoskeletal system incorporates two major systems: the muscular system and the skeletal system. The skeleton acts as a frame for the body's tissue and skin – the muscles make ambulation and movement possible.	**Cardiovascular** – The musculoskeletal system helps move blood throughout the system. **Respiratory** – The musculoskeletal system helps the lungs function. **Endocrine** – The musculoskeletal system protects some of the organs of this system. **Nervous** – The musculoskeletal system provides structure for the nervous system. **Digestive** – The musculoskeletal system allows the mouth to chew and protects some organs. **Urinary** – The musculoskeletal system controls the movements of the bladder using the sphincter muscle. **Reproductive** – The muscles of the musculoskeletal system facilitate the movement of the foetus through the birth canal. The musculoskeletal system helps with penile erection and subsequent ejaculation **Integumentary** – The musculoskeletal system moves the facial muscles to enable communication. **Lymphatic** – The musculoskeletal system assists the flow of lymphatic fluid. The musculoskeletal system helps with immunity.

Body system	Interaction with other body systems
Endocrine One of the major functions of the body's systems is to keep the body in balance. The medical term that describes the processes used to regulate the body is homeostasis. One of the systems that play a major role in homeostasis is the endocrine system.	**Cardiovascular** – The hormones of the endocrine system regulate and impact on heart rate. **Respiratory** – The hormones of the endocrine system assist with air flow to the respiratory system. **Musculoskeletal** – The endocrine system helps maintain and develop muscles and releases adrenaline to the muscles of the body. **Nervous** – The endocrine system makes sure the cells in the body have the required balance of minerals, enabling the nervous system to function effectively. **Digestive** – Hormones from the endocrine system affect the way food is digested within the body. **Urinary** – Hormones from the endocrine system regulate urinary excretion. **Reproductive** – Hormones from the endocrine system facilitate puberty, impact on sex drive and regulate pregnancy and lactation. **Integumentary** – The endocrine system affects the growth and distribution of hair. **Lymphatic** – The endocrine system helps activate the lymphatic system's immune response.
Nervous The nervous system is responsible for communicating information received by the senses to the brain. It is responsible for processing information and communicating required responses to the muscles and bones.	**Cardiovascular** – The nervous system regulates heartbeat within the cardiovascular system. **Respiratory** – The nervous system regulates breathing and respiration within the body. **Musculoskeletal** – The nervous system instructs the muscles how to move. **Endocrine** – The nervous system controls and stimulates glands in the endocrine system. **Digestive** – The nervous system controls appetite and faecal movements. **Urinary** – The nervous system controls urinary functions. **Reproductive** – The nervous system helps with lactation. **Integumentary** – The nervous system regulates sweating and temperature. **Lymphatic** – The nervous system works in conjunction with the lymphatic system to respond to pathogens.

Body system	Interaction with other body systems
Digestive The digestive system breaks down food into energy and basic nutrients. The food is broken down into simple forms, such as glucose, amino acids and protein. This converted food is then absorbed into the blood stream from the small intestine and nutrients are carried to the cells throughout the body.	The digestive system provides nutrients to all of the different body systems.
Urinary The urinary system consists of the kidneys, ureters, urinary bladder and urethra. The urinary system filters and eliminates wastes from the body.	The urinary system assists each body system by disposing of waste.
Reproductive As the name suggests the male and female reproductive systems are responsible for reproduction. These systems also help with development – in particular with the development of secondary sex characteristics such as pubic hair in both males and females, and breasts in females.	**Cardiovascular** – Pregnancy is associated with an increase in blood volume carried around the body by the cardiovascular system. **Respiratory** – Sexual arousal can place greater demands on the respiratory system by increasing the body's need for oxygen. **Musculoskeletal** – Facilitates growth and development of the foetus. **Endocrine** – Communicates with this system to help regulate hormone levels in the body. **Nervous** – The nervous system controls appetite and faecal movements. **Digestive** – The digestive system may contribute to heartburn and constipation during pregnancy. **Urinary** – Pregnancy can place pressure on the bladder and the urinary tract causing incontinence. This can continue after birth and is known as stress incontinence. **Integumentary** – The integumentary system is responsible for changes in the composition and distribution of hair. **Lymphatic** – The lymphatic system protects sperm from the female's immune system, which could otherwise be rejected by the lymphatic system.

Body system	Interaction with other body systems
Integumentary The integumentary system is made up of the skin, glands, hair and nails. This system plays a number of roles. The skin in particular acts as a barrier protecting internal organs, helps make use of vitamin D and is a major organ that allows us to sense heat, cold, sharp surfaces and other environmental factors.	**Cardiovascular** – The cardiovascular system is protected by the skin which ensures that blood stays within the system. **Respiratory** – Hairs in the nose are part of the integumentary system which helps to helps filter air for the respiratory system. **Musculoskeletal** – The integumentary system protects the muscles and helps with Vitamin D intake, a nutrient that helps with calcium absorption. Calcium is needed to build and maintain healthy bones and vitamin D is needed for healthy bone function. **Endocrine** – The integumentary system absorbs vitamin D, which is used by the lymphocytes to help the immune system function effectively. **Nervous** – The skin acts as a receptor for vital information, such as temperature and pain, for the nervous system. **Digestive** – Vitamin D is absorbed into the integumentary system which helps the intestines absorb calcium. **Urinary** – The skin helps with the removal of waste through sweating. **Reproductive** – The skin is a vital organ during foreplay. **Lymphatic** – The skin contains special cells that support the role of the lymphatic system.
Lymphatic The lymphatic system plays an important role in defending the body and its cells against pathogens. It filters, removes and reacts to pathogens. The lymphatic system forms part of the immune system.	**Cardiovascular** – The lymphatic system deals with pathogens in the blood. **Respiratory** – The lymphatic system removes waste from the lungs assisting the respiratory system. **Musculoskeletal** – The lymphatic system aids production and repair of muscles. **Endocrine** – The lymphatic system transports hormones used by the lymphatic system. **Nervous** – The lymphatic system works with the brain to stimulate defence mechanisms against infection. **Digestive** – The lymphatic system transports digested fats and aids waste. **Urinary** – The lymphatic system assists the kidneys to remove waste. **Reproductive** – Immunity is passed onto the baby via his or her mother's milk. **Integumentary** – The integumentary system is responsible for changes in the composition and distribution of hair.

Emotional impact of a life-threatening condition

It is important to understand that grief is a process that every person must work through in their own way. There is no set way to grieve and no specific time frame for people to come to terms with their loss. People usually work through different stages of grief over different lengths of time.

Common reactions to grief include deep sadness and yearning, but how a person grieves depends on many factors, including their own coping style, their age, their cultural background, their religion, their personal circumstances and, if someone is dying, the nature of their relationship with the dying person and the manner of the dying process. Some losses are particularly hard to bear, such as the death of a child or a spouse, or deaths that occur in traumatic circumstances.

People who have a diagnosis of a life threatening condition enter this state of grieving and work through the different stages of grief.

Stages of grief

1. **Denial**
   Denial is a conscious or unconscious refusal to accept facts, information or reality relating to the situation concerned. It's a defence mechanism. Death of course is not particularly easy to avoid or and is impossible to evade indefinitely.
2. **Anger**
   Anger can manifest in different ways. People dealing with emotional upset can be angry with themselves and with others, especially those close to them.
3. **Bargaining**
   For some people, facing death can involve attempting to bargain with whatever higher power the person believes in.
4. **Depression**
   Depression is conserved a preliminary level of acceptance with emotional attachment. It's natural to feel sadness, regret, fear and uncertainty during this stage. It shows that the person has at least begun to accept the reality.
5. **Acceptance**
   This is an indication that there is some emotional detachment and objectivity. People dying can enter this stage much earlier than the people they leave behind.

Common expressions of grief

Common expressions of grief include emotional and cognitive responses. There are described below.

Anger, guilt and remorse

Many people experience anger as a response to loss. They may feel as though they are being punished or that life has not been fair to them. They may lash out at others or feel that the dying person has somehow betrayed them or that it is unfair that they are deceased. Having a constructive way to let off steam, such as physical activity or a safe place to communicate these thoughts, can often help people feeling intense anger over their loss.

Feelings of guilt and remorse may stem from a bereaved person thinking about what they should have done or said while the deceased person was still alive. The bereaved individual may also feel that they are somehow to blame for the deceased person's death. Guilt and remorse are common reactions to the loss of someone close and should decrease over time.

Anxiety and confusion

Anxiety is a common feeling among people who are grieving, especially if they were very dependent on a person who has died or who is facing death. They may feel anxious about their ability to survive on their own, both emotionally and practically.

An individual may also experience anxiety about the next stages of life before death.

In the early stages of intense grief, an individual may experience confusion, difficulty concentrating and forgetfulness. They may have difficulty carrying out basic tasks and be easily overwhelmed. This usually gradually fades with time.

Change in world view

Losing someone close or a facing death can often bring about a change in the way an individual thinks about the world. This is particularly true of people who lose someone in sudden or traumatic circumstances. A person experiencing a change of world view may:

- lose or take up a religious faith
- see the world as a less benign or safe place
- change the way they think about death
- become more determined to make a difference in life; for example, they may begin to do volunteer work.

Chronic sorrow

Chronic or ongoing sorrow is often an expression of complex or unresolved grief. Instead of experiencing a range of emotions, including happy memories of the person who has died or of their life, the grieving person cannot move past their deep feelings of loss.

Depression and despair

It is natural to experience feelings of sadness and depression over the loss of someone close or when facing death; however, it is important to understand that grief and what is known as clinical depression are two separate conditions.

Clinical depression involves ongoing feelings of sadness and emptiness that do not go away over time. People experiencing grief have fluctuating emotions, including sadness, but the deep sadness associated with loss lessens over time as the person integrates the loss into their life.

A person who has depression prior to a significant loss may experience a complex grief reaction as they try to deal with both their depression and their grief.

The feeling of despair stems from a sense of hopelessness, futility and lack of comprehension about what has happened or is going to happen. It is a common reaction in the early stages of normal grief as an individual struggles to come to terms with their loss, but if it persists, it can also be an indicator of a complex grief reaction.

Decreased self-esteem

People who are grieving often feel emotionally drained. This can result in a loss of confidence and self-esteem. They may also feel they have lost some of their own identity if a spouse or partner dies, or their lifestyle is significantly altered in the process of dying. Loss of self-esteem in grief is usually only temporary. If it continues, it may indicate that the person is also suffering depression.

A fear of going mad and feeling unable to cope

Grief is often described as a roller-coaster because people go through a range of fluctuating emotions. They may experience intrusive thoughts or hallucinations, and periods of intense grief are often followed by a feeling of numbness or flatness. This may lead some grieving people to think they have lost their minds or their ability to control their thoughts and emotions.

Intense grief reactions should lessen over time. If bereaved individuals continue to experience intrusive thoughts, hallucinations or flashbacks, they may have a traumatic stress reaction requiring specialist help.

Dealing with loss and grief can be overwhelming and all-consuming. This can lead some people to feel that they cannot cope and will never come to terms with their loss. This is particularly true where the loss of the deceased person or facing death has been sudden or traumatic. In normal grief, feelings of being unable to cope should gradually fade over time, but they may persist in complex grief reactions.

Helplessness, hopelessness and loneliness

Loneliness is a common feature of grief when bereaved individuals lose the companionship of someone who was close to them or when they are facing death. They may also feel that no one else can understand what they are going through. Feelings of loneliness should abate as individuals draw support from others and resume their former lives or have their needs met through palliative care services. Ongoing loneliness and isolation may be an expression of a complex grief reaction.

Questioning values and beliefs

People may become disillusioned with life and the things they used to believe in when they experience a major loss, particularly when the loss occurs in a sudden or traumatic manner. Grief and loss can cause significant changes to the way an individual views the world. They may re-evaluate long-held beliefs and values and change the way they live.

Feeling relief

A person may experience relief when an expected death occurs; for example, when a person suffering from a painful, terminal illness dies and their suffering is over. Feeling relieved is not heartless or uncaring, but a normal response to an expected event.

Shock and disbelief

Shock and disbelief are common initial responses to a sudden or unexpected death or diagnosis. On first hearing of someone’s death or diagnosis, an individual may find it difficult to comprehend. One of their first reactions is often to feel that it cannot be true. As time passes, these individuals usually experience other emotions such as anger and sadness.

Suicidal ideation

Some people who experience a significant loss may think about ending their own lives. In most cases these are just thoughts, but some, particularly people who are having a complex grief reaction, may try to act on their thoughts. Most people thinking about harming themselves start to make statements or behave in ways that indicate what they are planning; for example, they may say things like, ‘I wish I were dead’, or start to give away their belongings.

Loss

There will be times when you need to support and care for someone who has experienced a loss and is grieving. People grieve when they lose someone or something that is important to them. In palliative care we usually associate grief with the death of someone close, but people may grieve a wide range of losses. Losses may include the loss of a limb, the loss of sight, the breakdown of a relationship, the death of a pet, a miscarriage or the loss of a job. The more significant the loss is to an individual, the stronger their grieving response is likely to be.

The impact of loss and the common features of grief and trauma

When a person is dying, or when a person loses someone or something significant to them, they experience grief. Loss and grief affect people in many ways, and also have an impact on families and communities. Here are some examples of various types of loss.

Loss

Loss occurs when a person loses someone or something that is important to them. After a loss, people usually go through a period of grieving. Grieving is a normal and expected reaction to loss. Individuals experience and express grief in different ways, and often the more personally significant the loss, the greater the sense of grief experienced.

Primary loss

Primary loss is the initial loss that a person experiences; for example, the death of someone close or a loss of health.

Secondary loss

The consequences or outcomes of a primary loss are considered to be a secondary loss. Secondary losses may include:

- losses related to the internal world, such as a loss of cognitive or sensory capacity (for example, an individual losing a long-term marriage partner may experience a loss of identity, or a person who is involved in an accident may lose their memory, sight or hearing)
- interaction losses, such as the loss of support and companionship when someone close dies
- losses of the external world, such as material or personal losses that include the loss of financial security or loss of possessions.

Cumulative loss

Cumulative loss occurs when a person experiences a number of successive losses; for example, an individual may lose their partner, experience poor health and have to sell their house because they can no longer pay the mortgage.

The broad spectrum of loss

Loss and grief are usually associated with the death of a life partner, relative or friend, but there are many other losses that cause people to grieve.

Losses that may cause a grief reaction include:

- the loss of health
- the loss of sensory or physical ability, such as hearing, seeing or walking
- the loss of a job or career path
- the loss of financial security
- the loss or death of a pet
- the breakdown of a relationship
- a miscarriage
- the loss of a home or other valued possession
- the loss of personal security and safety
- the loss of a sense of control.

Loss and grief

Loss may affect physical health in a number of ways. The impacts of loss can be life-changing experiences that disrupt an individual's sense of equilibrium. A bereaved person or a person transitioning to palliative care often struggles with a feeling of disbelief or shock at what has happened. This sense of being unbalanced affects their emotional, behavioural and mental health, which in turn impacts on their overall wellbeing. Disenfranchised grievers (that is, those who are not recognised as having suffered a loss) may be most at risk of experiencing negative health and wellbeing consequences.

Physical impacts

Physical impacts of grief and loss include:

- exhaustion and a lack of energy
- headaches
- lowered immunity
- high blood pressure
- disrupted sleep
- a rapid pulse
- shortness of breath
- digestive complaints
- a loss of appetite
- worsening of pre-existing conditions, such as asthma or skin conditions.

Social/emotional impacts

Social and emotional impacts of grief and loss include:

- social withdrawal
- increased anxiety
- strained relationships
- marriage problems
- increased substance abuse
- confusion
- clinical depression
- an inability to carry out basic tasks
- suicidal ideation.

Additional impacts

It is important that you recognise signs that indicate a person may need additional support or professional help to deal with their grief. Warning signs may include the person:

- feeling an ongoing sense of numbness and disconnection from others
- experiencing a range of physical symptoms
- having difficulty carrying out basic tasks such as maintaining hygiene, cooking or going to work
- showing signs of deep ongoing sadness or depression
- making statements about life being meaningless or not worth living.

The impact of loss

Some losses have a greater impact on individuals than others. These losses may result in long-term changes to the way an individual thinks about the world, their behaviour and their social and emotional life. Some specific types of loss are described below.

Losing a child

Losing a child is one of the most painful and devastating of all losses, because parents expect their children to outlive them. The grief reaction a parent experiences is often multilayered, with intense feelings of grief, as well as guilt, anger, disorientation and a sense of failure.

A parent may never get over the feeling that a part of them died when they lost their child. Siblings are also affected, often feeling that they must compensate for the death of their brother or sister.

Losing a spouse or partner

Losing a spouse or partner causes deep grief and often results in more life changes than other types of loss. The surviving person loses their life partner, as well as their co-parent if they have children, and their source of emotional and practical support. They may also lose many of their hopes and dreams for the future.

In this situation, feelings of isolation often dominate, because friends may not know how to respond to such a devastating loss and may assume that others are supporting the person grieving.

The surviving person often must deal with the fear of an uncertain future, which may include financial difficulties. If they have children, they may feel that they must be a source of strength and support for them.

A child losing a parent

Children are rarely prepared for the death of their mother or father. The loss of a parent can leave a child feeling deeply confused and alone. Life as they know it is disrupted and changed forever. They often search for meaning in their parent's death and may conclude that it is somehow their fault. Children must be allowed to express their grief and be supported, nurtured and provided with continuity throughout the grieving period.

Losing someone in a sudden, violent or traumatic way

The way someone dies can have profound impact on their family and friends. Violent or traumatic death, such as murder, suicide or accident, leaves those closest to the deceased feeling deeply shocked and traumatised. A person's sense of grief may be heightened if others do not acknowledge the death because they believe the deceased person was in some way responsible for their own death; for example, because they were involved in criminal activities, drove too fast or took their own life.

Other impacts

Loss, grief and trauma do not only impact individuals. Every death affects a range of people, including family members, friends, work colleagues and people within the community. In cases where a death involves trauma, such as a young person killed in a car accident or a person killed as a result of a natural disaster, whole communities may experience a deep sense of shock, loss and grief that may take years to come to terms with.

Loss and grief also have wider social and economic impacts. Bereaved people need time to grieve, which often means taking time off work. Those who experience complex or traumatic grief responses require more time and help to come to terms with their loss, and may need specialist support or treatment. Those who do not receive the support they need may be more susceptible to a range of health concerns, including mental health and substance abuse problems

Family members and friends may also need support to help them cope and respond appropriately to an individual experiencing complex grief and trauma. They may find it difficult to understand the emotional and behavioural changes the grieving person experiences and wonder why they cannot simply pull themselves together and get on with life. This can be a source of friction within a family and among friends.

Social, cultural and spiritual differences in loss and grief

In every society and culture, people feel sadness and grief at the loss of someone or something significant to them. The ways people from different backgrounds express and cope with loss vary, and you need to take into account individual differences when supporting bereaved individuals.

An individual's beliefs, attitudes, feelings and behaviours associated with death and dying are influenced by a range of factors, including their social, cultural and spiritual background. It is important for you to understand and acknowledge these differences, although it can be difficult to know how to respond appropriately when working with bereaved individuals from different cultural or religious backgrounds to your own.

This difficulty often stems from a lack of information about different responses to loss and grief, so to provide appropriate support community service organisations should develop links and networks with cultural groups in their communities to obtain relevant information.

By doing this, you can:

- feel confident about offering appropriate bereavement support to people from different backgrounds
- recognise and accept different responses, rituals and customs associated with death, grief and bereavement
- ensure that people from different backgrounds have an opportunity to grieve and participate in the mourning rituals and customs relevant to them.

It is important to be aware that people who cannot follow traditional practices associated with bereavement may experience further stress and unresolved grief. Here is some more information about working with individual differences regarding loss and grief.

Reactions to loss

What is considered an acceptable reaction or emotional response to death varies widely between different cultures. For example, some cultures frown upon public displays of emotion, especially negative emotions such as grief, while others consider public displays of grief important and necessary.

Individual expressions of grief

Even within a particular culture, there may be differences in the way individuals respond to loss and in the intensity and duration of their grief. This may be because of different roles they must adopt in the mourning process or differences in personality and their experience of bereavement.

Some people prefer to grieve in a very private way, not expressing signs of emotion. Ensure that you do not judge them or imply that you think they are callous or unfeeling.

Individuals and families may have their own practices associated with grief and bereavement. These include preferences about how funerals are conducted, whether a person is cremated or buried, whether children are encouraged to attend funerals and how a death is dealt with within the family and by each of its individual members.

Cultural expressions of grief

Every culture has rituals and practices associated with the expression of grief and bereavement. In many cases these are based on the religious and spiritual traditions of the particular culture.

The rituals and customs associated with mourning, such as funerals and wakes, give people a framework for expressing their grief and receiving sympathy and support from the community.

Try to provide culturally sensitive support by developing an understanding of the different social, cultural, ethnic and spiritual practices associated with grief and loss.

Spiritual and religious beliefs relating to loss and grief

A person’s spiritual or religious beliefs can help them make sense of death and ease the loss of someone significant. Most religions and spiritual traditions have a theory about the afterlife that allows those facing death or those who are bereaved to feel comfort in the idea of an ongoing existence.

Coping strategies

The way an individual copes with loss is influenced by their background, their beliefs, their personality and their experience of loss.

Most people follow culturally and socially prescribed patterns of coping such as participating in mourning rituals, drawing on the support of families and friends, and recognising that their feelings of intense loss and grief will subside over time. Some are stoic in the way they face and deal with loss, and others may need to immerse themselves in their loss for a period of time.

Your role

To provide effective support for people who are grieving, you must understand the impact of loss, grief and trauma, and the range of reactions that people may experience.

Accept that people will grieve in different ways based on cultural, ethnic, social and spiritual influences, and learn to recognise signs that indicate a person is having difficulty coping with grief or trauma and may benefit from additional support.

You should understand that grieving people need you to acknowledge their loss or losses and that they may want to talk at length. Sometimes the most appropriate support you can provide is to listen and be accepting of the full range of emotions the bereaved person expresses. This helps to normalise the person’s grief reaction and helps them cope with feelings and reactions that sometimes seem overwhelming.

The ability to communicate and interact in a sensitive and empathetic way with people who are grieving is essential. You should be able to use verbal and nonverbal communication skills to listen, offer support, provide information and confirm that a person understands the range of resources available to them.

You should also be familiar with your organisation’s referral procedures and provide a person with options and information about appropriate referral sources.

Example

Identify care requirements based on the condition or illness of the person

Client name: Hamish Briggs
Date of birth: 11/08/1928
Gender: Male

Diagnosis: Epilepsy and dementia

Personal details

Hamish is Scottish. He is 87 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.

Person'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.

Practice task 2

1. Explain when a palliative approach takes over from a curative approach.

2. Identify two stressors of chronic illnesses.

3. List three effects of end stage dementia on the person.

Click to complete Practice task 2

1C Identify current specialist palliative care requirements

For some diseases there are specific groups of specialist healthcare workers that focus on relieving the symptoms of the disease. For individuals who have moved into a palliative model of care a major focus of treatment will be on symptom relief and pain management. Individuals may have many questions and fears about what to expect. Expert knowledge and communication can also assist the person at the palliative stage of a disease. Please see below a list of diseases with corresponding organisations that offer support for the person, family and/or career and the support worker.

Coronary heart disease

Specialist advice and information can be obtained from the Heart Foundation.

You can access more information on their website at: http://aspirelr.link/heart-foundation

Parkinson's disease

Specialist advice and information can be obtained from Parkinson's Australia.

You can access more information on their website at: http://aspirelr.link/parkinsons-aus

Multiple sclerosis

Specialist advice and information can be obtained from MS Australia.

You can access more information on their website at: http://aspirelr.link/ms-aus

Motor neurone disease

Specialist advice and information can be obtained from MND Australia.

You can access more information on their website at: http://aspirelr.link/mnd-aus

Alzheimer's disease

Specialist advice and information can be obtained from the Alzheimer's Association.

You can access more information on their website at: http://aspirelr.link/alzheimer-assoc

Cancer

Specialist advice and information can be obtained from Cancer Council Australia.

You can access more information on their website at: http://aspirelr.link/cancer-council-australia

Stroke

Specialist advice and information can be obtained from the Stroke Foundation.

You can access more information on their website at: http://aspirelr.link/stroke-foundation

A palliative care team

Comprehensive palliative care uses a team of people with varied and specialised skills and knowledge. A mix of services is regarded as an important feature of good palliative care as it supports a range of options for the person receiving palliative care, their family and their carers.

All these people work together to provide comfort, support and care for the person. The goals for the palliative care team are to:

- support the person by treating and managing symptoms to ensure the best possible quality of life
- help the person self-manage their condition and make their own decisions relating to their care
- educate individuals' families and carers about death and dying, bereavement and loss.

Palliative care differs for each person due to factors such as geography, services available in their area, and the needs of the person, their family and their carers.

Palliative care team members

- Allied health professionals – social workers, physiotherapists, occupational therapists, psychologists, pharmacists, dieticians
- 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 and/or carers
- Aboriginal and/or Torres Strait Islander health workers
- Alternative therapists skilled in massage, aromatherapy, relaxation music or colour therapy
- Bereavement counsellors and volunteers
- Spiritual carers from a range of pastoral, spiritual and cultural backgrounds
- Professionals with language skills and cultural knowledge of ethnic groups

Palliative care and dementia

Caring for someone with dementia or memory support needs, can be stressful and time consuming. Your understanding of dementia will help you find the best ways to communicate and care for a person who has dementia, as well as those connected to the person such as their family, carer and friends. As dementia is a condition that affects memory and thinking, developing a rapport and a relationship of trust with people with dementia can be extremely challenging.

Dementia is a progressive condition that gradually gets worse over time. The nature of the condition means people will lose skills and abilities. They will become more dependent on others for daily care. They will need more constant support and supervision. Support workers need to have a good understanding of dementia and be realistic about what to expect from someone with the condition. It is important that you approach your work with an understanding of the condition and an understanding of the individual needs of each person. It is also important that you understand the challenges and burdens that family members and carers face when someone close to them has dementia. The impact on the life of carers is significant and must be taken into account when planning and delivering support.

Death will occur as the disease progresses and complications arise. For example, these complications may arise due to poor nutritional intake, loss of mobility and poor respiratory function. The disease originates in one part of the body but affects all body systems, giving rise to a multitude of symptoms. This will require the support worker to constantly monitor and reassess the person’s condition, report new symptoms to the palliative care team and implement appropriate therapeutic strategies to manage the symptoms.

A person-centred approach for people with dementia

When providing care for a person with dementia it is important to ensure that care and other activities are adapted for each individual. People will have different skills, preferences and histories. Some will take longer to do tasks than others. Some may need extra time to develop trust in you, each time you provide support. It is important to be aware of these factors for each person. Tailor the way you communicate with the person; reassure them and provide support and activities based on their individual needs.

Below are the different factors you need to take into account when using a person-centred approach.

Relationship

The way in which you develop relationships with people who have dementia and their family members is important. Knowing about their interests, history, family, culture and so on means that you will be able to say and do things in a way that puts them at ease. Even though they may not remember who you are, showing that you know them and the things that are important to them will be reassuring when you are providing care. Understanding and acknowledging the challenges faced by family members of people with dementia, and being available to discuss them, will provide support and help them in their role as carers.

Control and choice

Taking a person-centred approach means ensuring that the person has as much control and choice as possible, while providing care that meets their needs in a safe and high-quality way. It means that the person is placed in the centre of the planning process. Their likes, dislikes, personal history, cultural and religious beliefs, skills and knowledge are central to the process of planning how their support will be delivered. It means adapting care and other activities to the person, rather than expecting the person to fit in with service models that are available.

Environment

Maintaining a stable and familiar environment for people can prevent distress and minimise inappropriate or challenging behaviours. This may mean ensuring there is not too much background noise, such as music or talking, as this can be distracting and confusing. It may mean decorating facilities in soothing colours and keeping furnishings comfortable and simple. It can be important to ensure the person has their own familiar items around them, such as photos and ornaments that are meaningful to them and evoke retained memories of their past. The environment in which you provide care to a person with dementia can be tailored to their individual needs so that their surroundings are calming and familiar.

Adapt support for people with dementia

How a person with dementia is supported can affect their experience, level of comfort and maintenance of social connections. Health professionals look at the person first, and their condition second. This is referred to as the social model of health. This model works from the expectation that, as far as possible, we should adapt the environment to enable people with dementia to participate in and access the community, rather than assume that their dementia is what is preventing them from doing so.

Here is further information about the different ways a support worker can adapt their approach to assist people with dementia who are in the palliative stage.

Ways to adapt your approach to support people with dementia

Recognition

Knowing that a person may not recognise you when you come to provide support will mean you must introduce yourself and reassure them of who you are and why you are there, every time – even if you have helped them many times before.

Disorientation

If part of your role is taking the person with dementia out into the community, knowing the effects of dementia will mean you know to watch them closely, not let them wander off, and observe and manage their interaction with other members of the public.

Communication

Knowing that a person with dementia may not be able to find the words to tell you what they want, or when something is wrong, will mean you communicate with them carefully and watch for other cues or a sign to show you what is going on.

Perception

It can be very distressing for a person with dementia to struggle to understand what is going on around them. It is important that you are gentle, patient and reassuring in assisting them to function in their world.

Individuality

Each person will be different. It is important to acknowledge and support each as an individual – not just a person with dementia. Different approaches will work better and will be more reassuring to different people with dementia. You may need to try a number of approaches before being able to provide assistance.

Therapies in palliative care

Specialised palliative care therapies are utilised for the person and their family and/or carer as the need arises. This can occur as an illness progresses, giving rise to new symptoms. Specialised therapy should be undertaken if it is identified as one that will give comfort or relief to the person and their family and/or carer.

Some therapies that are used for the person accessing services in palliative care are also used for aged care residents and people suffering from dementia. The therapies aim to promote a sense of self and wellbeing and provide comfort for the individual and the person's family and/or carer. See below for some examples.

Validation therapy

Validation encourages empathy with the person by not challenging their reality but rather entering their reality. As the person loses short term memory they lose the ability to make sense of their current reality. They regress back to their past realities and experiences to try to make sense of their life. Validation therapy acknowledges the feelings of the person.

Music therapy

Music can trigger memories and feelings. Music therapists are trained in the area of dementia and can use music therapy to address complex behaviours.

Reminiscence therapy

Reminiscence is a way to review the person's past life. A 'This is your Life' book can be used to assist in this process.

Art therapy

Art can also be used as a trigger for memories for the person with dementia. It is an expressive form of therapy that uses the creative process of making art to improve a person's physical, mental and emotional wellbeing.

Behavioural therapy

Psychologists work directly with people who are experiencing difficulties. Family members and carers may also utilise the services of a psychologist, usually for counselling therapy.

Snoezelen therapy

Snoezelen therapy is a therapeutic environment to deliver high levels of stimuli to people with dementia. It is thought to reconnect them to their past and present life.

Massage therapy

The comfort of touch is important to all people. People with dementia are often soothed and take comfort by the sensation of touch. Hand massage is a very effective method to employ with people suffering from dementia and can be performed in any environment.

Physiotherapy

Physical therapy is essential to prevent contractures of limbs and promote comfort for the person.

Occupational therapy

Occupational therapists assess the person and recommend specialist equipment to assist the person in the activities of daily living.

Refer family members to other services

While caring for a person in the palliative stage it may be appropriate to refer the person and their family and/or carer to other services. As part of the care planning process, the family needs to have access other services that will be able to provide them with better information or more support services. Provide family with contact details and an explanation of the service provided, help them contact the service provider and follow up with them after their visit to the service provider. In some instances the social worker may be the best person to assist the family or carer to access further supports or equipment.

If you are concerned about their physical or mental health, the family member should be encouraged to visit their doctor. Information about other services that may be able to provide information is described below. You should add to this table, or prepare a database to keep track of the services specific to your area.

Local doctor or general practitioner

- Your local GP can provide referrals to specialists and will be able to provide factual information about different types of dementia.

My Aged Care

- My Aged Care, from the Australian Government Department of Social Services, provides information about assessment, service coordination and support to family members caring at home for a person with dementia (or other conditions). This service can also provide information about community services available in a certain area or region.

  More information is available on the My Aged Care website at: http://aspirelr.link/my-aged-care

Carers Australia

- Carers Australia can provide help and information for carers of people with dementia. There is also a free counselling service for carers.

  More information is available on the Carers Australia website at:

  http://aspirelr.link/carers-australia

Dementia Australia

- This service can provide information and support about dementia-related issues and they have a dementia helpline.

  More information is available on the Dementia Australia website at:

  http://aspirelr.link/dementia-aus

Dementia Support Australia (DSA)

- This service provides advice to carers, family and staff supporting a person with dementia who displays challenging or difficult-to-manage behaviours, which affect their care. The service is staffed by qualified and experienced professionals who can provide assessment and advice.

  More information is available on the DSA website at: http://aspirelr.link/dbmas

Centrelink

- This service can provide information about pensions and financial support that might be available to carers of people with dementia. They can be contacted on 13 27 17. For information in languages other than English you can call 13 12 02.

  More information is available on the Centrelink website at: http://aspirelr.link/centrelink

Support groups for carers

- Families who have experienced living with a person with dementia can be a great source of support. Sometimes there are support groups in local areas, which can be especially useful when a person is first diagnosed with dementia. The Carers Association in your state or territory will have information about carer support groups in a certain area or region.

  More information is available on the Carers ACT website at: http://aspirelr.link/carers-act

Example

Identify current specialist palliative care requirements

Beverley speaks about her experiences with her husband Vincent, who had severe dementia.

'At first Vincent and I even joked about Alzheimer's. From time to time he would forget things like where he left the car keys and we would laugh and say, "It must be Old Timers' Disease". Then he started to have trouble remembering some basic words. He started to lose interest in things. Then he forgot our daughter's name. We looked up the Alzheimer's website and became quite concerned regarding the disease progressing. We decided to see a doctor. Our local GP, Dr Blackwell, has looked after Vincent for the last 23 years and listened to our concerns. Dr Blackwell referred us to a geriatrician who specialises in Alzheimer's disease.

'Vincent was diagnosed with mild dementia. We coped alright for a couple of years but then he started wandering. Looking after Vincent was a full-time job. I lost contact with friends. I had to cope with new things too. Paying bills, doing repairs – these were all things that Vincent had taken care off. I felt trapped. Claire, our social worker, assigned to our case was very helpful. Claire always caught up with me to find out how I was managing and organised some respite care for Vincent that allowed me to take a break and rest. I received financial assistance from government agencies that Claire referred me to and this also alleviated some of the pressure.

'Vincent continued to go downhill. His behaviour worsened and his mobility decreased. Claire organised a referral to a physiotherapist and occupational therapist to assist with mobility and specialist equipment. Vincent still had emotional outbursts and was referred to both a psychologist for behaviour management and a psychiatrist for a review of medication to assist him. This did not help much and eventually it got to the point where I felt unsafe around my own husband.

'We moved him to a home. This sounds terrible, but there were times I wished he had died. Sometimes he was so horrible to me and the kids. The aged care facility was wonderful with Vincent and they encouraged me to visit often. This was such a bad time in my life and I often lay in bed and slept for long periods of time. I sometimes felt that i I had always enjoyed cooking but now I just ate sandwiches or dry biscuits. My daughter became concerned and encouraged me to talk to Dr Blackwell regarding how I felt. Dr Blackwell referred me to a counsellor to be able to talk freely about my feelings.

'It's like the Vincent we knew has died and all we are left with is someone who looks like Vincent. We've had a good life together but the last 10 years have been trying.'

In this example Beverly moved through a variety of emotions including denial, despair, and guilt. She experienced social isolation and the financial burden. Specialist assistance with counselling allowed Beverly to acknowledge her feelings. Then, having accepted the condition, she is able to reflect on her life with her husband without regrets.

Practice task 3

1. Identify two chronic illnesses that have specialist advice available online.

2. List three therapies that may be used in caring for people with dementia.

3. List three services a family or carer might be referred to for support.

Click to complete Practice task 3

1D Ensure planning involves and supports the person, family members, carers and/or significant others

Ensure planning includes involving and supporting the person, family members, carers and/or significant others. Palliative care aims to achieve the best quality of life possible for a person with a life-limiting illness or in the final stages of their life. Encouraging a person's independence is an important part of this philosophy. To successfully do this you should consult with person, give them access to information and let them choose the type of care they want. Respecting a person's values, goals, beliefs and decisions is crucial.

The family and/or carer also need to have access to information so that they can support themselves while supporting the person. Palliative care can be a lengthy process and the family/carers need to have support and respite to maintain their quality of life.

It is important to consult with stakeholders to:

- identify and share information about the person's changing needs and preferences, respecting the person's lifestyle
- find out about social context, spiritual needs and cultural choices.

Palliative care respects the roles of the person and carer in planning and delivering care, addressing person's issues or referring them appropriately, and using effective communication skills to provide emotional support.

Person-centred approach

Involving the person and their family in planning is consistent with a person-centred approach to proving care and is essential in maximising the person's quality of life and comfort. It is also consistent with a human rights approach.

Person-centred care means getting to know the person as an individual and treating them with the respect and dignity they deserve. It is about respect for people and their values, needs and individual preferences. Person-centred care aims for a partnership and teamwork between the person, their family and the professional care team offering support. The person should be at the centre of care and the health services should revolve around the service user rather than around funding and/or mental health professionals.

A person-centred service model responds to the whole person and focuses on a social model of care rather than a medical model of care. A person-centred approach embraces a process that sees the person making decisions about their own care needs, which forms part of their human rights. Person-centred practice relies on person-centred planning. This is where the person, or in instances where the person cannot make sound judgements, their advocate, family and/or primary carer, state what they want their plans to focus on.

Ensure planning involves family members, carers and/or significant others

Encourage the person and their family to participate in the planning process. They need to know what a holistic palliative approach means for the person. All information gathered from the person and their family must be documented in the care plan. Give people and their families as much information as they need to make informed decisions about issues such as treatment options or social support.

People who provide care, support and affection to those with life-limiting illnesses are referred to as carers. They could be parents, partners, grandparents, sisters, brothers, friends, neighbours or children of the person. They may also be people appointed by an agency.

Carers play an important role in palliative care and provide an important link between the person and the palliative care team. As a carer sees the person daily, they have first-hand knowledge of the person; for example, they can tell when the person's mood changes, if they dislike new treatment or if their condition deteriorates.

Consult with family members

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

To comply with the Standards, organisations take a holistic view of a person's needs when developing their care plan. Holistic care emphasises an interdisciplinary team approach. It also places importance on building respectful and trusting relationships with the person's family unit. A detailed assessment of the family unit including their strengths, weaknesses, dynamics, and short- and long-term needs is crucial to effective palliative care. By involving family members, you can identify a person's social, spiritual and cultural needs, their thoughts and preferences, and any issues they may not have told you at an assessment.

Having a supportive network of family and friends is an important part of coping with a life-limiting illness. In applying a palliative approach, family members should be actively involved in all aspects of the person's care, where possible. Each family member is able to provide important information on the person's personal history, changing needs and preferences. Encourage family members to participate in the person's care and to voice any concerns they may have.

Family members may include:

- the biological family; for example, parents, sons, daughters, uncles, aunts, grandparents
- the family people acquire through marriage or a long-term relationship; for example, a husband or wife, de facto partner, mother-in-law
- the 'family of choice' – friends and loved ones who are not related biologically or by marriage; for example, close friends, neighbours, carers
- the palliative care team, especially when the person has no immediate family.

Build relationships with family members

There are many ways to develop trust and build a satisfactory partnership with family members of a person receiving palliative care, some of which are described below. Whenever you receive information, make sure you record it and pass it on to the appropriate members of the care team.

Develop trust and build a satisfactory partnership with family members

- Ask family members to inform you whenever the person's needs or preferences change.
- Listen to and act on family members' opinions, complaints and suggestions.
- Encourage family members to speak about how they feel so you can help prepare them for the person's death.
- Provide privacy so they can speak to you in confidence.

Human development across the lifespan

The transition from one life stage to another does not always account for the characteristics of people with disabilities, who may develop in different ways and at different rates.

This is particularly true of people with physical or cognitive impairments, who may not progress through the expected stages of development, or may do so in an uneven or variable manner. For example, a person who has an intellectual disability may display some of the characteristics often associated with the childhood life stage, even though they are an adult.

In a workplace context, you should build your knowledge of the particular life stages present in your person group. By doing further reading, you can become familiar with the range of characteristics and features for their particular life stage. For example, if you work with young children, you should learn about the infancy, toddler, preschool and middle childhood stages. If you are working with older people, you should focus your further learning on the late adulthood and older age groups.

Life stages

- Infancy: from birth to approximately one year of age
- Childhood – Toddler: 1–3 years
- Childhood – Preschool: 3–5 years
- Middle childhood: 5–12 years
- Adolescence: 12– 18 years
- Early adulthood: 18–30 years
- Middle adulthood: 30–45 years
- Late adulthood: 45–67 years
- Old age: more than 67 years

Identify behaviours and stages

You need to carefully consider the interactions you have with person. Although some adult people may display behaviours and characteristics often seen in the childhood life stage, this does not mean you should interact with them as though they are children. As a professional, you should aim to interact with the person in a way that largely reflects their chronological age, rather than their developmental age.

You may find some people have difficulty understanding and communicating effectively with you as a result of a cognitive impairment. The key here is to modify your interactions to suit the situation, while always remembering the person's chronological age.

Tips for working with a person with a significant cognitive impairment

- Speak in shorter sentences.
- Avoid using complex words with many syllables.
- Reduce your use of abstract terms and colloquialisms.
- Be clear and specific in your interactions.
- Keep your tone and voice pitch low and regular.
- Communicate directly with the person, rather than solely speaking to a family member or other significant person.
- Check for understanding before moving on.
- Provide information in various ways, such as using graphics or images to offer choices as well as spoken language.

Psychosocial development across the life stages

Psychosocial development occurs through stages that are similar to those of cognitive development. It is affected by physical changes in the brain and how it functions, as well as through the influence of parents, peers and others in society. Here, psychosocial refers to the brain functions as it relates and matures with an awareness of the world in which the person interacts.

In early life, the family and primary caregivers are the key influences on a child. As children move out from family and enter childcare centres, schools and the community at large, they begin to form other attachments that influence their behaviour. In adolescence, they become more influenced by their friends and peer group, with much of their behaviour at this stage reflecting this change. Adulthood sees a growing independence and reliance on one's own skills, and often a change in role to caregiver rather than receiver of care. As humans move into the older life stage, there is an increasing need for dependence on others, and a change for some people to being a receiver of care.

Intellectual development across the life stages

Intellectual or cognitive development and its relationship to psychological development have been well described by many researchers over the years, including Jean Piaget (1896–1980) and Erik Erikson (1902–1994). According to them, humans move through a number of stages that can be identified by the presence of particular characteristics. Intellectual development is a series of stages through which people make qualitative changes as they acquire new knowledge. Decision-making is a cognitive process resulting in the selection of a belief or course of action.

Here is further information on the characteristics of different stages of intellectual development.

Characteristics of different stages

Infancy

A child in the sensorimotor stage in infancy is characterised as experiencing the world largely through the senses. Actions are repeated frequently at this stage and, over time, results mean some actions become more frequent, while others fade.

Preschool childhood

Preschool children embark on a period of discovery and very rapid cognitive development, which mirrors significant gains in language skills over the same time span. The world and everything in it is explored, discovered, manipulated and employed. The child adds new words and language forms on a daily or weekly basis.

Older childhood

Older children in the concrete operational stage (approximately 7–12 years) are able to use logic to solve problems, manipulate objects in their head and imagine doing things that are not actually happening. Memory skills increase and they are able to repeat skills they have been taught previously.

Adolescence

As the child moves into adolescence, they become able to use abstract thought and can create visual images and use objects to represent thoughts, feelings and concepts. They have a well-developed vocabulary and are able to communicate effectively with people from various age and social groups. It is important to note that the adolescent brain is still developing and does not reach full maturity until well into early adulthood.

Adulthood

Adults are capable of more complex and reasoned thought than children. Their response to a situation tends to be based on environmental, learnt and genetic factors.

Most adults have developed a moral code for deciding what they believe is right and wrong. This is based on what has been learnt during adolescence.

In some groups, this judgment is limited through the effects of mental illness, dementia or cognitive impairment.

Older adulthood

In older adulthood, some people become more susceptible to conditions such as dementia. By the age of 85, around one in five adults is affected by some form of dementia.

Palliative approach to supporting children and young relatives

Children require support from the palliative care team when experiencing the death of a parent, sibling or significant care giver. Depending on their age and stage of development, children will have different conceptions of what death means. The age and developmental stage will also affect the way in which a child will communicate with the palliative care team. Increasing the positive interactions of the child with the person and increasing their knowledge of the illness and its impact will provide support to the child. The ways this will be communicated will vary according to the child's age and development. Children take their cues from adults around them and their behaviour will portray their emotional state or fears. It is important to be honest with the child and to accept their feelings, while being careful not to overwhelm them with medical facts.

Here is some more information about supporting children and young relatives.

Reactions to death

Like adults, each child will react differently to death. The reaction may be linked to the relationship the child has had with the dying person, sibling, parent or friend.

Children often express their grief through behaviours and expressions of grief may also be influenced by the child's cultural background.

Death of a parent

This is usually a devastating time for a child. The parent provides the nurturing and caretaking of the child and the child may have fears about what will happen now the parent is no longer able to fulfil this role.

Death of a sibling

Children have strong bonds with siblings. They have known this person for all of their life and have shared history and memories. They may feel guilty and may also feel lost if the parent is overwhelmed with grief at this time.

Young carers

There are a number of young people who provide care and support to a parent. Caring for a parent may increase skills of the younger carer but it can also have negative effects that result in poor health and social isolation from peers.

The young carer will require additional support from the palliative care team as they are often not of age to make legal decisions for the person they are providing care for. They may have increased feelings of guilt about the person who is dying and often have a lack of family support at this time.

The younger carer may require more respite services to allow them to continue school activities, sport and interactions with other young people.

Example

Ensure planning involves and supports the person, family members and/or carers

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, a palliative care worker, that his father is very demanding and difficult to care for.

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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, and how to approach a transition to 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 4

1. Explain the term 'person-centred approach'.

2. List two ways you can build a relationship with a person's family and/or carer.

3. Explain the negative effects on a young carer of caring for an individual.

Click to complete Practice task 4

1E Ensure care plan addresses the person's ongoing needs holistically

A person's individual care plan is a vital document addressing all aspects of their needs including their immediate physical needs and their social, psychological, cultural and spiritual needs. Holistic care meets all these needs. Palliative care begins when a life-limiting illness is diagnosed and continues, regardless of whether or not the person receives treatment directed at the life-limiting illness. Palliative care should not only be provided in a person's final weeks or days of life; rather, it should be offered as soon as necessary, to support people to live as actively as possible until their death.

Palliative Care Australia's *Standards for Providing Quality Palliative Care for all Australians* details the care that must be provided from a holistic perspective. Its aims and philosophies must be considered when preparing care plans. For example, the Standards dictate that the person's, carers' and family members' holistic needs should be acknowledged when assessing a person and preparing a care plan, and that their wishes should be taken into account when determining strategies to address their needs.

Review a person's care plan

Beyond the palliative care team, a number of other services may provide support to people who are dying, their family and/or carers; for example, financial planning, legal advice and funeral arrangements.

A person's needs may change, so their care plan must be regularly reviewed and updated. The person accessing the service, 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.

The palliative care team needs to actively participate with the interdisciplinary team in addressing the following concerns.

1. **Unit of care**
   Identify the person, their family and/or carers as the unit of care and provide support for them.

2. **Holistic needs**
   Understand the holistic needs of people approaching the end of their life.

3 **A team approach**
Participate in a team approach to address the needs of the person, their family and/or carers, ensuring a palliative approach.

4 **Other people**
Seek advice from appropriate people.

5 **People's needs**
Understand that the person's needs may change and that their care plan should be regularly reviewed and updated accordingly.

6 **Self-care**
Maximise self-care and self-determination for the person.

7 **Psychological and spiritual care**
Assist in the psychological and spiritual aspects of person care.

8 **Pain**
Recognise symptoms of pain and discomfort.

9 **Death**
Recognise the signs that death may be imminent.

10 **A palliative approach**
Practise an approach that reflects an understanding of the impact of a palliative approach in an organisation.

11 **Dignity**
Maintain the person's dignity.

Organisational policies and procedures ensure a holistic approach

To comply with the Standards, organisations take a holistic view of a person's needs when developing their care plan. Holistic care emphasises an interdisciplinary team approach. It also places importance on building respectful and trusting relationships with the person's family and/or carers. A detailed assessment of the family including their strengths, weaknesses, dynamics, and short- and long-term needs is crucial to effective palliative care. By involving family members, you can identify a person's social, spiritual and cultural needs, their thoughts and preferences, and any issues they may not have told you at an assessment.

Beyond the palliative care team, a number of other services may provide support to people who are dying, their family and carers; for example, financial planning, legal advice and funeral arrangements.

Plan holistic care

There are a number of ways to plan holistic care. Firstly, all relevant members of the team should contribute to the person's initial assessment. This will save time and ensure that all the person's needs are addressed. The person's physical, social, spiritual and cultural needs must be identified and considered. For example, you may arrange social outings or friends to visit to maintain social contacts and raise morale, or encourage the person to talk about spiritual issues and/or arrange pastoral care.

Encourage the person and their family to participate in the planning process. They need to know what a holistic palliative approach means for the person. All information gathered from the person and their family must be documented in the care plan. Give people and their families as much information as they need, so they can make informed decisions about issues such as treatment options or social support.

Prepare a framework for reviewing and evaluating the care plan, so everyone can see how it will be continually adjusted as the person's needs change. Assist the person and their family to decide whether they wish to prepare an advance care plan for when the person is no longer able to make these kinds of decisions themselves.

Holistic palliative approach for children and young people who are dying

Like adults, children suffer from chronic diseases that can become malignant illnesses requiring palliative care. The support that needs to be given to children and adults is the same. Palliative care aims to provide quality of life for the person and their family and/or carers. The information and communication will be different depending on the stage of development of the child. Here are some examples of how palliative care addresses the needs of the child who is dying and their family.

Capacity to understand

A child's understanding of what is happening will vary from one child to another depending on stage of development and age. The child will often react to emotional cues given by the caregiver. The child will ask for information as changes occur. They are concrete thinkers until adolescence.

Understanding of death

Infants and toddlers:

- do not understand death but will react to the carer's emotions; maintain the normal routine of daily living to provide comfort for the child.

Pre-schoolers:

- have misconceptions about death and often view it as temporary; they are concrete thinkers and need simple clear explanations.

School children:

- have an understanding of death but are often unsure about what causes death; they require clear communication and explanation as they need to ground the information in their understanding of the world.

Adolescents:

- are able to think abstractly but often are reluctant or hesitant to express emotions; social relationships are very important that this stage of life and adolescents can often feel isolated from social relationships with peers.

Open communication

The amount and type of information the child will ask for will vary according to age and development. It is important to be honest with the child. It is often necessary to give the information many times and the child may ask lots of questions.

Indirect communication

Children will sometimes ask for information through play, drawings or behaviours. It is important to observe nonverbal communication. Often young children will regress to behaviours of a younger age in response to changes occurring in their body or as a comfort measure.

Feelings of the child

Like any person the child will experience a variety of emotions such as fear, anxiety, anger, sadness and loneliness. The younger child is often unable to express these emotions in words and often these emotions are expressed through behaviour.

Living

Routines of daily living are comforting to the child. The social model of health for children recognises that children need to play and have fun, and that social interaction is part of their daily living and to make sense of the world around them.

Resources

Hospices have specialised trained staff and facilities to assist the dying child and their family. Other organisations such as Make-A-Wish Australia, CanTeen or Starlight Children’s Foundation are also able to assist.

Support family

An important way to assist the dying child is to support the family and other important adults in the child’s life. The child is dependent on the caregiver for all aspects of social, emotional and physical activities of daily living.

Support siblings

It is important to acknowledge the feelings and emotions of siblings of the dying child. Fears may arise that they too will die, and they may experience anxiety and confusion about the changes to their life, and about missing their brother or sister.

Parents need to support other children through this process, which can be very difficult as they are going through the grieving process themselves.

End-of-life plans

Circumstances and opinions may change, especially when death seems imminent, so the palliative care team may arrange a conference with the doctor and the family to make sure the goals of care are agreed on, and to check that the person's preferences remain current. Consider the following seven strategies when meeting with the person, their family and carers to discuss the process for making end-of-life ethical decisions.

Ways to help a person and their family make end-of-life ethical decisions

1. **Suggest involving others**
Suggest to the person that they involve family members, carers or others close to them, so as to minimise the decision-making burden.

2. **Encourage the person to make directives**
Some individuals may not have an eligible substitute decision-maker or person responsible, or may prefer that no-one makes medical decisions on their behalf. Encourage the person to consider making a more detailed directive in these circumstances, if appropriate.

3. **Choose care team members carefully**
The care team member/s selected to conduct discussions about end-of-life care with a person should be those who are identified as significantly involved in the active care of the person.

4. **Be aware of opportunities for end-of-life discussions**
Opportunities for you to begin end-of-life discussions may arise when the person and/or their family or carers inquire about palliative care; when a person says they want to forego recommended life-sustaining treatment; or when they express a wish to die. In Victoria, a person can choose the manner and timing of their death if they have a terminal illness or disease.

5. **Consider timing and environment**
Advance care planning is most easily accomplished during stable health or after a person has adjusted to a new illness. Utilise a non-threatening environment such as the person's room or a quiet meeting room

6. **Ensure the person understands advance care planning**
Find out how familiar the person is with advance care planning and explain the goals. For example, plan for the potential loss of their capacity to make decisions, either temporarily or permanently, to ensure they are protected from either unwanted treatment or under treatment.

7. **Explain the details**
The person usually needs information from you to understand the meaning of the types of therapeutic and comfort scenarios that may arise in their situation, and the benefits and burdens of various treatment options. Key medical terms should be explained in plain English. Allow time for reflection and discussion after this information has been provided.

Example

Care plan for ongoing needs of people

Here is an example of a completed plan for a person over time. The plan incorporates care for the person and also acknowledges that the person's condition may change and need constant reassessment.

Care plan		
Person name: Darryl Appleton		Date of birth: 12 December 1932
Worker name: Audrey Gates		Assessment date: 27 July 2015
Participants in the care planning process:	**Person:** ☑ **Yes** ☐ **No**	**Others:** ☑ **Yes** ☐ **No**
Participant name:	Anna Appleton	Dr Peter Lutis
Relationship to person:	Wife	GP
Contact phone number(s):	9876 5432	0412 345 678

Plan details	
Diagnosis:	Dementia, significant hearing loss, reduced blood supply to the heart caused by coronary artery disease, prone to deep vein thrombosis (DVT) in legs. Has developed a pressure area on right leg with necrotic and heavily infected right foot, post-surgery.
Personal details:	Male, 82 years old, Catholic, likes listening to classical music, enjoys gardening, watching old movies.
Person's environment:	Single room in a residential aged care facility. Has photos of his wife and family. Also has three plants he likes to care for and a DVD collection of old movies to watch.
Person's condition:	Often in pain (due to coronary artery disease and infected foot), has balance issues and is very shaky and at risk of falls in the shower. Experiences breathlessness, shows signs of mental confusion and is often frustrated and angry and occasionally aggressive. Wears two hearing aids, but often forgets to turn them on.
How to meet person's physical needs:	The person is regularly assessed for pain and discomfort and the appropriate intervention is taken. Medication for side effects (nausea and vomiting) is also provided. Antithrombotic stockings required to prevent DVT. Shower chair provided and carer to supervise personal grooming. Specific dressing management routine undertaken for infected foot. Oxygen provided when appropriate. Opioid administered regularly via patch. Rest time has been allocated during the day – no visitors after 5 pm (except immediate family). Needs reassessment regularly for skin integrity, pain, and constipation and falls risks – to be commenced on charting for these assessments. Vital sign monitoring needs to include oxygen saturations both on room temperature and on administration of oxygen.

Example

continued ...

Plan Details			
How to meet the person's psychological, social and cultural and spiritual needs:	Encourage family members to visit and spend time with Darryl – watch a movie together. Have family members bring in gardening magazines for Darryl to look at. Encourage Darryl to listen to his classical music. Darryl's local church priest visits him every fortnight.		
Services available:	For Darryl:	Complementary therapies, social groups	
	For family members and carers:	Social workers, counsellors, support groups, funeral services, religious ministers	
Copy of care plan given to person?	☑ Yes ☐ No	Copy to team members?	☑ Yes ☐ No
Report if necessary to:	Registered nurse or care team supervisor		

Example

Ensure the care plan addresses the person's ongoing needs holistically

Bernard lives alone and has a chronic degenerative condition, requiring 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 has a stroke and is immediately transferred to St Mary's 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 palliative care. Bernard dies one week later surrounded by his family. His preferences were respected and the changed goals for care achieved.

Practice task 5

1. Identify two areas the palliative care team assess on a regular basis to ensure the best quality of life for a person.

2. Explain holistic care planning for the palliative care.

3. Explain the concept of death for the following developmental stages: infancy, preschool childhood, older childhood, adolescence.

Click to complete Practice task 5

Summary

1. Curative care treats non-malignant illnesses and promotes recovery, while a palliative approach provides relief and comfort to people with life-limiting illnesses.
2. Palliative care takes place in a range of settings and is provided by a team of people with varied and specialised skills and knowledge.
3. A person's individualised care plan documents the holistic care and support to be provided to them. Holistic care ensures all aspects of the persons needs are considered.
4. Palliative care principles and values emphasise quality end-of-life care, ethical behaviour and respect for the person, their family and carers.
5. The beliefs, values and aims of a palliative approach are enshrined in palliative care standards.
6. Specialist palliative care staff are able to manage a person's individual issues in line with palliative care standards.
7. Palliative care is a dynamic model of care that adapts to the changing needs of the person and their family and/or carer.

Learning checkpoint 1

Plan a palliative approach to individual care

This learning checkpoint allows you to review your skills and knowledge in planning a palliative approach to individual care.

Part A

1. Compile a point-form list comparing the aims and practices of curative care against a palliative approach. Include when someone should be offered palliative care. Use these headings:
   - Aims and practices of curative care
   - Aims and practices of palliative care

2. Explain two ways that you can involve and support family members in the care of a person with a life-limiting condition

3. How does involving a person's family contribute to ensuring that a care plan holistically addresses the person's needs?

4. List five care roles that can meet specialist palliative care requirements.

5. What is an important difference between providing palliative support to children and young people, and providing it to adults in a family?

6. Explain three possible emotional impacts experienced by a person who has had the diagnosis of a life-threatening condition.

7. List and describe three types of therapy that may be used for the person accessing palliative care and suffering dementia.

8. Explain how you can give a person with dementia control and choice when delivering palliative care.

Part B

Read the case study, then answer the question that follows.

Case study

Jayne Hetherington is 85 years old. She is a practising Roman Catholic, was previously a regular church goer and participated in social activities with church members. She is married and has one daughter. She enjoys listening to jazz and blues music.

Jayne has breast cancer. She has had a total mastectomy and received chemotherapy; however, the disease has recurred and Jayne has had further treatment. Jayne is now in the hospice wing of a residential facility.

Jayne now has increased pain, chest swelling, periodic seizures, a second incidence of pneumonia and progressive weakness. At all times she is bed-bound and fed via artificial means. Her chest swelling is uncontrollable.

Jayne is assessed regularly for pain and discomfort and the appropriate intervention is taken. Pain is described as mild and is currently being managed using morphine. Medication is provided for side effects such as vomiting and diarrhoea. Oxygen is provided when appropriate.

Alternative therapies used are massaging legs and feet with essential oils. Rest time has been allocated during the day.

How would you demonstrate a palliative approach when caring for Jayne?

Topic 2

In this topic you will learn how to:

- **2A** **Consult to identify and share information regarding current and changing needs and preferences**
- **2B** **Respect the person's lifestyle, social, cultural and spiritual choices and needs in developing the care plan**
- **2C** **Ensure the planning process supports discussion of spiritual and cultural issues in an open and non-judgemental way**
- **2D** **Demonstrate respect for the roles of the person and carer in planning and decision-making**
- **2E** **Refer issues outside scope of own role to appropriate member of the care team**
- **2F** **Communicate to show empathy and provide emotional support**

Support individuals to identify their preferences for quality of life choices

Palliative care aims to achieve the best quality of life possible for a person with a life-limiting illness or in the final stages of their life. Encouraging a person's independence is an important part of this philosophy. To do this successfully you should consult with people, give them access to information and let them choose the type of care they want. Respecting a person's values, goals, beliefs and decisions is crucial.

2A Consult to identify and share information regarding current and changing needs and preferences

A care plan provides people with the opportunity to maintain a sense of control over their lives. In the plan they can communicate their wishes for their care and support, their spiritual, cultural and social needs, and explain how they want to include their family and carers.

However, circumstances change over time and the care plan needs to reflect the person's current needs. It may be your responsibility to ensure that care plans are up to date and responsive to the changing needs and preferences of the person, their family and/or carers and the changing phases of the person's illness.

To do this, you must regularly consult with the person and encourage family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates) and/or carers to share information about the person from their perspective. Collectively, these people are known as the person's 'unit of care'. You must build good working relationships with everyone so information is willingly shared, and the best and most appropriate care can be provided. People are more likely to share information if they know they will be listened to and their opinions acted upon. Ensure you maintain a supportive environment that is comfortable and non-threatening, where people are willing to listen and share ideas.

Consult with the person

Each person has their own likes, dislikes, preferences and needs for their end-of-life care. They also have a legal right to be offered appropriate and accurate information, to make their own choices and have these choices respected, to accept or refuse treatment and to appoint someone to speak on their behalf.

A person's needs may change, so it is important that their preferences are regularly reviewed. For example, a person may change their mind about the type of treatment they want, decide they don't want to see visitors anymore or decide they want to leave the hospice and spend their final days at home. People need to tell the care team exactly how they feel and what they want, as the care provided relies on accurate, up-to-date information.

Information to know about a person

Here is a summary of the type of information the team needs to know about a person.

How the person feels about their life-limiting illness and death

- This may change as the person's condition worsens. Everyone is different and their reactions vary. Some people become fearful, angry and abusive about their condition; others are accepting, peaceful and calm. Attitudes can influence the type of care provided; for example, you may suggest pastoral care, counselling or increased visits for a person who hasn't yet come to terms with their situation.

The type of care the person wants

- As a person's needs change, so does the care provided. For example, a person may request as much medication as possible to relieve pain, if it worsens. Others may consider alternative therapies. Some may prepare advance care directives that record their preferences and decisions about the type of care and pain relief they want to receive if they lose the capacity to communicate their wishes.

Whether the person wants their life to be prolonged

- As a person's condition worsens, they may change their mind about whether they want their life prolonged or not. For example, they may request that life support be turned off at a specific point.

How social they would like to be

- People may become more withdrawn as they approach the end of their lives. They may be more sensitive about their appearance or simply be too tired to see people. The need for company may disappear, or they may want family members and loved ones to be near.

Their cultural and spiritual needs

- People often become more attuned to their cultural and spiritual needs toward the end of their lives. For example, they may want you or a person from their culture to perform a traditional ceremony. They may want spiritual counselling or they may decide they want a specific type of funeral.

How to help manage their affairs

- A person may ask for assistance to change their will, or to make arrangements for who will manage their affairs when they are unable to do so. They may ask for someone to help them finalise their financial affairs.

Where they want to be

- Some people decide that they want to spend their final days at home. Others may want to do the opposite and leave their home and go into a hospice.

Use effective communication skills

Some people may find it difficult to talk about certain issues. To assist them, you must be a good listener and build a supportive relationship based on effective communication and honesty. Make sure the person is comfortable when you are speaking with them and they are not in pain or discomfort. Use appropriate body language; for example, sit facing the person in a relaxed manner, lean towards them when they are speaking and make regular eye contact. Physical touch is occasionally helpful, for both you and the person.

Be sensitive to each person's particular needs. It may take a while until a person responds, so when you ask questions, give the person time to answer. Remember to record what they tell you and to let them know that what they say is confidential.

Express empathy by acknowledging the person's feelings and showing you understand and appreciate their situation.

Using active listening may help you understand the person and encourage them to explore their feelings and beliefs. Active listening involves verbally acknowledging what the person has said and asking questions to clarify what they mean. Ask open questions that encourage people to answer with more than one or two words.

Build relationships with carers

It is important to build a good relationship with the person's carers, letting them know you understand the importance of their role. Use your communication skills and body language to support, encourage and assist when needed.

Carers can tell you:

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

Consult with family members

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

Having a supportive network of family and friends is an important part of coping with a life-limiting illness. In applying a palliative approach, family members should be actively involved in all aspects of the person's care, where possible. Each family member is able to provide important information on the person's personal history, changing needs and preferences. Encourage family members to participate in the person's care and to voice any concerns they may have.

Communicate with family members

It is not always easy or comfortable having conversations about a person's prognosis and end-of-life decisions with the person and their family members. Some families may be unable or unwilling to share information and provide support. It may not be part of their culture to do so, or there may be internal family reasons.

Family conferences can provide emotional support to family members and carers and give them an opportunity to discuss concerns about the person's life-limiting illness. Such organised meetings benefit the family and carers, as any information gained may be used to improve significantly the quality of life for the person.

Remember, family members are your people too, so be aware of their changing needs. When palliative care is the next step for a loved one, they generally have questions and continue to want as much information as possible. For example, they may want to know more as the person's illness progresses; they may require additional emotional support as they learn to deal with their grief and understand more of the situation; or they may need you to arrange respite care for them.

Liaise with significant others

There are other people who can contribute information about a person. These people are often referred to as significant others, as they play a significant part in the person's life and care.

The responsibilities of these people are very similar and in many cases their roles may overlap; however, they are all able to provide the care team with information on behalf of the person. You may be present at meetings they attend or have access to documents that describe their legal empowerment. When working in a palliative care environment you must understand each of these people's responsibilities and roles; for example, make sure you know which people have an appointed enduring power of attorney, guardian or advocate.

Arrange a family conference

Following is a step-by-step process for arranging a family conference. This is one example; organisations' procedures may vary.

Process for arranging a family conference

1 **Determine the purpose of the meeting**
Clarify conference goals in your own mind. What do you hope to accomplish?

2 **Determine where the meeting should be held**
Select a comfortable room with privacy and circular seating.

3 **Determine who attends**
Attendees could include the person (if capable of participating), a substitute decision-maker, the power of attorney, family members, carers, social support and other key members of the palliative care team.

4 **Introduction and relationship-building**
Introduce yourself and others. Review the meeting goals and any specific decisions that need to be made. Establish the ground rules; for example, explain that each person will have a chance to ask questions and express views uninterrupted. Identify the importance of supportive decision-making.

5 **Determine what the person, family members and carers already know**
Ask attendees about their understanding of the person's current medical condition. Ensure you ask everyone in the room to speak. Also ask about the past 1 to 6 months; for example, if anything has changed in terms of functional decline such as weight loss or the ability to perform social activities.

6 **Review the person's medical status**
Review the person's current medical status, prognosis and treatment options. Ask each family member in turn if they have any questions. Respond to emotional reactions and defer discussion of decision-making until the next step.

7 **Family discussion with the person**
Ask the person to identify what decisions they are considering. Ask each family member and carer if they have any questions or concerns about the person's treatment plan and how they think they can support the person.

8 **Family discussion with an advocate**
Ask each family member what type of care they believe the person would choose if they could speak for themselves. What do they think should be done? Ask if they would like you to leave the room to let them discuss matters privately.

9 **When there is no consensus**
Restate the goal. Schedule a follow-up family conference the next day. Consider utilising other resources such as a minister of religion or specialised palliative care members such as a social worker, assigned care worker, palliative care nurse, physiotherapist or ethics committee member.

10 **Finalise the meeting**
Summarise the consensus, disagreements, decisions and the care plan. Caution against unexpected outcomes and identify a family spokesperson for ongoing communication. Then, document in the care notes who was present at the meeting, what decisions were made and the follow-up plan.

11 **Follow up**
Maintain contact with the family members, carers and other members of the palliative care team including the medical team. Schedule follow-up meetings as required.

Types of significant others

Significant other people who can contribute information about a person are listed below, with their titles and a description of what their roles involve.

Enduring powers of attorney

In Australia, no medical service may be provided without the consent of the person concerned. Consent is considered informed consent when the person agrees to a treatment without duress, voluntarily gives their consent after a reasonable time and has been provided with adequate information to consent.

The only exception to this is when the person's capacity to consent is impaired; for example, by a serious illness. In these situations, an enduring power of attorney is legally appointed to make decisions on the person's behalf, regarding financial, medical treatment or guardianship matters. A person may only appoint an attorney themselves if they are over the age of 18 and are able to demonstrate capacity to make the appointment. The power of attorney has an important role as he or she can provide instruction about the person's continuing care.

Guardians

A guardian is a person formally appointed to make personal, lifestyle and healthcare decisions for a person with an impaired capacity. When making decisions on behalf of the person, a guardian must take into account any wishes the person has expressed, act in the person's best interests and, wherever possible, make the same decision that the person would have made. Each state and territory has legislation and guidelines defining the role of a guardian.

Advocates

An advocate is a person who supports or speaks in favour of a person's needs, rights and opinions. 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.

Persons responsible

A 'person responsible' (formerly called 'next of kin') is a substitute decision-maker who consents to, or refuses to consent to, medical treatment when the person is no longer able to communicate their wishes. This person is required to consider the views of the person but is not bound to follow them. The process for appointing a person responsible varies depending on state or territory legislation.

Social workers

Social workers assist in a number of areas and can provide workers with information and guidance about the person's changing needs.

Specialist palliative care nurses

Specialist palliative care nurses have extensive knowledge and experience in the management of pain and complex symptoms associated with terminal illnesses. They may be able to tell you when a person's specific care should change to reflect their current needs. You may also use the services of palliative care nurses to help teach other workers how to assist the grieving process of family members, carers and friends.

Share information

Effective communication is a vital skill for healthcare professionals working with people with progressive life-limiting illnesses, their family members and/or 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 will help the person feel calm and well-informed and will assist them to make decisions and plan for the future.

Organisations may have a range of mechanisms in place to encourage people to share information, such as those shown below.

Phone contact

Make sure family members know that they can telephone a member of the team whenever they need to.

Arranging for an interpreter

During times of emotional stress, it is comforting for people, their family members and/or carers to describe feelings and thoughts in their primary language. Medical and cultural interpreters, who have completed specific training and follow national standards of practice, should be used for people with limited English proficiency.

Organising a family conference

Organising a family conference can facilitate support and information exchange and help reduce the sense of loneliness, loss and social isolation.

Working with an advocate

Work with an advocate if a family is unwilling to share information and provide support.

Power of attorney

Legislation governing the appointment of a power of attorney or guardian varies between states/ territories. In New South Wales, the person responsible is determined according to the hierarchy within the *Guardianship Act 1987* (NSW) in the following order:

- An appointed guardian (enduring guardian) with the function of consenting to medical and dental treatment
- A spouse or de facto spouse who has a close and continuing relationship with the person
- The carer or person who arranges care on a regular basis and is unpaid (the carer pension does not count as payment)
- The carer of the person before they went into residential care
- A close friend or relative

Example

Consult to identify and share information

Mrs Gabrielsen is in hospital as she has recently been diagnosed with breast cancer. She discusses her prognosis with her husband, whom she trusts more than anyone else. She knows he will respect her wishes about the types of treatments she will and won't accept. Mrs Gabrielsen has never trusted doctors and prefers to rely on complementary therapies, such as aromatherapy, after seeing her father suffer many years of invasive treatment for cancer. In her mind she is clear that she will refuse such treatment for herself, even with the knowledge that she may die without it. She asks her husband to act as her carer and to make welfare and healthcare decisions on her behalf when she lacks the capacity to make her own decisions. She wants him to refuse life-sustaining treatment on her behalf.

Mrs Gabrielsen is transferred to the local aged care facility for respite as she does not want any further treatment and her husband is unable to care for her at home until her mobility and physical condition improve. Mrs Gabrielsen was affected by the chemotherapy given in the hospital and is quite debilitated. Mrs Gabrielsen was referred to the palliative care team for ongoing support.

Mr Gabrielsen attends the family conference where puts forward his wife's wishes regarding care and future treatment.

Practice task 6

1. Why should family members be actively involved in the person's care? Give two reasons.

2. List two strategies you can use to assist a person to talk about difficult issues.

3. List three things to consider when planning a family meeting.

Click to complete Practice task 6

2B Respect the person's lifestyle, social, cultural and spiritual choices and needs in developing the care plan

Everyone has a right to the best quality of care. This includes having their needs, likes, dislikes and preferences regarding their lifestyle, social activities and spiritual needs taken into account when planning their treatment. These aspects will be discussed during the person's initial assessment, outlined in their care plan and regularly reviewed to ensure currency. All members of the healthcare team must follow these directives and respect the person's preferences.

Lifestyle and social needs

A person with a life-limiting illness will be affected by the symptoms of their condition and any medication they are taking; common experiences are nausea, pain and fatigue. They may also be affected by a lack of activity – if they are no longer able to perform activities of daily living their lifestyle may have changed considerably.

People have the right to maintain their quality life for as long as possible, so the way a person wants to live must be respected and their preferences considered when delivering care. A palliative approach takes into account the social needs of the person, such as the need for social support, personal supports and relationships. A lack of social support may lead to deteriorating psychological wellbeing, depression and diminished functional health. The team must therefore make a thorough assessment of the person's social network, including the person's perception, appraisal and interpretation of the contact that is most important to them. Appropriate interventions can then be undertaken to maintain or improve a person's situation.

The care plan should detail the person's lifestyle, their closest family members, friends and the social network they have established. It should also describe the most appropriate way of communicating with the person and their family.

Personal relationships

A palliative approach takes into account the type of personal supports needed and how the person's relationships can be maintained. Be familiar with the person's family, the relationships within the family unit and the support network the person currently has. Identifying the social relationships and functioning of a person's family enables you and other members of the palliative care team to provide appropriate family care. Each family unit may have a different make-up and dynamic. You should first identify the type of family unit.

Communicating with a person's family about their relationships may help you identify a key family member through whom communication with the broader family is best achieved. This may depend on the person's culture. For example, within some

Indigenous Australian communities, the oldest person in the family may not be the person who makes the decisions regarding care; this may be the role of a community Elder. Some people may want to have their whole family involved. Another example may be a family situation where one member of the family has medical or nursing experience and recognised expertise by the family. The family may rely on this family member for information, direction, interpretation of medical information and support in decision-making.

Social networks and activities

Social interaction, continuing personal contact and having a strong support network is essential for people with life-limiting illnesses, as a lack of social support may have a negative effect on people.

The healthcare team should assess the person's social network and the contacts they want to continue, and provide opportunities for people to maintain their social relationships. A social worker or pastoral care worker may help to ensure the person's social support needs are addressed. Volunteers may also be able to provide social support for people receiving palliative care.

People often have hobbies, interests and activities they have pursued during their lives, in a social group or individually. People should be encouraged to continue with these social activities for as long as possible, as this may assist them to maintain their quality of life and contribute to their emotional and physical wellbeing.

Hindrances to social engagement

Some people may withdraw from social contact, so it is important that new social relationships are established if this is in the best interest of the person. To provide appropriate care, the team may need to determine the reasons a person may be rejecting social activity. Here are some factors that can affect a person's ability to engage in social contact.

Factors that can affect a person's ability to engage in social contact

- Their appearance, which may be affected by symptoms or medication
- Their condition, which may seem socially unacceptable, such as incontinence
- The demands of treatment routines, making it difficult to keep in touch with others
- Their behaviour, which may be 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

Personal participation in social activities

Remember, a person's ability to participate in social activities may be affected by specific physical effects of their symptoms, the treatment provided for pain relief and the loss of some functions. People may not wish to participate in what they consider to be activities of their previous life, when they were well, so it is important to encourage them to participate. Always remember to respect their decision if they decide against it.

Most aged care facilities or nursing homes have a roster of social activities for their residents. These activities provide opportunities for social contact between the aged care team, the residents, their family members and friends. They may have a staff member who arranges this part of a person's routine. Community care programs also offer activities in local community centres for people living at home.

If a person is living at home, their family should be encouraged to help them continue with any activities and hobbies they feel comfortable with. For example, they could take the person to sports events, enrol them in a community program or buy items to ensure they can continue with their hobby.

Types of social activities

Social activities may be particularly beneficial to a new resident of a facility who is having trouble adjusting to their new environment, or for someone who is finding it difficult getting along with people they don't know. Here are some examples of social activities which may be relevant.

Social activities
Physical activities Physical activities such as carpet bowls or handball
Group activities Group activities such as singing, drawing, beauty therapy sessions, bingo nights or walking
Special events Special events such as music recitals, food events and programs with visiting experts
Chores and housekeeping Chores and simple housekeeping tasks like gardening or sweeping
Outings Outings such as visiting shopping centres, a restaurant or an attraction such as a museum

Social networks and activities

Overall, socialisation is an important factor that may affect how well a person deals with the effects of a life-limiting illness. As detailed below, there are a number of strategies a care team can introduce to ensure their person's social networks and activities are maintained and their decisions respected.

Strategies for maintaining a person's social networks and activities:

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

Sexuality and intimacy

Being diagnosed with a life-limiting illness may pose specific problems that have a strong psychological impact, including body image, sexuality problems and interpersonal issues.

Intimacy and sexuality are basic human needs that are often neglected in discussions about the wellbeing of people receiving a palliative approach, yet neither need disappears because a person ages or becomes ill.

Sexuality encompasses body image, self-esteem, mood, support, emotional connection and intimacy. Concerns about current or potential sexuality problems are associated with anxiety and may be a major stress factor for people. 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. It may be assumed that people requiring palliative care have more important things than sexuality to be concerned about; however, this is not always the case. You must always be non-judgmental and be able to acknowledge and discuss issues of sexuality and individual needs.

Factors that affect intimacy or sexuality

Be aware of any factors affecting needs for intimacy or sexuality from people with life-limiting illnesses, and facilitate support for these needs as appropriate.

Factors affecting sexual adjustment include:

- the person's age
- pre-existing problems in relationships or sexuality
- treatment-induced changes in hormonal status
- alterations in body image; for example, alopecia, weight loss or gain, or disfigurement resulting from surgery
- treatments that directly impair sexual function or reproductive organs; for example, radiation therapy in the pelvic region.

Address a person's intimacy needs

Understanding the importance of touch and personal bodily contact is important for both workers and people. Often people experience touch through routine procedures connected with their medical treatment and therefore may perceive touch in a negative way, especially if it is associated with pain or discomfort. Comfort touch, such as massages and hand-holding, may enhance a person's sense of wellbeing and self-regard, improve communication between you and the person and decrease their pain.

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

Use your discretion and follow confidentiality procedures when discussing and documenting sexuality and intimacy issues in a person's care plan.

Emotional supports

People with life-limiting illnesses may experience a range of emotional and social difficulties. They often report feeling in a state of shock, feeling out of control or being angry, fearful or helpless. Grief and loss are often key reactions to distress when life has changed in many ways, especially regarding a person's loss of independence. Family members and carers may also struggle to deal with their emotions and this may have a negative effect on the person.

Some people simply don't have the words to describe how they feel, some don't want to be a burden on others, some fear they may break down if they discuss how they feel and others may be ashamed of admitting problems with coping. Some people think that their doctor is too busy to listen to them. At times, care team members may avoid discussing issues out of fear of causing distress, harm or worry to the person, or feeling out of their depth. It may be your responsibility to assist workers to provide emotional support to their people.

Support people

The extent to which a person with a life-limiting illness has support and feels supported has been identified as an important factor in their adjustment to palliative care. You and other members of the palliative care team can help people, their family members and carers by using the strategies shown below.

Help that members of the palliative care team can provide
▶ Provide clear, simple and honest information.
▶ Provide reassurance about the person's care and practical issues.
▶ Ensure people, family and carers have a clear understanding of what is happening regarding the person's condition.
▶ Treat each family member and carer with respect and acknowledge their feelings and their approach to the situation.

- Provide family members with the opportunity to be involved in care and to share their ideas.
- Identify family members who need extra support; for example, from support group meetings.
- Provide information on grief and bereavement counselling.

Legal and financial supports

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

Money and finances may be an issue for people with life-limiting illnesses. End-of-life care services, including palliative care and home nursing, are usually covered by Medicare. Some people may be eligible for benefits that assist with the costs of this care; others may incur small costs. In some cases, private health funds may cover extra costs.

People receiving palliative care, their families and/or carers must be told as soon as possible about any costs that are involved in receiving care and what financial assistance is available. Workers should understand the financial support services that exist and how they can assist.

In Victoria, a person facing inevitable imminent death as a result of an incurable disease, illness or medical condition can choose the manner and timing of their death. This is permitted under the *Voluntary Assisted Dying Act 2017* (Vic.). This law means that a person may be assisted by medical practitioners to access medications to use to end their 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 this choice.

Support a person's spiritual needs

Spirituality relates to a sense of something greater than oneself, which may be met through faith or religion.

When working with a person with a life-threatening 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. In fact, some people may refuse treatment based on their religion.

A person's spiritual beliefs often become more important when they have a life-limiting illness. For example, religious practices, rituals and beliefs may resume an important place for the person, family members and/or carers. Turning to spirituality is a common coping mechanism that has been found to 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 regain a positive outlook.

Spiritual care

Spiritual care involves sensitive listening rather than providing answers. It is not necessary for you and other members of the palliative care team to share the same beliefs as the person in order to understand the person's spiritual needs, nor is the aim of spiritual care for members of the palliative care team to impose their own views. Spiritual care involves being aware of the feelings of isolation the person may experience at the end of their life, listening to the person and providing a healing and peaceful atmosphere.

Some people may want to talk to a member of the clergy, a rabbi, imam or pastoral care worker. You should ask questions to learn more about the person's beliefs so you can better understand the rituals that are important in cultures other than your own.

The person's spiritual needs should be documented in their care plan as an early assessment and not left until their end-of-life period when they may not be able to make decisions for themselves. For example, a person's care plan may indicate that they want a priest to deliver the last rites. Ensure all members of the team are familiar with the person's beliefs and requirements and that the plan reflects the person's current wishes.

Spiritual needs

Strategies that may be required to support people's spiritual needs are shown below.

Support people'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 clergy or pastoral care workers, family, carers and friends.
- Ensure access to spiritual activities such as prayer times, Bible study and worship ceremonies.
- Obtain requested items for spiritual practice such as books, rosaries or statues.
- Avoid interrupting the person during spiritual activities.
- Help people celebrate specific religious events.
- Encourage any pre-death rituals the person may wish to follow.
- Follow spiritual beliefs in regard to medical treatment; for example, some beliefs may forbid a blood transfusion.

Organisations that provide financial support

In Australia, there are various resources and organisations that provide practical help and advice to assist people, their family members and/or carers with finances for palliative care. Some of these are outlined below.

Australian Securities Investment Commission (ASIC)

- A practical guide to personal financial advice, which may help a person choose an advisor to help with any financial issues

Centrelink

- Financial information services where the person, their family members and carers can have a confidential interview, receive advice and financial assistance; Centrelink also has information about carer payments

Private Health Insurance Administration Council (PHIAC)

- PHIAC is an independent statutory body that regulates and provides information about the private health insurance industry

AIDS Trust of Australia

- The AIDS Trust provides financial support for people living with HIV/AIDS

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 communities. Workers must ensure that they are sensitive to, and respect, customs that are different from their own. To do this they must understand the concept of death and dying in other cultures and how these cultures deal with this process. For example, words like 'death', 'dying' and 'cancer' may be taboo for some cultures.

The concept of family may also be perceived differently in different cultures. For example, in some cultural groups, the family has traditionally been the main source of security. 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. At care planning meetings families need to be encouraged to identify any cultural care needs for the person to the rest of the team.

Other cultures

Understanding other cultures, what culture means to a dying person and how cultural issues can impact on palliative care is an essential part of the skills and knowledge of a worker. Many people have a limited knowledge of other cultures and customs; for example, a worker may be unable to understand what a person or their family members are saying. They may be nervous when confronted with a situation they are unsure of, or be confused if a person refuses assistance due to their cultural beliefs. Workers may unwittingly insult, be disrespectful to or otherwise breach important cultural beliefs and customs if they don't take the time to learn about other cultures.

Consult with the person, their family members and any other stakeholders who understand the person's cultural wishes, so they can be met.

Culture-related choices

At their initial assessment, people may make choices for their care and treatment based on their cultural beliefs. These should be recorded and integrated in the person's care plan and made known to all members of the palliative care team. The more you understand other cultures, the more you appreciate the reasons for providing care in a certain way.

By following the person's cultural care instructions, you ensure the person's needs are met and that they wear the clothing they want, eat the appropriate food and speak in their own language. The following examples illustrate how a person's culture may influence their choices and care.

Clothing

A person may need to wear:

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

Food and drink

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

Language

If a person wants to speak in their first language and asks for the services of an interpreter, the interpreter may need to be a certain gender or age.

Body language

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 while holding a conversation. In some cultures, people must not stand too close to another person.

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

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

Forms of address

A person may want you to call them by their family name and their title; for example, Mr Gates.

Treatment of the deceased

In Indigenous Australian culture, the name of the deceased person is not spoken for a certain period of time.

Islam forbids autopsy and cremation.

Example

A person's cultural choices indicated on their care plan

Care notes	
Person name: Max Phillips	Date of birth: 6 September 1946
Date: 25 April 2014	Time: 11.30 pm
Observations:	
Person behaviour: Mr Phillips looks pale and weak. He is also is stressed, anxious, experiencing depression and can't sleep. He has identified feeling nauseous, and has lost his appetite, but can drink liquids. He is dehydrated as he has been vomiting. Level/Intensity of pain – acute (8/10) Location of pain – abdominal area	
Action:	
Cultural requests: Lutheran local community priest to visit to give communion and to read from the Bible (New Testament). Members of Lutheran church committee to visit once a day to have discussions with the person and to play recordings of the Sunday church services Max is missing out on attending.	
Worker name: Jana Collins	Signature: Jana Collins

Manage cultural issues

Here are some strategies to help manage cultural issues.

Consult references

Read and refer to Palliative Care Australia's National Standards at: http://aspirelr.link/pca-national-standards.

Learn about cultures

Learn as much as you can about other cultures. Information may be available in pamphlets and brochures provided by different cultural groups. Remember that the information provided is only a guideline. Everyone is different so make sure you understand the specific needs of each person and their family members

Consult the family

Call a family meeting and ask who the appropriate decision-maker is. In some cases, it may be the person themselves, or it may be the spouse or the eldest son. Find out who should be present at such meetings (in some cultures it is the whole family).

Identify a representative

Identify a representative of the person's cultural group who can visit the person. This may be a religious or spiritual leader, a neighbour or friend.

Language support

Provide information in the person's preferred language. Pamphlets are often available in many languages to cover cultural, spiritual and social issues and procedures.

Arrange interpreters

Arrange an interpreter for the person when necessary. Communication difficulties can cause distress and it is essential that everyone understands instructions and procedures.

Show sensitivity

Show sensitivity if a person makes a cultural choice to refuse medical attention; it is their right to do so.

Respect the person's wishes

Respect the cultural wishes of the person and their family in regards to death, dying and after-death care.

Confidentiality

Always respect a person's right to confidentiality.

Example

Respect the person's lifestyle, social, cultural and spiritual choices and needs

Rosa requires abdominal surgery. Following surgery she is unable to be weaned from the ventilator. She has a history of severe cardiac disease and recovery can only be achieved by having a heart transplant. Her husband has Alzheimer's disease and her son lives a considerable distance from the hospital.

Steven, a palliative care worker, speaks to Rosa about her feelings, beliefs, values and goals in life. Rose understands the condition of her heart and is clear about her wishes if her heart stops: she does not want to be resuscitated. As the conversation continues Rosa explains what is important to her at this time. She comes up with the following list, which is documented in her care plan. She wants to:

- have access to plenty of chairs when members of her extended family visit her
- be able to eat special foods her family bring
- always be kept clean and for a little bit of make-up to be applied
- be dressed in her favourite casual clothes
- have pictures in her room of her family
- have the Bible and rosary beads her husband gave her before he became ill, and have her favourite Catholic priest visit her weekly
- be able to speak to her family on a regular basis, and asks for a phone to be placed in her room
- have relaxing music to help her sleep at night
- stay on the ventilator
- have pain medications when she requires them
- have an enduring power of attorney (medical treatment) appointed so her husband is not bothered.

Steven calls a conference to discuss the impact of Rose's wishes and to update her care plan.

Practice task 7

1. List three ways the palliative team can provide support to people accessing services.

2. What does spiritual care involve?

3. Explain why sexuality needs to be addressed in planning care for the person accessing palliative care services.

Click to complete Practice task 7

2C Ensure the planning process supports discussion of spiritual and cultural issues in an open and non-judgmental way

People should be encouraged to talk openly about their spiritual and cultural needs in a supportive environment. They need to feel that these issues will be discussed freely in a sensitive and non-judgmental way.

As they face the knowledge they are approaching the end of their life, people may be:

- wondering what life is all about
- questioning the existence of God
- asking why God has turned his back on them
- thinking about what death means
- wanting to know how to make amends for things they have done in their life
- discussing the concept of life after death
- speculating on what will happen to their body after their death.

Facilitate a supportive environment

You should develop a rapport with the person and their family members to enable them to talk comfortably about their spiritual and cultural needs. It can be a very sensitive area. Some workers may find it difficult to talk openly and honestly if they don't know the person very well or share the same beliefs and values. However, with understanding and good communication skills, workers can provide a valuable and supportive environment. Ten tips to help you achieve a supportive environment are given below.

Ten tips to help you achieve a supportive environment

1. Encourage the person or family member to speak to you. Respect their fears and anxieties. Let them know you are willing to listen – a good listener is what they need most.
2. Always respond to people's questions regarding spiritual needs in an open, non-judgmental manner.
3. Learn about the person's current or desired practices, attitudes, experiences and beliefs.
4. Arrange for the person to see a pastoral care worker with experience and knowledge of spiritual issues, or arrange for people from their church, temple or mosque to visit.
5. Ask people about any personal items identifying their culture that are in their room.

6 Help people talk about what they have done in their life. This helps them see their achievements, the friends they have and what life has meant to them.

7 Ensure people know that everything they say will remain confidential.

8 Encourage the person's family to participate in discussions about cultural and spiritual issues and involve them in any customs and rituals.

9 Provide an opportunity for people to continue their cultural and spiritual practices, such as celebrating a festival.

10 Assign a care coordinator to work closely with the person's family.

Respect cultural differences

Each culture has its own unique ways of communicating. What you consider rude, someone else may consider the usual way to communicate. Similarly, gestures and other body language that you consider usual, others may find offensive. The following are some examples of cultural differences you may find useful in helping you understand your person's communication style.

Personal space

Many people prefer to stand at least an arm's length from the person they are speaking with. If someone enters into their personal space, they may feel intimidated or uncomfortable. However, people from some cultures tend to stand closer and are quite comfortable with less personal space.

Touch

Different cultures have different rules about who can touch whom. In most cases touching is inappropriate and should be avoided unless specifically required; for example, in the case of a distressed person needing assistance.

Eye contact

In some cultures, making direct eye contact can be seen as disrespectful, especially if it is prolonged. This can be the case with Indigenous Australian people, and in some Asian cultures direct eye contact is avoided as a sign of politeness and respect.

Gestures

Gestures that you may consider harmless may be considered offensive in some cultures; for example, the thumbs-up gesture that is commonly used to indicate 'okay' is considered rude in Middle Eastern cultures.

For many people, nodding the head means 'yes', 'I understand' or 'I hear you'. However, in some cultures, it may mean 'no'. People from some cultures may nod their heads to avoid any disagreement as they don't wish to appear disrespectful. In some cultures, people will avoid disagreeing with someone to avoid being seen as rude and causing either themselves or the other person to lose face (honour). In Indigenous Australian culture, a person may agree with you as a way of indicating a willingness to be cooperative, rather than actually agreeing with what you say.

Smiling can also be misinterpreted. While in Western culture smiling generally means happiness, in some cultures it can also be used to demonstrate anger, embarrassment or sadness.

Polite conversation

Conversation is often a two-way exchange where each person takes their turn at talking and listening. However, in some cultures it is acceptable for people to talk over each other.

Some cultures have a direct conversation style, and in others a more roundabout way of conversing is used. For example, some people consider it rude to say 'no', so use indirect ways of saying it. In Indigenous Australian cultures, among others, direct questioning is avoided.

Questions

Some people do not consider it polite to disagree with someone they perceive to be in authority. If you ask a question such as, 'Would you be happy for me to arrange a referral to a psychiatrist for you?', it may result in a 'yes' response even if the person does not agree and has no intention of attending any meeting arranged for them. This is often called gratuitous concurrence.

In other cultures, direct questioning is considered impolite and a more indirect questioning style is more appropriate. Indirect questions tend to use words such as 'Can you tell me ...' before a closed question, allowing the other person the opportunity to say 'no'.

Communicate with the person and their carers

Always address the person and their family and/or carer when speaking, even if the person's understanding is limited. Likewise, make sure the family and/or carer knows that you recognise their role and position. A palliative care worker's job includes providing support, answering questions, providing information and making an often difficult situation easier for everyone. Never do anything that may cause disagreement between person and carer.

Coping with end-of-life issues is very emotional for everyone and each person must be allowed to express their grief, anger and sadness. Appreciate that the family and/or carer may be physically and emotionally exhausted due to their close relationship with the person. Ensure sensitivity to their needs and that co-workers understand why a carer may sometimes seem rude or impatient.

Help provide an understanding of the details relating to the person's illness. This will assist both the carer and person to cope and may reduce their fear, stress and anxiety. Both written and verbal information, as well as opportunities for discussion and clarification, are important for the carer and family members.

Respect that the family and/or carer and the person have the right to privacy and that there may be times when they want to be together without you. Show respect and sensitivity by giving them time alone. Also be aware of the person's cultural identity and their needs relating to this. Keep in mind that their relationship with their carer may have cultural influences.

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.

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.

The person accessing palliative care must still be able to make their own choices regarding care. One area that is important for the person to have control over is the environment that death occurs in. Other areas the person accessing palliative care should have control are:

- the right to choose to have treatment
- the right to try alternative methods of treatment
- the right to pain relief.

Level of risk

With many activities, it is not possible to eliminate risk altogether. Risk is a part of our daily lives and it is through taking risks, trying something new and making mistakes that we learn. This is why dignity of risk should be upheld; all people have the right to make their own choices and to take risks. A support worker's adherence to duty of care and safety must be coupled with the concept of dignity of risk.

When considering the legal and ethical considerations of dignity of risk, a key issue is to determine an acceptable level of risk compared to the benefit of the activity. This should be discussed with the person and appropriate others offering support.

The three questions to ask about risk:

- What are the potential risks?
- What are the potential benefits?
- How can the risks be reduced without reducing the benefits?

Example

Ensure the planning process supports spiritual and cultural needs

Yusuf is a 53-year-old man with terminal cancer. His family members are offered counselling to help them deal with their distress at finding out he only has weeks to live. They are also assigned a care coordinator to work very closely with them, comfort them, listen to their needs and keep them up to date with Yusuf's care. An interpreter is assigned to help the family understand the procedures and treatments that are being provided.

Because Yusuf and his family are Muslim, there are certain cultural rituals that must be followed when Yusuf dies. Through the interpreter they explain that Yusuf's body should ideally only be touched by Muslims of the same sex and that his body should be moved so that his head faces towards Mecca. Also, Yusuf's parents ask that the hospital not discuss their son's illness with anyone else. They don't want anybody, especially other community members, to know about their problems.

The palliative care coordinator organises for pamphlets about Islam faith to be given to all those working with Yusuf.

Practice task 8

1. List three things a support worker can do to maintain an environment that is supportive of spiritual and cultural needs.

2. Explain why cultural beliefs are important to consider when planning care.

3. How can discussing and incorporating spirituality into a person's care plan provide comfort?

Click to complete Practice task 8

2D Demonstrate respect for the roles of the person and carer in planning and decision-making

When a person is receiving palliative care there must be a coordinated team effort between health care professionals, workers, the person, family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates) and/or carers. In many instances workers spend as much time with the family and/or carer as they do with the person.

Family and/or carers often know the person best as they may see the person on a day-to-day basis. The relationship between the person and their carer must be respected and can be very close; therefore, any suggestions they make about the person's preferences and needs are valuable insights. Recognise and acknowledge family and/or carers' suggestions. Show them you respect their ideas, as the carer is an important link between the person and the palliative care staff.

For example, a family member and/or carer is likely to know how the person may respond, think and feel in certain situations, the person's allergies and reactions to certain foods or medications and preferences regarding personal comfort, pain relief and treatment options. They will also know their person's preferences for care at home, in a hospital or hospice and the nature and types of support needed.

Make decisions

Involving the person in the planning of their care gives them the opportunity to maintain control over their lives. They can 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/or carers.

As a palliative care worker you should 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's views and behaviour, or those of their family and/or carer, but be approachable and caring.

Practice task 9

1. Why is it important to involve the person in the care planning process?

2. Explain how providing knowledge of a person's illness will assist the person and their family and/or carer.

3. Explain what dignity of risk relates to when planning and delivering care.

Click to complete Practice task 9

2E Refer issues outside scope of own role to appropriate member of the care team

People working in a palliative care environment must know their level of authority and responsibility, and who they should refer issues and problems to if they don't have the expertise themselves. It may be your job as a supervisor or coordinator to advise or refer others, as appropriate.

Each staff member's job description outlines their role, responsibilities and who they should report to. Make sure you are familiar with your responsibilities as an individual and as part of the health care team, and that you can assist others if they are unsure about their roles.

When you first begin work, there is an induction process that provides an overview of the job role, including tasks, the equipment to be used and the organisation's procedures manual, which describes how to carry out specific procedures and operate equipment. Ensure you know where it is located so you can use it and refer other workers to it when necessary. New staff members may also be paired with a mentor, whose job it is to explain and guide them through their role.

Limitations and responsibilities within work role boundaries

Coordinating a palliative approach requires you to have a comprehensive set of business and organisational skills. Although roles and tasks may differ between organisations, your main task is to provide high-quality end-of-life care in the ways listed below. It is always a good idea to explain your role to the person, their family and/or carers so they understand the extent of your job. For example, they need to know that you are not allowed to give medication or medical advice.

Ways to provide high-quality end-of-life care

1 **Assessment**
Assist with the assessment of people, including initial assessment and ongoing review and evaluation.

2 **Coordination**
Coordinate care and support across settings (within your level of authority and expertise).

3 **Comfort**
Provide the person's desired physical comfort in accordance with their care plan, including assistance with mobility, activities of daily living and relief from discomfort.

4. **Rights**
   Uphold people’s rights to be listened to, respected and treated with dignity.
5. **Independence**
   Help the person to remain as independent as possible and to maintain their social, cultural and spiritual needs.
6. **Care notes**
   Keep accurate and up-to-date observations in care notes.
7. **Guidelines**
   Follow duty of care and ethical, privacy and confidentiality guidelines.
8. **Liaise**
   Liaise with other healthcare services.
9. **Work cooperatively**
   Work cooperatively with healthcare professionals, services and volunteers to ensure continuity of care if the person is moved from one setting to another.
10. **Policies and procedures**
    Follow the organisation’s policies, procedures and protocols, including contacting the appropriate person when a situation is beyond your authority.

Issues that may arise

There may be times when you are confronted by issues that are not easy to deal with, or that may need to be referred on to someone qualified to find a solution. For example, a person may refuse the treatment options prescribed for them. In this case, notify your manager immediately, as the palliative care team may be able to identify an alternative treatment the person finds acceptable.

Some states have legislation that protects health professionals when they follow a person’s wishes and withhold treatment, so they are not liable for the person’s death if it occurs due to a lack of treatment. Understand your state or territory’s legislation in regard to this.

Below you will find details of some other issues that may arise while working in a palliative care environment.

Voluntary euthanasia

A person may request assistance to die (voluntary euthanasia). This is only available in Victoria through the *Voluntary Assisted Dying Act 2017*. All other states and territories deem voluntary euthanasia illegal.

Cardiopulmonary resuscitation (CPR)

A person may ask that no cardiopulmonary resuscitation is given if the need arises. This should be documented in the person’s advance care directives in their care plan. Make sure all staff are familiar with such directives.

Choice of pain relief

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.

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 may prolong life. Make sure you follow care plan instructions.

Incapacity

When the person cannot make their own decisions, you should refer matters to family and/or carers, or the person with the enduring power of attorney (medical) if the person has not provided advance care directives. Never make any decisions on your own, even if you believe the person would agree with you.

Confidentiality

All information about a person and their condition must be treated in confidence. Be clear about what (if any) personal information about a person can be released to 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 discuss a person with your friends or family.

Changing needs

As their condition progresses, respect the person's right to change their mind regarding their care. Ensure regular opportunities to discuss the person's preferences are provided.

Disclosure

All information about the person's condition, treatment and potential life expectancy must be provided to the person, their family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates) and/or carers. This is referred to as disclosure. These people must be able to make informed decisions based on the facts provided to them.

Disclosure should include information about pain relief, alternative treatments available, nutrition and hydration issues that may arise, how long the person is expected to live, visiting guidelines, support provided and the person's preferences.

The palliative care team has an ethical obligation to fully inform all individuals regarding their observations and intervention recommendations. Once the person has been fully informed and has been assessed as having the cognitive ability to make decisions, the palliative care team must respect the person's needs and their right to choose their preferred intervention. Be aware of your own and your team's level of authority and refer any queries you are unable to answer to the appropriate member of the care team.

Refer issues that are outside your role

It is important 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. Know whom to refer to regarding particular issues and if you are unable to cope with a situation, contact your manager, a health professional or a designated person immediately, remembering to always document your observations and actions.

Example

Refer issues outside scope of own role

Jason has been working in the palliative care section of the local residential aged care facility for the last nine months. Although the majority of people who have come through the facility have been older people who have had a chronic illness for a number of years, there has recently been an admission of a person of Jason's age – 29. Peter has been admitted due to suffering after surgeons attempted to have a large brain tumour excised. Unfortunately the cancer is an aggressive cancer that has not responded to chemotherapy or radiation and the decision was made to transition Peter to palliative care.

Jason and Peter have hit it off well as both share a number of the same interests and hobbies.

Peter continues to have excruciating headaches that are becoming more frequent and severe. Peter asks Jason to obtain some marijuana as the morphine prescribed does not seem to be holding the pain at bay. Jason explains that he cannot do this but he will ring the doctor straight away and organise for him to come over and reassess Peter's pain and pain relief medication.

Practice task 10

1. If you follow a person's wishes and withhold treatment from them, are you legally liable if the person dies? Explain your answer.

2. Is it legal to actively assist a person to die if they request this assistance? Explain your answer.

3. Who should decide what form of pain relief is used for a person?

Click to complete Practice task 10

2F Communicate to show empathy and provide emotional support

Providing emotional support to people, their family and/or carers is a key responsibility for those working with people in end-of-life care. This means you listen to what the person and their family and/or carers say, acknowledge the impact the illness is having on them and provide the most appropriate support. In some cases you may only need to be there to listen; at other times you may need to provide information.

Family and/or carers anticipating the loss of a significant relationship often experience many varied emotions. The contemplation of the loss of a loved one may lead to feelings of guilt, anger, frustration and distress. It may cause family conflict. Do not assume that the person's family will always be supportive as there may be disputes within the family.

One of the most important functions of a worker's role is to listen and respond with respect, understanding and empathy. Genuine, effective communication means never trying to change the subject, making a joke or responding with comments such as, 'It's all for the best' or, 'At least they won't suffer for long'. It is also important to come to terms with your own beliefs and attitudes about death and dying so you are able to provide calm support that is not guided by your own emotions.

Empathy

Empathy is the ability to appreciate or understand the feelings of others, and is something you should always show the person you are supporting. To be empathetic you need to be genuine in your desire to help and in your interest in the person. Being empathetic does not mean that you agree with the person, but that you acknowledge their situation. When listening to the person, pay attention to their nonverbal communication as well as to the words they are actually saying. Nonverbal communication is often referred to as body language.

People who are grieving as a result of loss are emotionally vulnerable. It is important that you interact with family and/or carers in a sensitive and respectful manner and take into account social, cultural, ethnic and spiritual differences that may influence how they respond to their grief and loss.

The most important support you can provide someone who is grieving is to listen to them and acknowledge their loss. You should never tell a grieving person how they should feel or deal with their grief. Your ability to listen empathetically and communicate in an appropriate manner helps grieving people to feel supported and to trust that you will provide them with the information and support they need.

Body language

Body language forms between 50 and 80 per cent of human communication. Body language can communicate many things, such as whether a person is nervous, afraid, angry, and anxious or in pain. We can generally tell when someone is happy; that is, not feeling any discomfort or concern, and feeling at peace with their current situation. For example, think about someone asking you what the time is. If they are not under any pressure or experiencing pain, they are likely to have a smile on their face and ask in a calm manner, ‘Excuse me, do you have the time?’ What if that same person is late for their scheduled pain relief, they are pale, sweaty and are having a new treatment? Although they may ask exactly the same question, they are not likely to be smiling. Instead, they are likely to be very agitated, they may be wringing their hands, and their face and body may look tense.

The following table gives some examples of body language. These are a guide only and care must be taken not to make assumptions. Instead, use this information as one piece of a jigsaw puzzle that helps you understand a person’s emotional state.

Body language	**Possible meaning**
Standing with hands on hips	Readiness, aggression
Arms folded across the chest	Defensiveness, reluctance
Shoulders hunched, hands in pockets	Dejection
Hands clasped behind their back	Anger, frustration, apprehension
Playing with their hair	Lack of self-confidence, insecurity
Tugging or pulling at their ear	Indecisiveness
Rubbing eyes	Feeling upset, tiredness, disbelief
Biting lips	Tension
Nail biting	Frustration, suppression, nervousness
Clenched fists	Hostility, defensiveness
Finger-pointing	Aggression, threatening
Walking fast, blinking rapidly, tense facial muscles	Fear, vulnerability, anxiety
Holding tightly to bag, papers, etc.	Confusion, insecurity
Wringing hands, crossing or uncrossing feet/ legs	Nervousness, concern, stress, anger
Fast breathing	Nervousness, anger
Bloodshot/puffy eyes, slurred speech, illogical talking, constantly sniffing, runny nose, dilated pupils, smell of alcohol, difficulty keeping still	Alcohol/drug impairment

Voice

The way a person speaks can also provide some clues about their emotional state. For example, the tone, pitch, volume, inflection, rhythm and rate of speech can provide useful information about the person's emotional state. Think about how you use your voice when you express sarcasm, anger, affection, fear, happiness or confidence. The following table gives some examples of emotions that the person's voice might reveal.

Tone

- A flat tone may indicate that the person would rather be elsewhere.
- An abrupt tone may mean irritation.

Pitch

- A high pitch can indicate nervousness, excitement, fear or anger.
- A low pitch can indicate despair, sadness or loneliness.

Volume

- A loud voice can indicate anger or aggression.

Inflection

- Usually a rising inflection means a question and a falling inflection means finality.
- Inflection is also used to express sarcasm or doubt.

Rate

- A fast rate of speech can indicate excitement, happiness or anger.
- A slow rate of speech can indicate sorrow or exhaustion.

Questions

It is important to understand how to use questions so that you know which type will help you collect the information you need to support the person. Asking the wrong types of questions could result in incomplete information, which in turn could mean the person does not get the support they need. The responses to your questions reflect the person's understanding of what you ask, and in some cases may be what the person thinks you want to hear.

Open questions	Closed questions
▶ encourage the other person to speak	▶ are used to obtain 'yes' or 'no' answers
▶ include or start with the words what, why, when and who	▶ help to obtain specific information
▶ are used to encourage the other person to say what they know or feel.	▶ can constrain the conversation if necessary.

Questions to clarify information

The use of clarifying questions demonstrates to the person that you are listening and taking the time to understand their needs. You would usually use a clarifying question in response to something a person says. Examples of clarifying questions include:

- How did that happen?
- Why do you think that?
- Can you give me an example so that I can understand better?

By listening carefully to what the person has said, observing their body language and then repeating back to them what you believe they are saying, you are demonstrating that you are listening and trying to understand the person's point of view. This also enables the person to correct your understanding if necessary.

It is important to remember that at the same time as you are trying to identify your person's needs by interpreting their verbal and nonverbal communications, they are interpreting what you say and do. Be conscious of your own verbal and nonverbal communication and ensure that it is culturally appropriate and communicates what you intend it to.

Respond to distressed people

There may be times when you are confronted by a person who is upset or angry. This could result from a misunderstanding or the person feeling that they have no control over a situation impacting their life or their family. Your ability to recognise signs of distress can enable you to adjust your own behaviour, manage the situation and obtain support quickly if necessary. On the other hand, there will be times when you need to recognise what is usual behaviour and what is not. For example, when dealing with a person with an acquired brain injury it may be usual for them to behave in ways that would usually indicate distress. Always listen closely to someone in distress, keeping in mind the following potential difficulties in understanding.

Reasons why it can be challenging to understand what some people say

- They may use words that you do not understand; for example, terms used by their doctor/psychiatrist/counsellor.
- They may have an accent, a speech impairment or may not speak English well.
- Their speech may be slurred or they may jumble their words, forget what they are saying or ramble.
- They may be crying or exhibiting other signs of distress, making it difficult to understand them or to focus on their communications.
- They may have a medical conditions and exhibit distracting behaviours, such as constantly repeating words or movements, or not being able to sit or stand still while talking.

Recognise behaviours

People accessing palliative care services may be anxious, overwhelmed, at risk of losing control or may have lost control over their own emotions and behaviour. They may be affected by feelings of mistrust, shame, anger, grief or avoidance.

The way you respond to distressed people can either reduce or increase the likelihood of aggressive or violent behaviour. Be observant of cues about a person's emotional state.

Here are some examples of emotional indicators or cues you may observe in people.

Verbal

- Abusive language
- Direct threats
- Fast, non-stop talking
- Shouting/yelling

Behavioural

- Grinding teeth
- Fists clenched, or clenching and unclenching
- An inability to sit still
- Uncontrolled gesturing
- Flaring nostrils

Intuitive

- Your own sense that there is something wrong
- Your own feeling of suspicion
- Your own fear or apprehensiveness

Causes of distress

A person can become distressed if their needs are not being met, if they are forced to do something they do not wish to do or if they feel they are unable to control events in their life. For example, a person's welfare payments may have been stopped because they have not complied with the conditions of payment. This may lead to a situation where the person is unable to pay their rent and risks becoming homeless, understandably a distressing experience.

People who are distressed may feel misunderstood or wronged. It is not unusual for them to want to:

- be taken seriously
- have the situation rectified
- have something done so that the situation does not arise again

- be treated with respect
- be acknowledged and listened to.

Some people may exhibit signs of distress because of cognitive impairment such as intellectual disability, dementia, mental illness or brain injury resulting from an accident, illness or substance abuse. A person with a cognitive impairment may have difficulty with one or more of the basic functions of their brain such as perception, memory, concentration and reasoning skills. This may lead to communication difficulties, aggressive or impulsive behaviours, paranoia, lack of motivation or other behaviour which may not be usual or appropriate for the situation.

Techniques for responding to distressed people

When someone has a problem, or thinks they do, they want to be heard. They may want someone to understand and help to solve the problem. Sometimes they just want someone simply to listen to them; other times, people may want someone to blame.

Your focus should be on understanding the person's needs or situation from their perspective so that you can be in a good position to support them. Sometimes people who are distressed become aggressive; for example, they may become angry and start shouting or being abusive. Your organisation's policies and procedures will guide you on how aggressive behaviours should be managed.

Tips for responding to distressed people:

- Give the person your undivided attention.
- Ensure your own body language is attentive and open.
- Be respectful and avoid lecturing or telling the person what to do.
- Speak calmly and in an unhurried manner.
- Do not take comments personally; you may wrongly be seen as the person who controls the authority or power, but avoid retaliating as this may aggravate the person's emotional state.
- Be sensitive and empathetic, and not judgmental.
- Be aware of cultural and linguistic differences.
- Control your own emotions; do not allow yourself to become frustrated, angry or upset.
- Use listening and questioning skills to determine what the person's needs are; use open questions.
- Follow your organisation's policies and procedures and know the support services provided by your organisation; for example, access to interpreters or private meeting rooms.

A supportive environment

People in a palliative care environment have a range of emotional needs, including the needs to grieve, hope, express their feelings freely, maintain their self-esteem and dignity, and come to terms with fear, uncertainty and impending loss.

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

You should also have strategies in place to provide the family 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. These are valuable communication tools and may help alleviate the fears of family and/or carers, as well as generate questions and discussion.

Use efficient communication strategies

Efficient communication with the person and other members of the palliative care team is essential. The palliative care team should conduct regular meetings to maintain awareness of the person's current situation and the care being provided. These meetings should also involve the person, their family and/or carers, allowing them to receive current information about the person's status and give them an opportunity to voice their concerns. The following communication strategies may help you develop efficient communication skills.

Speak to the person

Ask the person who they want involved in their care and at what level they would like them involved. Be sensitive to who is considered to be immediate family, as friends may play the role of relatives for the person.

Clarify the decision-makers

Clarify who the decision-makers are in 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.

Communicate appropriately

Understand the communication styles and patterns of interaction in the family and communicate in ways that are appropriate. Avoid using jargon. Speak clearly and in plain English as it is easy to misinterpret information even if a person speaks English fluently. Translate information into terms people understand.

Use the person's language

For people who don't speak English, provide information to them, their families and/or carers in their own language through an interpreter. Don't presume people have low literacy levels or levels of understanding, as these assumptions can leave a person feeling patronised.

Respect cultural customs

Respect the customs, practices and beliefs of people from different cultures when communicating with them. For example, for some Indigenous Australian people, speaking the name of a deceased person may cause considerable distress.

Be self-aware

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

Develop networks

Develop communication networks with cultural representatives who can help the palliative care team assist grieving families and provide bereavement support that respects a family's beliefs and attitudes.

Ensure understanding

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

Use communication skills

Here is a step-by-step guide to preparing and having a discussion with a person and their family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates) and/or carers about a person's condition.

Prepare for the discussion

- Prepare for the discussion – confirm the reason for the meeting and determine whether you want others present (for example, a nurse, consultant, chaplain or social worker) and obtain the person's permission. Create an appropriate physical setting with a quiet room and comfortable chairs and ensure privacy and uninterrupted time for the discussion. Ensure the legal decision-maker is present and consider special circumstances; for example, if the person is not competent or doesn't speak English.

Build rapport

- Build rapport – show empathy, care and compassion during the entire discussion. Speak in terms that can be understood; continually assess and reassess the understanding of the person, their family and/or carers.

Provide information

- Provide information – tailor it to the needs of the person, their family members and carers. Explain the uncertainty, limitations and unreliability of prognostic and end-of-life information. As stress can make it difficult to hear or process information, avoid overloading people with too much information. Instead, find out how much they know already and how much they want to know, and respond to their questions. Be prepared to spend as much time discussing issues as necessary. Offer additional resources for information and support if appropriate, and anticipatory guidance about the illness, treatments and possible outcomes.

Acknowledge emotions and concerns

- Acknowledge emotions and concerns – explore and acknowledge the person's and family's fears and concerns and their emotional reaction to the issues you discuss. Respond to distress regarding these issues, where appropriate. Watch people's body language, eye contact, gestures and voice intonation for signs of anxiety or that the person, their family and/or carer doesn't know how to communicate their needs.

Foster realistic hope

- Foster realistic hope – be honest without being blunt or providing more information than necessary to the person. Never give misleading or false information to try to give the person hope. Reassure them that support, treatments and resources are available to control pain and other symptoms, but avoid premature reassurance. Explore and facilitate realistic goals and wishes, and ways of coping on a day-to-day basis, where appropriate.

Encourage questions

- Encourage questions – offer people the opportunity to ask questions and clarify information. Be prepared to repeat explanations and check people's understanding of what has been discussed, ensuring the information provided meets their needs. Explain that topics can be discussed again in the future, if necessary.

Document

- Document – write a summary of what has been discussed in the person's care notes. Make sure you also inform other key healthcare providers involved in the person's care, including the person's general practitioner.

Example

Communicate to show empathy and provide emotional support

Danielle visits her grandmother Annette at her aged care facility every Sunday morning. Annette has advanced dementia and no longer recognises Danielle. She sometimes screams for her to leave her room when she visits.

One Sunday, the support worker, Dora, notices that Danielle looks very upset when she leaves her grandmother's room. Dora thinks about how she would feel if her own grandmother could not recognise her. Dora asks Danielle if she can help. Danielle responds by telling her how upsetting it is that her grandmother doesn't recognise her anymore. Dora takes Danielle to a quiet area and sits with her.

Danielle says, 'I don't feel like there's anyone to talk to. I can't talk to my mother about this as it upsets her too much.'

Dora waits until Danielle has finished speaking and then suggests that she talk with the bereavement counsellor on staff to help her deal with her feelings about her grandmother. Dora offers Danielle brochures about the benefits of counselling and suggests her mother might wish to come along as well. She also suggests that Danielle visits on Sunday evenings, as Annette is usually more settled and receptive to visitors at this time. Dora has shown empathy in identifying and communicating with Danielle about her feelings and needs.

Practice task 11

1. Explain what emotions a family may feel when they anticipate the death of a loved one.

2. Identify two ways that a palliative care team can show support in the way they communicate.

3. Identify two skills that will allow you to develop effective communication capability.

Click to complete Practice task 11

Summary

1. Person care plans should change to reflect the person's changing needs. A good rapport with a person's unit of care fosters sharing of information that contributes to appropriate care being provided.
2. Key stakeholders in the palliative care process include people, carers, family members and significant others such as powers of attorney, persons responsible, guardians, advocates, social workers and palliative health care professionals.
3. Effective communication is a vital skill for those involved in a palliative care environment. Ensure:
   - honest, clear and respectful communication with people
   - open, timely and efficient communication with other members of the care team.
4. Care plans should detail and document a person's lifestyle, social, cultural and spiritual needs, including:
   - personal supports and how relationships can be maintained for those with a life-limiting illness
   - social networks and activities
   - sexuality and intimacy supports
   - emotional supports
   - managing legal and financial affairs
   - how cultural and spiritual needs can be met and connections maintained.
5. Carers are vital links between the person and palliative care staff. Carers must be supported and respected at all times.
6. Palliative care staff must know and understand their level of authority and responsibility, both individually and collectively. Be aware when you have reached the limits of your knowledge, competence or authority and know who, where and how to refer issues.

Learning checkpoint 2

Support individuals to identify their preferences for quality of life choices

This learning checkpoint allows you to review your skills and knowledge in supporting individuals to identify their preferences for quality of life choices.

Part A

1. List some suggestions for how you could encourage family members and/or carers to be involved in the care planning process and end-of-life care of a loved one.

2. Identify and explain three ways to manage cultural issues for the family and/or carer and the person accessing services.

3. Identify and describe three ways you can provide a supportive environment so that the person can discuss spiritual and cultural issues in an open and non-judgmental way.

4. Explain the concept of dignity of risk and give an example of how it can be maintained for the person accessing palliative care services.

Part B

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

Case study

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's advanced care directives, which she made before dementia had set in, state that she doesn't want any pain relief beyond the usual treatment. Marilyn demands that her mother's preferences be overridden. Sophie asks her co-worker, Gary, for his opinion and advice about what she should tell Marilyn and what else she should do. Gary explains that workers must always uphold the person'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.

1. Identify the legal and ethical issues facing Sophie in following Joan's advance care directives.

2. Explain the concept of empathy and identify how Sophie is empathetic towards Marilyn.

Topic 3

In this topic you will learn how to:

- **3A** **Assist with determining advance care directives**
- **3B** **Assist with documenting advance care directives and ensure communication about them respects confidentiality requirements**
- **3C** **Actively support the person's ethical end-of-life decisions in line with organisational policy and care plan directives**
- **3D** **Identify and document the person's ongoing decisions, preferences, needs and issues in relation to end-of-life care**
- **3E** **Observe the impact of the person's end-of-life decisions, needs and issues and provide support**

Assist with advance care planning

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

3A Assist with determining advance care directives

Advance care directives outline the person's preferences for their end-of-life and post-death treatment. They provide the person the opportunity to clearly record their wishes and preferences in advance while they are capable of doing so. Advance care directives offer 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.

Advance care directives are formal, legally endorsed documents, signed by the person. They are sometimes referred to as 'living wills'. They only come into effect if the person is no longer legally considered capable of making their own decisions about medical treatment. It is the responsibility of all members of the healthcare team to follow the advance care directives in the person's care plan.

Advance care planning documents vary considerably and 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.

Information in an advance care plan

Here are some types of information and documents that may be included in an advance care plan.

Information and documents in an advance care plan
▶ The names of family 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 and options regarding their future medical care (these come into effect only if they can't make decisions regarding their care)
▶ Information identifying how long the person wishes the advance care plan to be in force 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

Legal considerations

Legislation, regulations and guidelines ensure people receiving palliative care have their rights upheld in terms of receiving quality care, choosing their own treatment, privacy and confidentiality, being able to complain and refusing treatment. It is part of your role and responsibilities to ensure people understand these rights.

In many states, specific legislation is in place that protects both the person's right to refuse treatment and the health worker's duty of care to provide treatment. Each state and territory also has legislation and guidelines regarding advance care directives, which vary from state to state.

Most directives are only effective for people in the terminal stages of an illness or in a persistent vegetative state, who are not competent to make treatment decisions, and if the presenting condition is the one specified on the advance care document.

Substitute decision-makers

When people can no longer make decisions for themselves, a substitute decision-maker is used. The substitute decision-maker must have been nominated by the person as the individual responsible for making decisions about future medical treatment. You must understand the ethical and legal dimensions of this role, specifically that substitute decision-making only comes into effect when a person loses the capacity to make decisions or is unable to understand the nature and complexity of the treatment, and is therefore no longer considered legally capable of making their own decisions regarding medical 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. If the person's wishes regarding treatment are known and the document stating this has been signed, then these take priority over the wishes of any family members. Any disagreement about the person's prior wishes is usually resolved by further discussion and support by social workers, pastoral care workers or others.

Ethical considerations

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 instructions that have been recorded in the person's care plan.

Behaving ethically requires a delicate balance between the standard practice of providing quality palliative care and the wishes of each person. For example, while a person may request assistance to end their life, this is illegal in Australia. It is often a matter of balancing preference with reality.

Follow organisational policies and procedures in line with current best practices and within your skill level, knowledge and qualifications. Report any observed failures of standard of care through the appropriate complaints process.

Examples of ethical considerations

You should be aware of, and apply, the following ethical considerations when working with a person's advance care plan.

Ethical considerations when working with a person in palliative care
Demonstrate respect for the dignity and basic human rights of people in your care.
Acknowledge that, within legal constraints, every person has the moral and legal right to decide what will be done with them.
Every person has a right to privacy and confidentiality.
People in palliative care have the right to be told the truth.

Duty of care, negligence and dignity of risk

Community service 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.

Duty of care describes the legal obligation that individuals and organisations have to anticipate and act on possible causes of injury and illness that may exist in their work environment or as a result of their actions. Duty of care is part of common law and it requires you to do what is fair and reasonable to prevent harm or injury to the person or their property. While aspects of WHS legislation may vary between states and territories, there are common legislative requirements and obligations under the duty-of-care principle.

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.

Informed consent

Another important ethical consideration is obtaining a person's informed consent. This means that people receive a full explanation of their condition and possible treatments so they can then make informed decisions based on the information provided, and can consent to treatments or interventions. The person's preferences are recorded in their care plan and signed by them, if they are able to do so. The signed consent must remain in the person's file and be sighted before assisting the person in any way.

Below are some common advance care directives and information on how to comply with legal and ethical considerations.

Treatments

Advance care directive:

- Medical treatments

Comply with legal and ethical considerations:

- Ensure medical treatments meet the person's preferences.
- Ensure you are honest if treatment goals are not met.
- Comply with the person's advance care directives.

Person's wishes

Advance care directive:

- Maintaining the person's wishes

Comply with legal and ethical considerations:

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

Decision-making

Advance care directive:

- What to do when the person can no longer make decisions

Comply with legal and ethical considerations:

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

Life-sustaining treatment

Advance care directive:

- Life-sustaining treatment

Comply with legal and ethical considerations:

- 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 care

Advance care directive:

- Aspects of care that are important to the person during their dying phase

Comply with legal and ethical considerations:

- 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.

Conflict

Advance care directive:

- Dealing with conflict

Comply with legal and ethical considerations:

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

Example

Assist with the determining of advance care directives

Here is an example of one person's advance care directives. The plan clearly records the person's wishes and preferences for care should she become incapable of making her own decisions about her medical care.

Advance care directive

Person name: Lucy Grable

Address: Unit 2/149 Lakemont St, Chirnside, Qld

To my children, grandchildren, family members, doctors, nurses or other medical or dental professionals associated with my care.

Having discussed with my doctor, Dr Orson Peates, my current state of health and having been assessed by him, at this point in time, as being capable and competent to make decisions regarding my life, the following are my express wishes with regard to my person.

I am aware that I have had a history of throat cancer. In 2004 I underwent chemotherapy and have been in a state of remission in the following four years.

I am aware that I am vulnerable to the development of further cancer having experienced it once. I would therefore like to prepare for future scenarios now.

Should I ever suffer from:

- a severe irreversible cancer
- a severe irreversible brain disease (such as dementia, Alzheimer's disease, Parkinson's disease, Huntington's disease, muscular dystrophy or other)
- serious brain damage (as a result of stroke, injury or illness)
- a severe incapacitating disease of nerve or muscle
- any other condition of similar gravity

and therefore as a result I am personally unable to participate in decisions regarding my care, then I would like the following to be considered with respect to my future health care:

- In the event that my heart stops (regardless of the cause), I do not wish to be resuscitated.
- In the event that I should not be able to swallow food, fluid or medication, I do not wish to be artificially fed nor have tubes inserted into me for these purposes.
- With the development of any life-threatening medical situation I do not wish to be given any active treatment such as antibiotics, ventilation, surgery or blood transfusion.
- I do not wish to have any treatment that is painful, invasive or futile if it will not address my underlying condition.
- I would like to have ordinary nursing care and the use of medical interventions only to control distressing symptoms and not merely to prolong my existence.
- I would like to have medications that will control my symptoms of pain or distress (understanding that some of these medicines may have consequences to my health).

I have discussed my wishes with my grown children and grandchildren – they have a copy of this directive.

I, Lucy Grable, reserve the right to revoke this directive at any time.

Signature: Lucy Grable

Signature: Orson Peates

Date: 19 December 2016

Practice task 12

1. List three things that should be in an advance care plan.

2. List and explain two ethical considerations when planning care for a person.

3. When can another person make decisions regarding the care and treatment of a person in palliative care?

Click to complete Practice task 12

3B Assist with documenting advance care directives and ensure communication about them respects confidentiality requirements

Quality end-of-life and post-death care relies on good planning. Instructions for meeting these care needs, which a person may determine in advance when they are capable of making decisions for themselves, are outlined in the care plan as 'advance care directives'. These include details about medical treatment, their care preferences and how to deal with issues that may arise.

Workers must also be aware of the legal and ethical regulations that may influence end-of-life care, including confidentiality and privacy. Confidentiality refers to managing access to private information. Confidentiality provisions restrict an individual or organisation from using, storing and disclosing information about a person that is outside of the scope for which the information was collected. Confidentiality refers to both written and verbal information.

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.

Communicate instructions to the care team

If an advance care directive has been completed, it may be your responsibility to ensure it is followed by all members of the team, so the person's right to dignity and choice is upheld.

It is crucial that a person's advance care directives are communicated to each team member so everyone understands the person's wishes. This may be done at a team meeting, a case conference or during a family meeting. If a person's wishes change, this must be documented in care notes, the appropriate people informed and the information transferred to the person's care plan. Directives about which the palliative care team will need to be informed are shown below.

Medical treatment

Medical treatment – for example, the person may have asked not to have a specific treatment, such as a blood transfusion, due to their religious beliefs, or may have requested alternative therapies.

Unacceptable condition

Unacceptable conditions – this relates to states the person would find unacceptable; for example, the person may have requested that no life-sustaining treatment be provided if it results in severe brain injury with no capacity to communicate or for self-care.

Treatment

Consider how far treatment should go when the patient's condition is terminal, incurable or irreversible. For example, the person may wish to die with dignity and not receive treatment that only prolongs life for a short time, or they may ask only to be given pain relief when all other treatment options have been given. If they are in Victoria, they may wish to access voluntary assisted dying.

Non-medical aspects

Non-medical aspects – for example, who a person wishes to act on their behalf, who they want to see and how to comply with their cultural wishes.

Advance care planning

Advance care planning is an ongoing process, where all discussions should be documented, regularly reviewed and communicated to the key people involved. You should regularly reassess and review the person's preferences and update documents accordingly. If documents are changed, be sure to provide the team with the updated information

Communicate the person's end-of-life needs clearly to appropriate team members

The comfort, dignity and care of a terminally ill person at their end-of-life are distinct and important aspects of palliative care. Your role is to understand the person's wishes and preferences so you know the appropriate care to provide. Directives are documented in the person's care plan or advance directives and incorporated into an end-of-life plan. Make sure end-of-life decisions are discussed in team briefings and reviewed with the person and family and/or carers at regular intervals. This is crucial to ensure continuity of care, especially if the person has expressed a wish to return home.

When no plan or document exists, the family and/or carers should be consulted as soon as practicable when it is apparent the person is nearing the end of their life. You may arrange a family conference to make sure the care goals are agreed on, and to check that the person's preferences are respected. Quality and optimal end-of-life care is achieved only when relevant and essential matters are identified, discussed, determined and documented in advance.

Maintain end-of-life care notes

In most instances, new issues that arise in relation to changes in a person's wishes need to be documented and reported in the person's care notes. Other members of the team will read this and take the appropriate action. Make sure the person who writes the note includes their name and date so they can be contacted for further details.

Alternatively, you may be responsible for instructing carers, volunteers and others involved in the person's care to document any changes in care notes or to notify you as soon as possible. Always follow up so you know comments have been read and acted upon. Make sure team members know the type of information that should be recorded, who should have access to these records and how these documents are to be stored.

Other records that should be circulated include ongoing assessments, treatment reports, evaluations and medication charts. Make sure all records are current, accurate, clear, comprehensive and person focused.

Confidentiality

Confidentiality is critical when working in the community sector. You often have access to privileged and sensitive information about the people you work with. The way that the palliative care team manages confidential information can have a significant impact on a person's dignity, rights and choices, on their opportunities and access, and on their self-concept, self-esteem and wellbeing.

Confidentiality provisions restrict an individual or organisation from using, storing and disclosing information about a person that is outside of the scope for which the information was collected. Confidentiality refers to both written and verbal information.

Staff on a team involved in caring for people with life-limiting illnesses should share confidential information about people receiving support when necessary. Confidentiality means that workers must have a reasonable purpose for collecting, storing, accessing and distributing information about a person. Organisations and workers must also not collect generalised information without an implicit reason.

Information relating to people must be securely stored, with access limited to those working directly on the case, according to organisational policy and procedure.

Privacy

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:
http://aspirelr.link/aacqa-privacy-policy

Example

Assist with documenting advance care directives and ensure communication about them respects confidentiality requirements

Ruth, a personal care worker, provides care to 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 doesn't want to die without saying goodbye to his family. His carers notice Jacob has recently become 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.

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, in another situation Ruth may have been able to deal with the situation herself, or she may need to refer it to a health specialist such as a doctor, nurse, physiotherapist or a specialist such as a lawyer, financial expert, funeral director or advocate.

Practice task 13

1. Explain the privacy rule around collection of solicited personal information.

2. Explain the privacy rule regarding the disclosure of personal information.

3. Explain what a support worker must do to maintain confidentiality.

Click to complete Practice task 13

3C Actively support the person's ethical end-of-life decisions in line with organisational policy and care plan directives

End-of-life decisions relate to the actions taken when a person's death is imminent. These may be documented in the person's care plan or their advance care directives. Remember, it is a legal requirement under relevant legislation to comply with these decisions.

End-of-life decisions cover a range of issues, including the type of medical treatment and pain control the person permits, whether the person would like life-supporting equipment to be turned off and who they want to be with them at the end of their life.

As part of the care team it is your responsibility to actively support the person by implementing the end-of-life decisions that the person has requested. These decisions have been communicated to all members of the palliative care team and should be clearly documented, in line with organisational policy and procedures, in the person's care plan.

End-of-life discussions

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, or may want you to help them resolve a family quarrel before they pass away.

One of the most important wishes a person may have is to choose the location of their end-of-life care. If this is not in their care plan, you should raise the issue with the person and their family so the person's wishes can be made known.

If a person's wishes change, it is your responsibility to report the situation or the information to the relevant person in the team; for example, the manager or director of nursing. It may mean the person's care plan has to be revised. Family members should also be consulted so they are aware of any new needs or issues and have time to consider the decisions made by the person.

End-of-life decisions

Depending on a person's circumstances, you may be required to discuss and take action on the considerations described below.

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. Ensure you understand any legal considerations when doing this.

Deciding the type of funeral wanted

- Many people provide instructions about the type of coffin they want and how they want their funeral to be conducted. They may like to talk to you about this as it may help them to feel they are in control and alleviate their fears. Document their wishes.

Treatment or refusal of 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 acting as the person's proxy, providing information to the palliative care team about the person's preferences, personal values and history.

Deciding how family affairs are to be looked after

- In some instances, 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.

Location of death

- Some people want to return to their home. Others want to go to a hospice where they will receive quality care and cause less distress for their loved ones.

Currency of end-of-life plan

A person's plans and preferences regarding their end of life should be regularly discussed and reviewed for currency with the person, family members, guardian, carers, doctor and other palliative care team members, and all decisions documented and signed. Allow people every possible opportunity to contribute to the care planning and decision-making process.

Sometimes, a person living at home may have no end-of-life plan. If they require urgent treatment, decisions may be made quickly without thinking through the consequences. Here are a number of questions you need to consider in these situations so as to make ethical decisions.

Questions for urgent situations where person has no end-of-life plan

- Is the decision ethical?
- What is in the person's best interests?
- Has the person completed a statement of choices form, and is it current?
- Does the palliative care team, including the person, their family and/or carers, agree on the goals of care?
- Is the proposed treatment likely to be a benefit or a burden?
- Is there a structured/supported process for discussing ethical issues?

Modifying end-of-life plans

Circumstances and opinions may change, especially when death seems imminent, so the palliative care team may arrange a conference with the doctor and the family to make sure the goals of care are agreed on, and to check that the person's preferences remain current.

Consider the following seven strategies when meeting with the person, their family and/or carers to discuss the process for making end-of-life ethical decisions.

Ways to help a person and their family make end-of-life ethical decisions

1. **Suggest involving others**
   Suggest to the person that they involve family members, carers or others close to them, so as to minimise the decision-making burden.

2. **Encourage people to make directives**
   Some people may not have an eligible substitute decision-maker or person responsible, or may prefer that no-one makes medical decisions on their behalf. Encourage people receiving support to consider making a more detailed directive in these circumstances, if appropriate.

3. **Choose care team members carefully**
   The care team members selected to conduct discussions about end-of-life care with a person should be those who are identified as significantly involved in the active care of the person.

4. **Be aware of opportunities for end-of-life discussions**
   Opportunities for you to begin end-of-life discussions may arise when the person, their family and/or their carers inquire about palliative care; when a person says they want to forego recommended life-sustaining treatment; or when they express a wish to die.

5. **Consider timing and environment**
   Advance care planning is most easily accomplished during stable health or after a person has adjusted to a new illness. Utilise a non-threatening environment such as the person's room or a quiet meeting room.

6. **Ensure people understand advance care planning**
   Find out how familiar the person is with advance care planning and explain the goals. For example, plan for the potential loss of their capacity to make decisions, either temporarily or permanently, to ensure they are protected from either unwanted treatment or under-treatment.

7

Explain the details

The person usually needs information from you to understand the meaning of the types of therapeutic and comfort scenarios that may arise in their situation, and the benefits and burdens of various treatment options. Key medical terms should be explained in plain English. Allow time for reflection and discussion after this information has been provided.

Comply with end-of-life plans

It is your legal and moral responsibility under state and territory legislation to comply with all end-of-life decisions made by the person, their family members and carers. This responsibility is also part of your organisation's policies and procedures.

Violations of end-of-life decisions include:

- exchanging information in an insensitive way
- providing inappropriate treatment of pain or other symptoms
- continuing aggressive treatment not suitable to the person's condition
- providing unwanted sedation
- withholding or withdrawing treatment.

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 (and Norfolk Island Government) agencies.

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.

Example

Actively support the person's ethical end-of-life decisions in line with policy and directives

Doris lives at home with her 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 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
- to not be transferred to hospital.

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 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 and explain three ways a support worker can assist a person and their family to make end-of-life decisions.

2. Explain two ways support workers can violate end-of-life decisions.

3. List three end-of-life topics a person may wish to discuss with a support worker.

Click to complete Practice task 14

3D Identify and document the person's ongoing decisions, preferences, needs and issues in relation to end-of-life care

The comfort, dignity and care of a terminally ill person at their end-of-life are distinct and important parts of palliative care. As discussed previously, your role is to understand the person's wishes and preferences so you know the appropriate care to provide. Directives are documented in the person's care plan or advance directives and incorporated into an end-of-life plan. Make sure end-of-life decisions are discussed in team briefings and reviewed with the person and family members at regular intervals. This is crucial to ensure continuity of care, especially if the person has expressed a wish to return home.

When no plan or document exists, the family and/or carers should be consulted as soon as practicable when it is apparent the person is nearing the end of their life. You may arrange a family conference to make sure the care goals are agreed on, and to check that the person's preferences are respected. Quality and optimal end-of-life care is achieved only when relevant and essential matters are identified, discussed, determined and documented in advance.

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
- want a different pain relief treatment
- want to return home.

Example

Identify and document the person's ongoing decisions, preferences, needs and issues in relation to end-of-life care

Louisa is a personal care worker in a palliative care environment. She provides care for Don, a 45-year-old man who is in the last stages of cancer. Today he seems more upset than usual. When Louisa asks him if he is all right he tells her that his family keeps urging him to make a will. He says that he used to think that if he made a will it meant he had given up hope of living, but he now thinks making a will would be a good idea, especially for his wife and children. He asks Louisa how he can go about making a will. Louisa listens carefully and repeats Don's request so she knows she understands exactly what he wants. She explains the protocol and what she is able to do for Don. She tells him that she will let her supervisor know and she asks Don whether he wants his family to know. Louisa makes a note of Don's request in his care notes. Louisa follows up Don's request a day later to make sure that his needs have been recognised and that action has been taken.

Practice task 15

1. Give a reason that a care plan may need to be modified.

2. Explain the support worker's role in reviewing care for a person they are supporting.

3. Identify two changes a person might make to their care

Click to complete Practice task 15

3E Observe the impact of the person's end-of-life decisions, needs and issues and provide support

Providing care is often physically tiring and emotionally exhausting. A family member, spouse or family friend who has taken on the role of a carer may have to put their own life on hold. Fluctuating or overwhelming feelings and emotions during a difficult time may make it hard to concentrate, which may affect a carer's ability to make important decisions. Primary carers often experience as many emotions as the person receiving care, including anger, frustration and sadness. The carer's role may also change as the person's condition progresses.

Professional 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 the appropriate care and support for other people.

It is likely that a carer may become personally affected if they care for a palliative person for more than six months prior to the person's death. This can be made worse for the carer if they are saddened by the death; for example, because of the age of the person, if the person has a young family or if the death could have been prevented by early diagnosis.

The effects of grief

Palliative care coordinators must recognise the impact these end-of-life issues have on carers and support them, while also bearing in mind the following potential impacts that grief may have on carers.

Five effects of grief on carers

- Their future work may be affected negatively.
- They may isolate their emotions and withdraw from other people following the death of a person; this may result in a lower quality of care and prevent effective end-of-life care for people.
- They may develop a fear of death and dying themselves.
- They may become frustrated or depressed by their powerlessness in the situation.
- They may experience burnout from the emotional stress of working in a palliative care environment.

Support the carer

Part of your role as a supervisor is to provide carers with support. This is especially important for carers who are family members and not professional carers, as it may be the first time they have cared for someone.

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

It may be your job to assist the carer with their day-to-day support of the person or to explain to other workers what tasks they can help the carer with. This may involve showing carers how they can assist with activities of daily living or demonstrating how to use aids and equipment. You may also put carers in touch with allied health services and professionals such as occupational therapists or counsellors for advice, as the more information and skills they have, the better they are able to cope.

Inform the carer

You need to keep carers informed. Provide as much information as you can to the carer about their role and answer their questions so they understand the person's situation. You should also explain the person's progress and what is likely to happen to the person 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 person's conditions; for example, the Cancer Council phone support line. Information in the form of pamphlets or brochures about grief may be useful to help them understand their own feelings.

Spend time with the carer

Making time to spend with the carer is important to allow them to talk to you, explain their feelings and tell you about how they are coping.

You can support carers by:

- being available to talk with them and to answer any questions they have
- encouraging them to speak freely, listening to what they are saying and offering advice if you think it is necessary (sometimes they may just want someone to talk to)
- watching the carer for signs they are stressed or having difficulty coping so you can step in and provide support
- setting regular times to speak with them.

Provide the carer with practical assistance

Providing practical assistance is a good way to help a carer through a difficult time. This may involve setting goals for the carer on a day-to-day basis, as situations may change quickly and carers may become overwhelmed by their role.

The following practical assistance can be helpful for carers:

- Providing practical instruction and aids to help the carer support the person in their activities of daily living
- Arranging respite care for the person so the carer has a break from their role; for example, planning ahead so others can also care for the person
- Asking the carer what help they need and encouraging them to develop a good support network
- Encouraging carers to look after their own needs by eating and sleeping well, getting plenty of rest and exercise
- Where possible, encouraging carers to maintain their social life
- Providing bereavement support

Example

Observe the impact of the person's end-of-life decisions, needs and issues and provide support

Teresa is a palliative care worker. She is visiting Huong, 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.

Practice task 16

1. List three effects of grief on carers.

2. Explain two ways of supporting the carer.

3. List and explain two ways you can give practical support to the carer.

Click to complete Practice task 16

Summary

1. Advance care directives, also referred to as 'living wills', come into effect when a person is no longer legally able to make their own decisions about medical treatment. The healthcare team is obliged to follow the instructions contained in a directive.
2. Advance care planning documents vary considerably and may include a range of formal and informal documents.
3. Workers must be aware of and apply ethical considerations when working with an advance care plan. These considerations include respect for the person and their autonomy, privacy and confidentiality. Informed consent allows people to make informed decisions.
4. Workers and coordinators have a legal and moral responsibility to comply with end-of-life decisions. These decisions should be documented, discussed with the person and their family and regularly reviewed. If person wishes change in any way, these should be reported and documented.
5. Workers and coordinators also have responsibilities to carers, particularly to:
   - keep the carer informed of person progress
   - spend time with the carer, observing for signs of stress or emerging health issues
   - provide them with practical assistance to meet their own needs.

Learning checkpoint 3

Assist with advanced care planning

This learning checkpoint allows you to review your skills and knowledge in assisting with advanced care planning

Part A

1. Explain two areas of legislation that relate to advance care directives.

2. Describe two ethical considerations for the support worker working within the palliative care environment.

3. Explain what 'duty of care' means for the support worker in palliative care.

4. List and explain three pieces of information that may be included in an advance care directive.

5. List three aspects that a support worker needs to be aware of in the collection, use and storage of patient information that is covered by the 2014 Privacy Principles.

Part B

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

Case study

Client's name: Shirley Caroline Smithton

DOB: 12/07/1918

Address: 12 Mawson Way, Lakestone SA

To my children, my grandchildren, family members, doctors, nurses and other medical or dental professionals associated with my care.

Having discussed with my doctor Dr Fazah Ganapati my current state of health and having been assessed by her at this point in time as being capable and competent to make decisions regarding my life, the following are my express wishes with regard to my person.

I am aware that I have a history of bowel cancer, which, in 2001, required the removal of some of my large intestine. I have also undergone chemotherapy for the cancer and have been in a state of remission for five years following the procedure.

I am aware that I am vulnerable to the development of further cancer having experienced it once. Therefore I would like to prepare for future scenarios now, should I ever suffer from:

- a severe irreversible cancer
- a severe irreversible brain disease (such as dementia, Alzheimer's disease, Parkinson's disease, Huntington's disease, muscular dystrophy or other)
- serious brain damage (as a result of stroke, injury or illness)
- a severe incapacitating disease of nerve or muscle
- any other condition of similar gravity.

If I am personally unable to participate in decisions regarding my care, then I would like the following to be considered with respect to my future health care:

- In the event that my heart stops (regardless of the cause), I do not wish to be resuscitated.
- In the event that I should not be able to swallow food, fluid or medication, I do not wish to be artificially fed nor have tubes inserted into me for these purposes.
- With the development of any life-threatening medical situations, I do not wish to be given any active treatment such as antibiotics, ventilation, surgery or blood transfusion.
- I do not wish to have any treatment that is painful, invasive or futile if it will not address my underlying condition.

Case study continued...

I would like to have:

- ordinary nursing care and the use of medical interventions only to control distressing symptoms and not to merely prolong my existence
- medications that will control my symptoms of pain or distress (understanding that some of these medicines may have consequences to my health)

I have discussed my wishes with my grown children and my grandchildren-they have a copy of this directive.

I, Shirley Caroline Smithton, reserve the right to revoke this directive at any time.

Signed: Shirley Conran

Shirley Conran 2 July 2016

Witnessed by Fazah Ganopai GP

F. Ganapati 2 July 2016

1. Describe what actions the support worker looking after Shirley should take, in regard to their duty of care and advance care directives.

2. Identify two advance care directives that Shirley has documented.

3. What actions has Shirley taken to lessen the distress that might occur for the family?

4. What is the responsibility of the support worker toward the family in regard if Shirley's end-of-life decisions change?

Topic 4

In this topic you will learn how to:

- **4A** **Collaborate with others to plan and document strategies to maximise comfort**
- **4B** **Assess and report the person's need for pain relief in line with care plan**
- **4C** **Provide pain and symptom relief in line with role and requirements**
- **4D** **Provide appropriate information about the use of pain-relieving medication and treatments in consultation**
- **4E** **Observe, report, communicate and document effectiveness of interventions for pain and symptom relief**
- **4F** **Communicate and document the ineffectiveness of interventions**

Take action to alleviate pain and other end-of-life symptoms

Experiencing severe, unrelieved pain often takes a toll on a person's physical and emotional wellbeing. It may also affect their quality of life and be very stressful for family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates) and/or carers. It is the health care coordinator's responsibility to listen empathetically to the person's perception of their pain, support the recommended treatment and promote person's comfort.

4A Collaborate with others to plan and document strategies to maximise comfort

One of the aims of a palliative approach is to maximise relief and comfort when a cure is no longer possible. Pain management is therefore one of the most important aspects of care for a person with a life-limiting illness. As with all healthcare issues, people require a qualified medical opinion regarding any suggested treatments.

The development of a comprehensive care plan should be based on an ongoing assessment of the person's needs and preferences and early identification of their main symptoms. This provides effective symptom management in accordance with the person's goals for care and their specific treatment preferences.

Input from other members of the palliative care team and your supervisor will assist with identifying issues and providing solutions for ongoing care for the person.

Develop and follow the care plan

Part of your role as a palliative care worker is to help develop a care plan with input from health professionals, the person, their family members and carers. This follows the initial assessment of the person. The plan should address all aspects of care including medical, nursing, physical, spiritual and psychosocial, and the emotional care and wellbeing of the person, their family members and/or carers. In particular the care plan directives should detail the type of pain the person may experience and the strategies needed to make the person comfortable.

Ensure the person, their family members and/or carers are provided with the appropriate information so they understand the strategies selected and can agree that they're appropriate. Remember, a person's care plan is a living document that is contributed to and updated regularly by all parties.

You have a duty of care to ensure the care plan is followed according to organisational procedures and legislation regarding pain management. For example, you must know which pain-relief measures may be administered by a personal care worker, and which must be administered by an authorised health professional. Consult a healthcare professional if you are unsure.

Pain assessment tools and regular observation of the person

A pain assessment tool develops a baseline from which to evaluate pain interventions. The care plan identifies the types of tools that should be used to assess the person's pain and the results of any assessments that have taken place. Tools may range from simple rating scales to formal tests such as the Edmonton Symptom Assessment Scale, the Symptom Assessment Scale and the Abbey Pain Scale (for people with advanced dementia). Be aware that many tools are lengthy and people may not be able to tolerate multiple questions. For non-English-speaking people, use a face-rating scale translated into their first language.

The person's comfort must be regularly reviewed, assessed, reported and documented. You should be in constant touch with the rest of the care team to identify and communicate any changes in a person's condition and level of pain, and subsequent changes to their pain relief. Information from observation, or data from the bedside flow sheet specifically designated for rating pain, must be documented in the person's care notes, reported at the change of shift and transferred to their care plan.

Pain-relieving measures

All people have a right to pain relief, which should be administered, managed and documented according to care plan directives. The directives detail all forms of pain control and comfort measures required by the person as identified by their assessment. These may include traditional methods such as giving pharmacological pain-relief medication via tablets or injection, such as non-opioids like paracetamol, opioids like morphine or antidepressants. Application of heat or cold packs, physiotherapy techniques and/or managing features such as light and temperature may also help relieve the person's pain. Below are some examples of pain management for common symptoms associated with life-limiting illnesses.

Dyspnoea

- Dyspnoea is shortness of breath. Opioids are considered a standard treatment for dyspnoea in patients with advanced diseases. Other pharmacological treatments include bronchodilators, diuretics and steroids. Non-pharmacological treatments include improving air circulation, elevating the head of the bed to relieve choking, using focused breathing techniques, music, prayer and encouraging a calm environment.

Nausea and vomiting

- Nausea and vomiting are common for people with advanced illnesses. These symptoms can be due to medications, gastric irritation, liver failure, infections or the disease process; or it can be treatment-related and may reduce food or hydration intake. Assessment should determine the history or frequency of episodes, the characteristics of the vomiting and factors that contribute to or alleviate vomiting.
- Pharmacological interventions depend on the cause and may include using antihistamines or steroids. Non-pharmacological interventions include distraction, relaxation techniques, encouraging slow eating, and serving meals (that do not have strong smells) at room temperature, with clear fluids.

Oral complications

- Oral complications such as lesions, infections and bleeding can cause much discomfort. Oral hygiene can provide relief and promote healing; for example, teeth should be brushed daily to remove plaque and bacteria. People who can't tolerate brushing should have their teeth and tongue swabbed with saline, followed by an oral disinfectant or alcohol-free mouthwash. People with a dry mouth or lips may benefit from lubrication with a water-based lubricant. Ice chips may provide relief from thirst and reduce bacterial overgrowth; however, some people may find their mouth feels drier as the ice melts.

Constipation

- Constipation is a frequent symptom at the end of life, and may be due to opioid use, dehydration, disease-related intestinal obstruction or motility, pain or decreased activity. Constipation may cause abdominal pain, anorexia, anxiety and nausea, and in the elderly can lead to confusion. The palliative care team assesses the probable causes by obtaining a bowel history, assessing medication and food factors and performing a rectal and abdominal examination. Treatments for constipation may include laxatives, stimulants, stool softeners and dietary changes.

Diarrhoea

- Diarrhoea may be due to faecal impaction, bacterial infections, irritable bowel syndrome, anxiety, chemotherapy, radiation therapy or antibiotic therapy. Assessments should determine a bowel history. Interventions may include dietary modification, anti-diarrhoea medication and the promotion of hydration.

Other measures that promote comfort and relieve pain

There is an increasing use of non-pharmacological interventions by people who have a life-limiting illness; for example, adopting meditation or a special diet to treat cancer instead of undergoing surgery, radiation or chemotherapy.

People who are unable to tolerate or who refuse pain medications as part of a palliative approach may benefit from complementary therapies. These therapies may also fit better with a person's culturally specific preferences and/or their psychological or spiritual needs, and may enhance their sense of control. Complementary therapies should be administered by a professional, or you may receive training to administer some. Many people request an integrated approach to pain relief, combining treatments from conventional medicine and alternative therapies.

You should always ask people if they are already using any complementary and alternative therapies, as some may interfere with conventional medications.

Types of complementary therapies

Here are some of the types of complementary and alternative therapies that may be included in a person's care plan.

Massage

The sensation of touch is very important for a person with a life-limiting illness, and massage is an appropriate way of providing relief. Manipulation of muscles through massage can ease muscle tension, relieve headaches, provide reassurance and decrease anxiety. A physiotherapist can show you how to use a gentle, rhythmic touch to massage a person's hands, feet, neck or back.

Diversional therapy

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

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

Heat and cold

Applying heat and ice packs can reduce the pain caused by muscle spasms. Ensure you know when it is appropriate to apply them and how they should be applied; follow any instructions documented in the person's care plan

Aromatherapy

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

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

Other treatments

Other alternative treatments include:

- ginkgo for the treatment of dementia
- magnetic therapy for arthritis
- St John's wort for depression
- acupuncture to reduce dyspnoea and improve mobility
- hydrotherapy to promote muscle use and flexibility
- qi gong, a form of tai chi that combines movement, meditation and controlled breathing to improve blood flow, breathing and energy.

Hydration and nutrition requirements during a palliative approach

All people are entitled to food and drink of adequate quantity and quality, and to the help they need to eat and drink. A healthy level of nutrition and hydration can help to prevent or treat illness and symptoms and improve quality of life. Nutrition and hydration should be given in a way that meets the person's needs. The person should be given any necessary assistance 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
- ongoing assessment to monitor swallowing difficulties
- positioning to assist in safe ingestion of food and fluids for the person
- specialised equipment such as modified utensils and plate guards
- privacy, if requested.

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 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 supervisor. Some health problems that may be addressed include:

- advanced dementia
- apathy
- fatigue
- metabolic disorders
- oral health factors.

Hydration and nutrition requirements at end of life

As an advance care directive, some individuals request not to be given food or fluids artificially at end of life. Artificial food and fluids are nutrients and fluids that are given to a person through an intravenous line into a vein or direct to the stomach and intestines through a nasogastric tube or PEG tube. At times, family and/or carers can find this a confronting and difficult experience as food is associated with nurturing and providing comfort.

At all times, if a person requests food and fluids it must be given to them along with assistance to take it. Regular mouth care, ensuring the mucous membranes of the mouth do not dry out, is an important comfort measure when fluids and food are not taken orally. Artificial saliva may also be given to promote hydration of the mouth.

Example

Collaborate with others to plan and document strategies to maximise comfort

Jenny is a carer in a residential nursing home. Abigail has recently been admitted to the residential nursing home; her dementia has progressed to the stage where she can no longer remain at home. One of the main issues Abigail presents with initially is the control of pain that causes difficult behaviour, such as aggression. The palliative care team meets with Abigail's husband and together they decide to add aromatherapy and hand massage as complementary therapies to the medication they are already using for pain management. After three days Jenny notes that Abigail's behaviour is more manageable and that Abigail appears more comfortable as she now sits peacefully for short periods of time. Jenny documents these behaviours in Abigail's case file.

Practice task 17

1. Explain how aromatherapy can assist with pain control.

2. Explain what aspects of care a palliative care worker should assess to include on the care plan.

3. List two interventions that may be necessary when giving food and fluid to a person in palliative care.

Click to complete Practice task 17

4B Assess and report the person's need for pain relief in line with care plan

A major part of providing palliative care is to ensure the person's pain is controlled. The care team must make sure that person's care plan is followed and be familiar with the strategy chosen and who is permitted to administer the pain relief. Failing to relieve a person's physical symptoms and distress may decrease their quality of life and increase their suffering.

Therapeutic guidelines: palliative care (Palliative Care Expert Group, 2010) outlines the clinical assessment and therapeutic management of symptoms frequently experienced by people receiving a palliative approach. Issues covered include pain, symptom control and fatigue.

Although a medical professional will provide medical information and administer pain relief, it may be your job to assess the person for pain and report the results appropriately. Make sure all team members know that they must inform people at their initial assessment that pain relief is an important part of their care, and that they know to respond quickly to reports of pain. They must also ask people on initial assessment and in regular assessments about the presence, quality and intensity of pain. They should collaborate with you, the person and other palliative care providers to set a goal for pain relief and implement a plan to achieve it.

The adverse effects of pain

Here is a list of adverse effects that may be experienced by your person if they do not get adequate pain relief.

Experiencing pain may make the person:

- less able to function feel a loss of control
- tired and lethargic
- lose their appetite or be nauseous
- unable to sleep or have disrupted sleep
- experience less enjoyment and more anxiety
- be depressed, anxious or unable to concentrate on anything else
- limit contact with family, carers and friends
- less able to enjoy affection
- have a changed appearance
- feel they are a burden to their family and carers
- suffer more
- want to die.

Identify and assess pain

Support workers must monitor their people closely to identify whether they are experiencing any pain or other symptoms. As workers see people daily, they are in a good position to observe, assess and monitor pain levels. Remain familiar with the 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. Providing accurate, current and clear information about a person's pain is an essential and important part of work in a palliative environment. Pain may be either acute or chronic, as described in more detail below.

Acute pain

Acute pain:

- is due to acute injury or illness
- may last days or weeks, but has a predictable and limited duration
- has obvious clinical signs; for example, increased blood pressure, increased heart rate, sweating, pale skin
- may make a person anxious and distressed
- may cause the person to be inactive until they recover
- may require the person to temporarily use analgesics.

Chronic pain

Chronic pain:

- is caused by different medical conditions including (but not limited to) diabetes, arthritis and cancer
- has a gradual onset and becomes progressively worse
- often has no characteristic signs or indications of the disorder or disease
- may cause the person to appear depressed, withdrawn and lethargic; they may also be distressed and call out
- requires the person's underlying disease to be treated and the regular use of analgesics.

Determine whether a person is in pain

For a person receiving palliative care, 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 in palliative care suffer pain; however, pain and pain management are major factors for many people with life-limiting illnesses.

A person's perception of pain may be influenced by their mood, past pain experiences, and their social and physical situation. Know your person, and understand their pain management and medication history, including past interventions and responses, as well as their present pain management regimen and its effectiveness. This information is in the care plan and may also be provided by your supervisor or manager. Ensure you know how to interpret any medical words to help you be prepared to recognise any pain you may observe.

Monitor and identify the symptoms a person is experiencing

Sometimes it is easy to observe that a person is in 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. People may experience pain only at the end of the day or after they have taken medication. Always record these observations, especially as people may not always tell you if they are in pain. You need to identify the following nine things about the person's pain.

The site of the pain

The person may point to where the pain is or they may be clutching the area or part that is painful.

The quality of the pain

This refers to words the person uses to describe their pain, such as sharp, burning, stinging or stabbing. The person may also use words to describe their reaction to the pain, such as 'intolerable', 'unbearable', 'annoying' or 'uncomfortable'.

The intensity of the pain

This is a subjective measurement. Pain severity is usually measured using a numerical rating scale, a verbal rating scale and a visual analogue scale. A numerical rating scale is numbered from 1 to 10, where 10 is the worst pain and 1 is virtually no pain. A verbal rating scale uses words such as 'mild', 'moderate' or 'severe' to describe pain. Visual analogue scales are a simple line (similar to a small ruler) with numbers or words attached; the person moves the slide to match their pain severity.

The onset, duration and pattern of the pain

When does the pain start; for example, after they have eaten or exercised, at night, in the morning? Or is there no particular pattern?

The behaviour of the person

Some people may show pain visibly while others may not exhibit any outward signs.

What the person does to alleviate the pain

Watch to see whether they move about constantly, groan or ask for medication.

Effect of the pain

Is the pain making the person nauseous, tired, depressed or withdrawn?

Likely cause of the pain

You can refer to the person's care plan, the care notes from the previous shift or ask the carer; however, it is up to a health professional to make a judgment.

Impact of the pain

How does the pain impact all aspects of the person's daily function?

Ask the person to describe the pain

To better understand the pain the 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.

If the person has difficulty communicating, use pictures or a scale to determine their pain. You can also use a frame of reference; for example, a rating of three may mean the person is able to watch television for an hour without noticing the pain, but a rating of seven means they can only concentrate for a short time before being distracted by the pain. You may also require the services of an interpreter. Some organisations have brochures you can provide to people, written in languages other than English, that describe the pain and what can be done to manage it. Be familiar with the type of resources available to you. Here are some examples of questions you could ask people to get more information about their pain.

Questions that may help people to describe their pain

- Where is the pain located?
- Does it spread from one area to another or is it only in the one place?
- Describe how the pain feels; for example, 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?
- What makes the pain better or worse; for example, does getting out of bed make the pain worse?

Listen to what the person says about their pain

Always listen carefully to how a person describes their pain; for example, they may use words such as ‘intolerable’, ‘unbearable’ or ‘annoying’. Some people say they are not in pain, even though their behaviour suggests they are. If this is the case, try using different words such as ‘discomfort’ or ‘uncomfortable’.

Explain to the person that they should not wait until the pain is severe or intense before mentioning it, as delay may make it more difficult to control. Follow up immediately if a person says they are in pain by notifying your supervisor or another member of the care team. Here are some examples of the types of questions you could ask the person.

Questions about person’s perception of their pain

- What do you think caused your pain?
- Why do you think the pain started when it did?
- What effect does your pain have on you?
- What are the most important results you hope to receive from the treatment?
- What do you fear most about your pain?

Identify any changes in the pain

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

Pain intensity and pain relief should be assessed and reassessed at regular intervals. This information is then used to determine the appropriate therapeutic intervention. Reports of inadequate pain control should result in reassessment and possible revision of the person's pain management plan until pain is well controlled.

Talk to family members and/or carers

The person's family and/or carers 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. It is always best to gather a wide range of information in order to manage their pain as effectively as possible. Different people may require different pain-assessment techniques; for example, to monitor a person with dementia you need to collect observations from people such as family members and carers. Important symptoms and aspects of the pain assessment of people with dementia are listed below.

Changes in behaviour

- The person being more confused, refusing to eat or altering their usual behavioural patterns

Vocalisations

- Whimpering, groaning or crying

Facial expressions

- Looking tense or frightened, frowning or grimacing

Changes in physiological responses

- More rapid pulse or a change in blood pressure (may not occur with chronic pain)

Observations of family members or carers

- Ask people who know the person well, such as family members and/or carers, to identify changes.

Responses to a dose of analgesics

- Monitor the person's response to analgesics to determine whether they are having an effect.

Example

Assess and report the person's need for pain and symptom relief in line with care plan

Care notes

Client name:	Max Phillips
Date of birth :	6 September 1946
Date:	20 December 2016
Time:	11.30pm

Observations

Behaviour:	Max looks pale and weak. He is also is stressed, anxious, suffering from mental anguish (depression) and can't sleep. Has identified feeling nauseous, and has lost his appetite, but can drink liquids. Max is dehydrated as he has been vomiting.
Level of pain/ intensity:	Acute (8/10)
Location of pain:	Abdominal area

Actions

- GP notified and will be in to review Max before lunch.
- 4 x 24 hourly observations.
- Food and fluids to be withheld till after review.
- GP phone order for 10 mg of morphine to be given immediately.
- Max to remain resting in bed until after review.
- Next of kin have been notified.

Practice task 18

1. Explain what ‘intensity’ is in relation to pain and describe how it is measured.

2. List two questions a support worker might ask to assess if the person is in pain.

3. Why should a support worker constantly monitor a person’s behaviour?

Click to complete Practice task 18

4C Provide pain and symptom relief in line with role and requirements

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. Family members and carers become less distressed if they can see their loved one is being supported in this way.

To be an effective part of the palliative care team, all members should:

- have pain assessment skills
- know current therapeutic approaches
- understand the role of opioid treatment
- know how adverse effects are managed
- know their responsibilities and level of authority.

Legislation, organisational policies and procedures

Be familiar with the legislation relating to pain relief and administering medication in your state or territory. There are restrictions on who can administer opioid medication, such as morphine. This and certain other types of pain relief can only be delivered by an authorised member of the palliative care team; for example, a Division 1 registered nurse or doctor. Other pain treatment therapies may also have to be administered by trained, qualified or approved staff.

Always follow the organisation's pain management policies and procedures that determine your role and responsibilities. Pain management directives are recorded in the person's care plan, including conventional medical treatments and complementary and alternative treatments. The organisation's policies specify who can and cannot administer the medication, where the medication is located and how it should be stored according to state and territory legislation.

As a supervisor or coordinator, you must know which team members are responsible for administering pain relief using both conventional and alternative therapies, and the types of comfort a support worker or carer can provide.

Strategies to maximise comfort

Strategies to maximise comfort should be implemented in response to the person's needs or experience of pain. Assessment of the person is essential, along with their input as to what level of pain and discomfort they are experiencing. Observation is a vital tool for you as a support worker to assess whether a particular activity causes discomfort for the person. Listening to the person describe their experience is helpful, and gaining information from family members and/or carers about their perceptions of the person's pain can all help give an accurate picture of what the person is experiencing. There are some formal charting tools that can be implemented to assess pain and comfort levels. These can be used with all people as some charts have pictorial elements to assess pain and discomfort levels.

It is also useful to discuss with the person what they have found helpful in the past. Some examples of pain relief and comfort measures that can be utilised for the person include:

- positioning
- administering of opioid medication
- supplementary oxygen
- heat and cold pack
- aromatherapy
- meditation
- physiotherapy
- specialised equipment
- increased rest times.

The goals of pain relief provision

The following are goals of providing relief to those experiencing pain.

The goals of providing pain relief
Experience a consistent level of pain relief
Be comfortable while performing activities of daily living
Be able to comfortably take deep breaths
Be able to sleep for a minimum of two hours at a time
Not be overly sedated
Experience minimal side effects (constipation, nausea, vomiting or itching)

Pain relief in line with staff role

People who make up the palliative care team hold different roles in the management of a person's pain and comfort. Often different members of the palliative care team have different backgrounds, knowledge and roles. By working together as a team you can achieve the best pain management and comfort for the person. An example of this is the prescription of stronger analgesic by the doctor in preparation of certain activities such as wound care or physical therapy. This relies on each member of the team having a good knowledge of the pain medication and strategy. Usually after medication is administered there is a required length of time till the person feels the effect of the medication, just like going to the dentist and having the local anaesthetic applied before the commencement of treatment. The timing of procedures is dependent of each member of the team completing their work tasks and working together.

A support worker is the person who sees the person undertaking activities of daily living and usually spends more time with the person and their family and/or carers. They are required to observe the person, and record and report any instances where the pain relief strategy is not addressing the needs of the person. In some instances complementary relief measures may be initiated in conjunction with traditional medication to achieve a better level of comfort for the person.

Example

Record interventions in line with role

Stephen is on night duty, doing his first round of the people he is looking after. He has had a handover from Kim, the supervisor in charge of the evening shift, that there have been no problems noted with residents. All appears to have settled well for the night.

Stephen can hear noises coming from Joe's room. Stephen finds Joe curled up with his arms around his knees, slowly rocking from side to side in the bed and groaning into his pillow.

Stephen notes that Joe's skin is clammy and pale. Stephen reassures Joe and notifies the supervisor immediately of the situation. Alana, the night supervisor, comes and looks at the medication chart and notifies the doctor of the pain Joe is experiencing. Both Stephen and Alana document their assessment of Joe's condition in the case files. The doctor comes to review Joe's situation and adjusts the medication order for his pain.

Practice task 19

1. Identify three strategies to assist the person with pain relief and comfort.

2. Identify two goals of pain relief care provision.

3. Which members of the palliative care team can administer pain medication? Explain your response, providing examples of restrictions.

Click to complete Practice task 19

4D Provide appropriate information about the use of pain-relieving medication and treatments in consultation

An important responsibility of all support workers is to provide information about the use of pain-relieving medication and other treatments to staff, individuals and their family members and/or carers. People often have misconceptions about pain treatment, which may cause them to be concerned about the treatment being administered. For example, people sometimes think a person will become addicted to a medication or fear the adverse effects of a medication. Language differences and cultural issues may also impact the way people think about pain-relieving medication.

The person, family members and staff members should feel confident that they can ask questions and seek clarification about analgesics and additional therapies that are given to the person. They should also feel free to provide feedback if they feel a medication is having a negative effect such as making the person drowsy or nauseous.

Support workers should be aware of types of queries they may receive about treatment in general and about specific treatments, knowing that if they can't answer a particular query, they should refer it to the coordinator or a health professional.

Common ideas and attitudes about pain relief

Misconceptions about pain-relieving medication should be dealt with as quickly as possible to ensure everyone understands why a treatment is being given and the impact of any side effects. Here are some commonly held ideas and attitudes about pain-relieving medication and some information about each.

Pain relief should only be given for pain that is present

- Seek clarification about this from a doctor, as some pain relief may be used as a preventative measure.

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

- Pain is an individual response to a circumstance. Health professionals can help manage pain based on a person's description of that pain.

People should not receive pain relief until cause is determined

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

The person may become addicted to pain relief medication

- Drug addiction is often associated with people misusing drugs. However, addiction is not an issue when opioids are used correctly to relieve pain. A doctor can discuss any concerns a person, carer or family member may have.

Strong analgesics may shorten a person's life

- This is not necessarily true. Analgesics may be used as part of a pain management strategy. Their impact and effectiveness should be monitored and reviewed. Discuss any concerns with a doctor.

Pain management alone is not palliative care

- It is true that pain management alone does not constitute palliative care. Palliative care enhances the person's quality of life by treating pain and physical, psychological, social and spiritual problems collectively. A nurse or palliative care team leader can provide more detailed information.

The person may become too drowsy to communicate

- 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.

Use of opioids

As with any medication, opioids have side effects. With careful planning, these unwanted effects can be prevented or relieved. It may be the responsibility of the care team to inform the person and family members of these side effects in consultation with a health professional.

Ask your supervisor or manager to explain anything you are unsure about so you can provide the person and their family and/or carers with accurate information regarding the use of pain-relieving medication. Find out what information you may pass on to people and families, and what information should be provided by a professional health care worker. Always refer to your organisation's policies and procedures or refer the query to the appropriate person.

Here are some of the most common side effects related to the use of opioids.

Side effects of opioids

- Constipation (most common)
- Nausea and vomiting (occurs initially and is usually easily controlled)
- Daytime drowsiness and mental cloudiness (usually resolves within days)
- A dry mouth
- Urinary retention (more common in older people)
- Confusion and hallucinations (rare but may occur in older people)
- Sleep disturbances

Misconceptions about the use of opioids

There are many misconceptions regarding the use of opioids. Here are some details of such misconceptions, along with the facts to correct them

There are time limits for usage

- Misconception: there is a limit to the length of time a person can use morphine.
- Fact: 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 begun at a low dose and continued until the pain is relieved with minimal side effects. There is no limit to how long a person can use morphine, but additional medication may be required depending on the type of pain.

Use it now, and it's ineffective later

- Misconception: if the person uses an opioid now, it'll be ineffective when they really need it.
- Fact: 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, the drug should be used.

The person will become an addict

- Misconception: the person will become addicted.
- Fact: addiction is not an issue when opioids are correctly prescribed and used under the supervision of qualified health care workers, to relieve pain. Drug addiction is associated with people who misuse drugs.

Use of opioids means death is imminent

- Misconception: morphine is only used when death is imminent.
- Fact: 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

Provide appropriate information about the use of pain-relieving medication and treatments in consultation

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 concern that Katie seems to be experiencing severe pain as she regularly moans and appears restless. 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.

Practice task 20

1. List three possible side effects of opioid use for pain relief.

2. Is there a limit to how long a person can use? Explain your answer.

3. Explain the aim of pain relief for a person accessing services in palliative care.

Click to complete Practice task 20

4E Observe, report, communicate and document effectiveness of interventions for pain and symptom relief

One of your roles in pain management is to observe the person to determine if the pain management strategies used are effective. This means regularly reviewing the person's appearance and comfort, and documenting when the pain occurs and how severe it is. The health professional can then take your observations into consideration when making decisions about the person's treatment.

Support workers are in the perfect position to monitor a person's pain, especially if they have built a relationship with the person that fosters open, honest discussion of how the person feels. In addition to asking the person about the location, quality and severity of the pain, you can provide other information to the team that may show that the pain relief delivered is effective, that the person is still experiencing pain at the same level and/or that the pain appears to be increasing.

Evaluate the effectiveness of interventions

There may be side effects from the medication you give a person 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. Remember, pain is a personal experience and factors such as insomnia, fatigue, anxiety, depression, fear or anger can increase or decrease pain tolerance. They may also influence how a person reacts to the medication.

You must know what to look for when regularly monitoring the person to evaluate their pain management strategies. This includes taking note of the aspects covered below.

The person's appearance

Observe whether they look pale, if their face shows signs of pain such as screwing up their eyes or biting their lips, if they look scared or if they look peaceful.

The person's posture

Notice if they are curled up, slumped over or clutching a specific part of their body, or if they look relaxed and comfortable.

The feel of the person's skin

Test whether the person's skin is hot, cold, dry, clammy or normal for their condition.

The person's behaviour

Observe whether the person is moaning, crying or calm; if they are not sleeping; if they are refusing to eat or drink; if they are finding it difficult to communicate; or if they seem confused.

Any unusual smells

Detect any unusual smells in their urine, faeces, vomit, body, breath or coming from bandages.

How the person feels

Note whether they tell you they feel better and are comfortable, if they say their pain is worse or has moved to another area, or if they have a temperature.

Timing of pain relief

Observe how long the pain relief is effective, particularly if the person asks for more pain relief before the next dose is due.

Practice task 21

1. List three observations a support worker can make of the person to assess whether they are experiencing pain.

2. List two side effects of medication that you might observe.

3. Identify the support worker's role in pain management and give one example of an action they undertake

Click to complete Practice task 21

4F Communicate and document the ineffectiveness of interventions

As well as informing the medical team of symptom relief that is working, you must also observe and report on interventions that are ineffective. If an intervention does not bring relief, notify your supervisor or manager immediately, either by phone or in person.

These observations help to identify how effective the pain-relief strategies are and what you should report to the medical team. The observations may, for instance, conclude that the medication dose was too low, that the assessment was not thorough enough, that the person may not have taken the medication or that they may have an adverse reaction to it.

Remember to be aware of the range of side effects a person may encounter, as these can help determine whether the intervention was appropriate. Make sure any side effects are clearly recorded and the information is passed on to the healthcare team.

Another way to establish the ineffectiveness of interventions is to have follow-up meetings with supervisors and other health professionals to share information regarding a person's changing needs and preferences.

Document and report the effectiveness of interventions

As discussed previously, you must accurately document all observations as soon as you make them. In some cases, you may need to notify your supervisor or manager either by phone or in person, especially if you believe the person's condition has worsened.

It is important to note that in some cases, a person's appearance and behaviour may be a result of their condition and not the treatment; however, you should document everything you notice to allow health care professionals to make a judgment.

Follow your organisation's procedures for documenting observations, such as in care notes, assessment charts or in a formal report presented at a team debriefing.

Example

Document a person's pain

Care plan

Client name: Joe Ricardo	Date of birth: 4 October 1920
Date: 26 September 2016	Time: 12.05 am

Observations

Client behaviour:	Joe looks relaxed. Skin is normal temperature. Says the burning pain has stopped and he feels calmer.
Level of pain:	None
Location of pain:	Pain had been located in upper body, stomach area.
Intensity of pain:	0/10
Assessment type:	Question-based/verbal rating

Action

Care worker – to date, the cold packs applied, the massage and the morphine have been effective. Continue to assess each shift.

Nurse – continue to administer morphine regularly via drip (at the appropriate rate), plus sleeping tablet medication (temazepam) as appropriate.

Worker name: Bruno Agulera	Signature: Bruno Agulera

Practice task 22

1. Why does the support worker need to observe and document the pain management strategies that are used?

2. List two observations you would make of the person's skin to assess if the pain medication strategies were effective.

3. Explain what else the support worker needs to assess when evaluating the effectiveness of pain medication.

Click to complete Practice task 22

Summary

1. Care plan directives detail the type of pain that a person with a life-limiting condition may experience and provide strategies for managing that pain.
2. Pain-relieving measures include pharmacological medication as well as complementary and alternative therapies. Complementary therapies may harmonise with a person’s culturally specific preferences for pain relief.
3. A person’s comfort must be regularly reviewed, assessed, reported and documented. Support workers who see people that they care for using a palliative approach on a daily basis are well placed to observe, assess and monitor pain levels.
4. Pain observations must be accurately recorded and reported to allow health professionals to make a judgment about pain relief and management.
5. Organisational policy and procedure determines who may deliver pain relief. All members of the palliative care team should understand their role and responsibilities and follow pain relief directives in the care plan.
6. Support workers should be well informed about pain relief and able to provide information or referral for individuals, carers, families and other staff members. Seek advice from appropriate personnel when unsure of pain management issues.
7. Observation of the person to determine the effectiveness of pain management strategies requires regular review of the person’s appearance and comfort, as well as documenting pain location and severity. These observations will also assist in deciding if interventions are ineffective.

Learning checkpoint 4

Take action to alleviate pain and other end-of-life symptoms

This learning checkpoint allows you to review your skills and knowledge in taking action to alleviate pain and other end-of-life symptoms

Part A

1. What are four questions that you would ask a person regarding the pain they are experiencing?

2. Besides medication, identify three other pain management techniques that can be used.

3. List three observations you might take to assess the effectiveness of the pain medication.

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. Molly is aware that Katie's advance care directives have stated that she does not want to be fed artificially, that she would like enough pain medication to control her pain and does not want to be resuscitated or given life sustaining measures such as surgery or antibiotics.

At the latest meeting Molly expresses her concern that Katie seems to be experiencing severe pain as she regularly moans and appears restless. 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 is very sleepy and is no longer taking food and fluids orally except for small sips of water. Katie is no longer moaning and appears to be calm. Katie's doctor advises that Katie's death is likely to occur in the next couple of days.

1. In this case, it important to give food and fluids to Katie in the last days of her life? Explain your answer.

2. Explain the pain management that was provided for Katie.

3. In the above scenario, who should Val consult with for information regarding pain relief for Katie? In the final days what information does the family require from Val regarding the pain medication?

4. Why is it important to document Katie's appearance and behaviour even in the last days of her life?

Topic 5

In this topic you will learn how to:

- **5A** **Respect the person's preferences including cultural and spiritual wishes**
- **5B** **Maintain the dignity of the person when planning end-of-life care and immediately following death**
- **5C** **Observe and report signs of a person's imminent death and/or deterioration and report appropriately**
- **5D** **Provide a supportive environment for the person and their family and/or carers involved at end-of-life**
- **5E** **Ensure that decisions are reviewed regularly, communicated and recorded**
- **5F** **Identify the emotional needs of people affected when a death occurs and provide necessary support or referrals**
- **5G** **Prepare the person, family, other staff and self for any distressing end-of-life events**

Contribute to the development and implementation of end-of-life care strategies

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. If you are a palliative care coordinator it may be part of your role to contribute to the development and implementation of a person's end-of-life plan, so you must understand the type of care that should be provided at this time.

5A Respect the person's preferences including cultural and spiritual wishes

Meeting people'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. When a person enters the final stages of their life, an end-of-life plan should be prepared to take into account their current wishes and needs. These may have changed significantly since the original or subsequent care plans were written, and may continue to change. The care team must make regular assessments of appropriate treatment and document them to ensure the person's current needs are known.

If a person has advance care directives, these must be incorporated into their end-of-life plan. If there are no advance care directives, this is the time to discuss end-of-life issues with the person and their family members to identify what the person wants. An end-of-life plan is generally more about providing comfort and ensuring the person's right to die with dignity rather than about medical interventions. An end of life care plan should uphold the basic human rights.

Respect a person's wishes

Meeting a person's wishes is particularly important as people enter the end-of-life phase. At this stage, when a terminally ill person's condition can change rapidly, the team should review the care plan with family (including biological members, those related by marriage or contract, significant others, friends, neighbours or advocates) and/or carers to identify the person's wishes and to determine if the wishes are current. It is important that any new instructions are clearly documented in the end-of-life plan.

In some instances, services may need to be modified; for example, if a person has been taking part in social activities but is unable to do so anymore, the team should determine ways social interaction can still take place.

Gather as much information as possible from assessments, medical records, care notes, team debriefings, case conferences and family meetings to ensure all information is up to date. Confirm the person's wishes and enter the updated information into the person's end-of-life care plan. The person or their advocate may have to sign the document. Ensure the information is accessible to all members of the care team.

Examples of changes to a person's wishes

When preparing an end-of-life plan, always be sure to take into account the person's current wishes and needs. These may have changed significantly since the previous care plans were written, and may continue to change. Always listen carefully to the person as they express their changing wishes, and document them to ensure the person's current needs are known.

Examples of changes a person may wish to make include:

- changing their mind about the type of treatment they want
- being in pain and requesting more or different pain relief
- deciding they don't want visitors except family members
- deciding to go home to die
- wanting to change their will.

Human rights at end-of-life

A palliative approach has human rights built into its aim and philosophy. The values of palliative care are to ensure that a person's pain and suffering are alleviated. It is used when there is no curative treatment for the disease. It is not used to hasten or postpone death but to bring together the psychological and spiritual aspects of care. It offers a support system to help the person live as well as possible until death. All people have the right to palliative care.

Here are some of the human rights that are enshrined in the palliative care model:

- The right to be treated equally
- The right to be treated fairly when the person can no longer communicate
- The right to be shown respect for choices already made in an advance care directive

The Australian Government supports and respects many of the Universal Declaration of Human Rights developed after the Second World War by the United Nations. The declaration recognises the inherent dignity and the equal and inalienable rights of all people.

Freedom of religion and belief in Australia is recognised as a human right under Article 18 of the International Covenant on Civil and Political Rights.

Document a person's spiritual and cultural needs

People nearing death may place greater significance on their spiritual, religious and cultural values and may change their wishes accordingly.

Spiritual and cultural needs of people may include:

- requesting more visits from their religious representative
- changing their mind about cremation or burial
- refusing a treatment in accordance with their religious beliefs
- requesting to see a pastoral care worker regularly
- asking to take part in religious or cultural rituals and ceremonies
- wanting to return home to die surrounded by friends and family
- wishing to be spoken to in their native language, instead of English.

Example

Care notes to document change in person's wishes

The family of Yusuf, a 65-year-old man with terminal cancer, are offered counselling to help them deal with their distress at finding out he only has weeks to live. The family are also assigned a care coordinator to work very closely with them, comfort them, listen to their needs and keep them up to date with Yusuf's care. An interpreter is assigned to help the family understand the procedures and treatments that are being provided.

Because Yusuf and his family are Muslim, there are certain cultural rituals that must be followed when Yusuf dies. Through the interpreter they explain that Yusuf's body should ideally only be touched by Muslims of the same sex and that his body should be moved to face Mecca. Also, Yusuf's parents ask that the hospital not discuss their son's illness with anyone else. They don't want anybody, especially other community members, to know about their problems.

The palliative care coordinator organises for pamphlets about Islam to be given to all those working with Yusuf.

Practice task 23

1. List two rights a person accessing palliative care has.

2. What should a palliative care worker do if the person's condition changes rapidly?

3. List two things a person at end-of-life might change in their care plan.

Click to complete Practice task 23

5B Maintain the dignity of the person when planning end-of-life care and immediately following death

Promoting a person's sense of dignity is central to a palliative approach. When the person enters the final stages of life, their need for privacy, to retain their self-esteem and feel in control is crucial; this may vary for different people according to their condition and awareness of the situation.

People may hold different views about what dignity means and, in terms of a progressive illness or the ageing process, the meaning of dignity may change over time. The notion of dignity may be influenced by the nature of the person's illness, as well as by their culture. For example, most people like to retain a sense of privacy 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 health care team. For some people, this represents a loss of dignity.

Identify people's perceptions of dignity

Because individual perceptions of dignity vary, the best way to understand what dignity means to an individual is to ask each person and their family and/or carers to identify the most important factors for enhancing and maintaining their dignity during end-of-life care.

Factors that may contribute to a person's sense of dignity include:

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

Strategies to maintain dignity

Enhancing the person's dignity must be maintained both during end-of-life care and immediately following death. Specific strategies and considerations are shown below for each of these stages in the person's care.

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 following:

- What is the most appropriate clothing for the person: day clothes or bed attire?
- Would the person prefer to remain in their bed or be transferred to a chair?
- Would it help the person if they are massaged with lightly scented oil to remove hospital smells?
- Should the number of visitors be limited to only those the person wants to see?
- Should mirrors be removed from the room?

Following death

Each state and territory has legal requirements to follow when the death of a person occurs, including notification and certification of death. You need to understand what the requirements are of the organisation you work for. Each task must be done sensitively and with respect for the person so their dignity is retained even after death.

After-death procedures may include:

- removing any equipment from the body, such as tubes
- closing the person's eyes and placing their arms by their side
- maintaining the person's usual facial features; for example, replacing dentures
- gently washing the body
- providing the person's family and the palliative care team with a chance to say their farewells before the person's body is removed
- provide a formal debriefing for the palliative care team.

Example

Maintain the dignity of the person immediately following death

When preparing directives for end of life care, Miriam had explained that she and her family would like to be able to observe some of the rituals of their Jewish faith.

As her condition deteriorated, care staff were expecting family members and friends to gather, and they accommodated this. A rabbi was called to offer comfort and to pray for Miriam.

After death her eyes were closed and her body was covered. Candles were lit and members of the family were allowed to stay with the body until a funeral home collected it. In Jewish law, being around a dead body is considered to cause uncleanliness. The washing of the body and preparations for burial were be carried out by a special group of volunteers from the Jewish community.

Practice task 24

1. Identify three ways a support worker can maintain the person's dignity after death.

2. Explain two practical comfort measures that a support worker can implement to ensure the person's comfort, dignity and quality of care are maintained.

3. Identify two factors that contribute to a person's sense of dignity.

Click to complete Practice task 24

5C Observe and report signs of a person's imminent death and/or deterioration

End-of-life care refers to the phase where death may be expected to occur within hours or days. An important aspect of the worker's role is to recognise when the terminal phase has commenced, along with the signs of deterioration and imminent death. Part of your role may be to instruct and advise new team members in how to observe and report these signs; the crucial thing is to respond to signs quickly.

Changes to the person's body

There is no single description of an individual's last hours of life, so the palliative care team should be alert for various signs and the person's reactions to their impending death. Death may come sooner or later than anticipated. In many cases the person will be bed-bound and require frequent intervention.

Be alert and always notify the appropriate person, such as the doctor or nurse, if you believe the person's condition is worsening. Make sure you know who you need to contact and that all members of the palliative team are informed of the changes in the person. Immediately before death (within hours to days) several of the symptoms and signs listed below may be present.

Changes indicating that death is approaching

- Loss of appetite
- Profound weakness
- Difficulty in swallowing
- Dry mouth
- Weight loss
- Day-to-day deterioration that is not reversible

Signs of deterioration and imminent death

At some point the severity and number of symptoms a person displays may increase, as their condition rapidly deteriorates. Remember that physical changes may occur very rapidly and the symptoms and reactions to impending death may vary. Signs of deterioration and imminent death include those shown below. This list may be beneficial to carers or family members who ask for an explanation of the signs of death. However, not all the signs should be discussed with them, only those that seem appropriate to the circumstances.

Common signs of imminent death:

- Shutdown of the person’s external body functions
- Changes in breathing patterns, ranging from slow to irregular to rapid
- Decrease in urine output
- Drowsiness or a reduced level of response to verbal and/or physical stimuli
- Retained upper-airway secretions
- Semi-consciousness, with lapses into unconsciousness
- Heart failure or the absence of a pulse, and pupils fixed and dilated
- Seeing visions of friends or family who have already died
- Uncharacteristic or recent restlessness and agitation (this is referred to as terminal restlessness)
- Becoming detached and unresponsive and letting go

What you should do

If any signs or symptoms of impending death are identified, follow your organisation’s procedures. This may mean immediately informing the palliative care nurse 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, although they have the right to remain present. Be aware that family members may require more support at this time and you must be able to provide this. If family members are not present it may be your responsibility to notify them.

For a person being cared for at home, a contingency plan for sudden change is important. This may include who to notify if the person is distressed and what to do when the person dies.

Discuss the implications of calling an ambulance with family members and carers, as in some jurisdictions the person may be transported to hospital. To prevent inappropriate attempts at resuscitation, family members and carers should have a letter from a doctor confirming the person’s resuscitation status. This and any other written advance care directives should be kept in a prominent place to give to the ambulance team, if necessary.

Care for family and friends

Many people have never had direct experience of a death and may need time just to ask questions and be reassured about what may happen next. Ensure a doctor is available to regularly check on the dying person, their family members and carers. An expected death is not an emergency: family members and/or carers can have quiet time together and care for the person as they wish, prior to calling the doctor or palliative care service.

When death is imminent and reversible causes have been excluded, the person's comfort should remain the ultimate goal.

Example

Observe signs of a person's imminent death and report appropriately

Rhonda is a care worker in an aged care home. Penny is admitted there after being discharged from hospital. An assessment prior to her discharge identified a range of end-of-life symptoms including:

- loss of appetite
- profound weakness
- changes in breathing patterns
- mental anguish
- blood pooling along the skin
- day-to-day deterioration.

Penny is 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 watches, Penny lapses into unconsciousness. 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.

Practice task 25

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?

3. What is the ultimate goal of palliative care when death is imminent and reversible causes have been excluded?

Click to complete Practice task 25

5D Provide a supportive environment for the person and their family and/or carers involved at end-of-life

A supportive environment is one that is comfortable, calm and non-threatening, where everything is done to make conditions easier. Information must be regularly shared between all members of the palliative care team including the person, their family members and/or carers; people's concerns and fears must be listened to and their contributions valued. The emphasis at this stage of a person's life is on ensuring their comfort; a palliative approach does not mean withdrawing care.

At this stage, coordinators should listen to issues, act on queries promptly, provide what the person asks for (within organisational procedures and legal/ethical considerations) and refer issues to the appropriate person if necessary.

Coordinators should understand the stages of grief and loss and know what to do immediately following a person's death. After some time has elapsed, perhaps suggest bereavement support, ensure family members and others understand the process of meeting the person's wishes regarding their funeral, and provide as much support as possible in accordance with organisational policy and procedures.

Support strategies for the person

There are specific things you can do to provide support for a person who is dying. To support people at this time, their environment should be appropriate. Their rooms should be calm and you may want to play quiet music or reduce the number of visitors.

The person may want your support to:

- know when death is near and understand what can be expected
- maintain a sense of control and have their wishes upheld
- have control over pain relief and other symptom control
- have a choice as to where their death occurs (hospital, home or aged care facility)
- access spiritual and emotional support
- be afforded dignity and privacy
- have control over who is present and who shares their final moments
- issue advance care directives to ensure their wishes are respected
- have time to say their goodbyes
- not have their life inappropriately prolonged.

Use effective communication skills

Listening to, recognising and responding to a person's emotions is an essential skill for all palliative care team members. To respond effectively, you must be able to communicate well. Here are three tips for effective communication with the person you are supporting.

Listening

When listening to a person, don't interrupt them while they are talking. Let them finish what they are saying before responding.

Paraphrasing

Paraphrase what a person has said using their own words and phrases. This tells the person that you are listening and care, allowing them to confirm, correct or expand your understanding.

Being honest

Answer a person's questions honestly. Questions such as 'Can I see my friend outside of visiting hours?' may require a straightforward answer. You may have to refer other questions to a specialist; for example, 'How long have I got to live?' In this case inform the person that you are unable to answer their question and that you are referring it on to the appropriate person for a response.

Support strategies for family members and carers

Family members and carers play an important role in managing a person's symptoms of distress, communicating with the person and assisting with physical care needs. These people must also be supported physically and emotionally.

To help prepare family members for an impending death, and so they can better cope with the loss, members of the care team should provide a holistic, team-based approach.

It is impossible to predict how a person may respond to the death of someone close to them. Although they may have been caring for the person for a while, they may require additional support as the person's end-of-life draws near. They may struggle to articulate their emotions or feel numb.

Provide emotional support

To provide emotional support, become familiar with the types of emotions and behaviour people may experience at this time; anger, grief, denial, guilt and hopelessness may be expressed. People may become depressed, anxious, confused or appear forgetful or disoriented (in regard to time); they may exhibit changes in mood and behaviour or become more demanding or aggressive. These are all common reactions when dealing with the loss of a loved one; however, as these behaviours may upset or harm others, the care team should have strategies in place to support and manage them.

Family members and carers may have a lot of questions to ask at this time. Anticipate questions, but remember to refer those that are beyond your expertise to specialists.

Ensure that you and your team members have the appropriate skills and knowledge to provide a palliative approach. You may need to provide opportunities to staff to develop effective communication skills.

Example

Provide a supportive environment for the person and their family and/or carers involved at end-of-life

Anisha visits her grandmother Sushila at her aged care facility every Sunday morning. Sushila has advanced dementia and is expected to live only a few months longer. She no longer recognises Anisha and sometimes screams for her to leave her room when she visits.

One Sunday, the support worker, Dora, notices that Anisha looks very upset when she leaves her grandmother's room. Dora asks Anisha if she can help. Anisha responds by telling her how upsetting it is that her grandmother doesn't recognise her anymore. Dora takes Anisha to a quiet area and sits with her.

Anisha says, 'I don't feel like there's anyone to talk to. I can't talk to my mother about this as it upsets her too much and my brothers and sisters are too young to understand.'

Dora waits until Anisha has finished speaking and then suggests that she talk with the bereavement counsellor on staff to help her deal with her feelings about her grandmother. Dora offers Anisha some brochures about the benefits of counselling and says she may like to bring her mother along as well. She also suggests that Anisha visits on Sunday evenings as Sushila is usually more settled and receptive to visitors at this time.

Practice task 26

1. Explain how a support worker should answer questions from a person and their family and/or carers.

2. List three emotions a family member or carer might exhibit after the death of a person.

3. Explain two things a person who is entering the terminal phase of their illness wants from the palliative care team.

Click to complete Practice task 26

5E Ensure that decisions are reviewed regularly, communicated and recorded

Effective communication between members of the palliative care team is crucial, as everyone must understand the person's current situation. At this time, changes may happen quickly that require decisiveness. For example, a person may change their mind about the type of treatment they want, ask you to arrange for a pastoral care worker or decide they don't want to receive visitors anymore. Family and/or carers may also make new observations and decisions during this time.

Part of your job may be to regularly review and assess a person's needs, preferences and instructions and review and assess input from family and/or carers. The information gathered must be documented and passed on to the healthcare team as soon as possible to ensure care remains current and appropriate. This is especially important in an emergency that demands immediate action.

Manage information

Managing information is done in three main ways as shown below: gathering, documenting and communicating.

Gathering information

Changes to a person's care should be determined by the person in consultation with family members and/or carers, advocates and healthcare professionals. Information may be gathered in a variety of ways, such as through weekly assessment documented on the organisation's assessment forms.

Regular face-to-face family conferences may be arranged to discuss the person's situation and needs, or to keep in contact with the individual who speaks on behalf of the person. Information may also be gathered from healthcare professionals at case meetings and from care notes that identify requirements for follow up. Co-workers or family members may also advise of a person's changed preferences.

Documenting information

Information received from the regular review of a person's situation must be formally documented in their care plan. Clear, unambiguous and timely information is essential as the care team may consist of different people based at various locations. Reporting options include:

- the care notes made by carers
- a daily or weekly report
- organisational forms
- formal memos
- communication books.

Communicating information

Your responsibility as a palliative care supervisor or coordinator is to understand any changes in a person's preferences and to make sure you inform everyone involved.

You can do this by:

- updating the person's care plan weekly
- confirming the situation at team briefing sessions
- reading the progress notes from the previous shift to keep up to date with the person's wishes.

If there are new or inexperienced staff in your team, make sure they are aware of the need to constantly monitor and review a person's preferences according to the organisation's policy and procedures.

Example

Ensure decisions are reviewed regularly, communicated and recorded

Here is an example of effectively recorded care notes.

Care notes

Person name: Marjory Bicknell	Date of birth: 3 July 1938
Date: 3 January 2017	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; she is in the 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: Brad Loak

Practice task 27

1. Explain who should be involved in changes to a person's care.

2. Why are regular family conferences held?

3. List three reporting mechanisms that can be used for documentation in palliative care.

Click to complete Practice task 27

5F Identify the emotional needs of people affected when a death occurs and provide necessary support or referrals

A coordinator's role is to recognise the emotional needs of a person's family and/or carers and others accessing the service who may be affected by a person's death, and to support them at this time. While these people won't all have an emotional link with the person who has died, it is a reminder that death happens and that they may soon experience it in their own family.

In an aged care facility or hospice, death is a regular occurrence; however, it may be distressing for other residents to learn of a death, witness the death of the person they share a room with, or witness the reaction of family members.

This can also provide other residents with an insight into how the palliative care team treats all those involved and provide them with the comfort of knowing that they, too, will receive this level of care when they pass away. Some may feel significantly less distressed having shared the experience.

Residents with advanced dementia are also affected by grief and loss even though they may not have the cognitive skills to resolve or make sense of their grief. Be honest with all residents and allow them time to grieve even if they forget the details, as protecting residents from the truth often creates greater confusion.

Common expressions of complex grief

Normal and complex grief reactions usually start out the same way. People experience a wide range of intense emotions including shock, disbelief, sadness, anger and numbness. In normal grief, these reactions start to fade over time. In complex grief, expressions of grief may continue for six months or longer.

People with complex grief have difficulty accepting their loss and getting on with their own lives.

The most distinguishing feature of complex grief is that it is a long-lasting, unresolved grief. It is distressing for the person experiencing it, and is often difficult for those around them, such as family and friends, who may have difficulty understanding why the individual cannot get over their loss and move on with their life.

Complex grief may have a range of negative impacts on an individual's relationships, employment and life in general. An individual who is immersed in sorrow for a long period usually finds it difficult to get on with their everyday life. They may not be able to resume work, carry out basic tasks or maintain relationships. Here is some more detailed information about the characteristics of complex grief.

Common features

Common features of complex grief include:

- long-lasting grief; for example, an individual still grieving intensely months or even years after a death
- problems accepting the death, and sometimes imagining that the person is still alive
- extreme yearning for the deceased person
- intrusive thoughts and images of the deceased person
- numbness and detachment
- ongoing sadness and depression
- an inability to integrate loss into ongoing life
- extreme focus on the loss and reminders of the deceased
- an inability to enjoy life
- difficulty carrying out normal routines
- loneliness and a sense of isolation
- feeling that life has no meaning or purpose
- social withdrawal
- a lack of trust in others
- suicidal ideation.

Developing complex grief

The risk of developing complex grief depends on a range of individual and circumstantial factors. Complex grief may be more common when a person experiences a significant or traumatic loss, such as:

- the death of a child
- a death that is sudden and unexpected
- the death of a life partner
- a traumatic or violent death.

Other factors

Other factors that may increase the likelihood of complex grief occurring include:

- having a history of depression or anxiety disorders
- being very dependent on the deceased person
- having a history of difficulty coping with loss
- having a sense of remorse or guilt over the person’s death.

Depression

For some people, the grief associated with the death of someone they supported may lead to depression. Depression is a serious illness that requires specialist assistance to overcome. It has an impact on both physical and mental health.

Some signs and symptoms of depression are:

- loss of interest in work, hobbies and activities
- irritability and difficulty concentrating
- lack of energy, having difficulty sleeping or sleeping more than usual.

You can access more information about depression at the beyondblue website: http://aspirelr.link/beyondblue

Grief and depression

Grief and depression are often confused because they share a number of similar symptoms, such as deep sadness, loss of appetite and sleep disturbance. The main difference between grief and depression is that with grief these symptoms are present for a relatively short time, whereas with depression they are ongoing.

When experiencing grief, a person's mood tends to fluctuate. Grieving people experience a range of emotions, including positive emotions such as happiness and a sense of hope for the future. When experiencing depression, the feelings of emptiness and despair are constant, as is a loss of self-esteem. Bereaved people may also experience decreased self-esteem, but this is usually transient.

It is common for people to experience sadness and reactive depression after a loss, but if a person's feelings of deep sadness continue and become more pervasive over time, they may be suffering clinical depression. Below are some more details about general differences between grief and depression.

General differences between grief and depression

1. **Signs or symptoms**
   Grief: the signs and symptoms lessen over time
   Depression: the signs and symptoms are ongoing and may bet more pronounced over time
2. **General wellbeing and energy levels**
   Grief: fluctuating energy levels and agitation or restless for a period of time
   Depression: lack of energy and interest in life
3. **Loss**
   Grief: recognised by others
   Depression: often unrecognised
4. **Suicidal ideation**
   Grief: usually does not occur in normal grieving
   Depression: may appear often in thoughts
5. **Family history**
   Grief: not applicable
   Depression: may have family history of depression

6 **Thoughts**

Grief: focus is on the dying person, deceased

Depression: focus on self

7 **Mood**

Grief: fluctuates and can still experience moments of enjoyment in life

Depression: low and has an all-pervading sense of gloom and sadness

8 **Support**

Grief: responds to support and comfort from others

Depression: does not respond to support

9 **Rationalisation**

Grief: relates depressed feelings to loss experienced

Depression: usually does not relate depressed feelings to a particular life event

10 **Self-esteem**

Grief: may experience temporary loss of self-esteem

Depression: ongoing loss of self-esteem

Support strategies and referrals

The palliative care team can help family members and carers by using the following strategies to provide support in each of the 12 areas of responsibility.

Palliative care responsibilities and ways to provide emotional support

1 **Show respect**

Responsibility: Treat each family member and carer with respect and acknowledge their feelings.

How to provide support:

Acknowledge that each family member and carer is different and that their individual approach to a situation may therefore differ.

Recognise that family members and carers have already contributed significantly to the person's wellbeing.

2 **Provide opportunities for reflection**

Responsibility: Provide opportunities for family members and carers to share feelings, reflect and remember.

How to provide support:

Arrange regular meetings with family members.

3 **Keep family informed**

Responsibility: Keep the family informed.

How to provide support:

Keep the family and carers informed of changes to the person's condition. Ensure all carers have a clear understanding of the person's condition.

Provide information about grief and loss, and bereavement support groups so they can access these services if necessary.

4

Listen to issues

Responsibility: Listen to issues the family members or carers have.

How to provide support:

Respond to any dissatisfaction they express about the care being given. This may reduce the complexity of the grief and guilt experienced by family members and carers. If a family member complains about a worker, listen carefully, record their views, and assure them you will follow it up with the appropriate person.

5

Answer questions

Responsibility: Answer questions honestly and act on queries promptly.

How to provide support:

Provide clear, simple and honest information about what is happening, why it is happening and what is likely to happen next. If information about counselling services is requested, follow up immediately. Provide brochures and contact details of relevant services.

6

Encourage care-giving

Responsibility: Encourage family members to continue their care-giving role.

How to provide support:

Provide family members and carers with the opportunities and choice to be involved in the care of their loved one. Encourage an active and equal role in the care planning process.

Suggest ways the family member can support the dying person by touching them, listening to them or playing their favourite music.

7

Make arrangements with health professionals

Responsibility: Make arrangements with health care professionals.

How to provide support:

Suggest counselling services if appropriate. Refer family members and carers to pastoral care workers and social workers when appropriate.

Identify family members and carers who would benefit from support group meetings.

8

Make referrals

Responsibility: Refer issues to the appropriate person if you don’t have the necessary skills and knowledge.

How to provide support:

If a family member asks you to increase a person’s pain medication, record this in the care notes and notify the palliative care nurse or a doctor.

9

Provide privacy

Responsibility: Provide privacy.

How to provide support:

Provide as much privacy as possible at this time; perhaps offer a private room for taking visitors.

10

Provide respite

Responsibility: Provide respite for carers and arrange bereavement support.

How to provide support:

Offer and arrange respite services if carers or family members appear stressed or fatigued. Put family members in contact with the relevant bereavement services.

11

Keep it simple

Responsibility: Make processes and procedures as simple as possible.

How to provide support:

Make the family's access to the person easy; provide information about 24-hour visiting.

Help family members and carers to complete any necessary paperwork.

12

Document changes

Responsibility: Keep progress notes up to date.

How to provide support:

Document all observations and comments made by family members at this time.

Example

Identify the emotional needs of people affected when a death occurs and provide necessary support or referrals

Kim is a local member of the community who volunteers at the local aged care facility. Kim has been visiting and spending time with John for the last three years. The relationship at times is stormy as both Kim and John have strong opinions about everything. They both share a love of football and both support the same side. Kim regularly visits on Friday nights and Saturday afternoons to watch and discuss the games. One Friday night John says that he is very tired and would like to go to sleep early. Kim notes that John appears thinner than usual and that he has dark circles under his eyes.

Kim goes to the supervisor to enquire about John.

'John appears very tired this evening and doesn't even want to watch the Friday night game. That is definitely not like John,' says Kim.

'No it isn't like him at all. I have contacted the doctor because we have also noticed that he is not eating much and is getting more tired than usual,' says Julie.

Kim finds herself thinking about John constantly and finds it difficult to sleep. She makes an appointment to see her GP as she feels more tired than usual. The GP takes Kim's blood pressure and arranges for some blood tests, but feels that Kim is reacting to John's decline. The GP arranges for Kim to attend some counselling.

The next week Kim sees a sharp decline in Jon's mental and physical state. On Saturday, as Kim sits watching the game with John, he is dozing on and off. After the game has finished Kim speaks to Julie again.

'John appears very weak,' says Kim.

'Yes, the doctor is expecting John to die fairly soon. His condition has declined rapidly these last two weeks,' says Julie.

'I know it is coming, but I will miss him,' says Kim.

'You have been good friends. I will let you know if John deteriorates, but I think you should prepare yourself,' says Julie.

Later that night the telephone rings for Kim to let her know that John is not expected to last through the night. Kim goes in to say goodbye to her friend. 'I will miss you, John,' says Kim. John dies two hours later.

'Do you want to stay longer with John?' says Julie.

'No, I'll … I'll just say a final goodbye,' says Kim.

'Thank you for all you did for John. I really appreciated it,' says Julie.

Kim attends the funeral later that week and feels comforted by the fact that Julie and one of the other staff members who looked after John are also attending. John only had one sister, Veronica. Kim can see the resemblance, especially around the eyes.

'Hi Kim, how are you going?' says Julie after the funeral.

'I miss him a lot,' says Kim.

'I know it is hard for you at the moment,' says Julie. 'I have a few photographs that we have put into a book about John that I would like you to have.'

Kim thanks Julie and she can feel the tears on her face as she looks at the photographs of her old friend.

Practice task 28

1. What is the most distinguishing feature of complex grief?

2. Give three other signs of complex grief.

3. Explain the difference between a grief reaction and depression.

Click to complete Practice task 28

5G Prepare the person, family, other staff and self for any distressing end-of-life events

One of your key responsibilities is to prepare the person, their family members, carers and other staff for the person's death. To do this successfully you will require effective communication skills, empathy, sensitivity, an awareness of the processes involved and knowledge of the policies and procedures to be followed. It is useful to be aware of and understand the different ways people deal with death so you can provide appropriate support. You may encounter any (or all) of the situations below when you have a person who is nearing the end of their life.

Blocking out information

- Some people may not want to know any bad news, refusing to listen or blocking out anything negative. You may need to speak with another family member or arrange for a doctor to talk with them so they can gain a better understanding of the situation.

Denial

- People may be in denial that a person's illness is life-limiting and continue to talk optimistically about a recovery, or about future plans that you know are unattainable. This gives some people the strength to cope; however, you may need to speak with another family member who is more realistic, or provide educational material about the person's condition.

Concealing the truth

- Family members may decide not to tell the person the real situation, believing that ignorance may protect and help the person. In this case, determine the best way to proceed while behaving ethically to meet the person's and family's needs and wishes.

Extreme distress

- Some people may become extremely upset, depressed and unable to cope. If carers and family members exhibit this behaviour it makes it difficult for the team to carry out their palliative care duties. They may need counselling or a support network.

Acceptance

- Some people are able to accept that death is inevitable; for example, a person with a life-limiting illness may be at peace with their mortality, allowing family members and carers to spend the remaining time making them as comfortable as possible.

Describe what to expect when a person is dying

Family members look to you and other members of the palliative care team to help them understand what to expect when a loved one is dying. In the final days and hours before death, a person may display a number of signs and symptoms that often occur in a predictable pattern. Changes in daily habits, bodily functions and a decline in functional status are observable and often distressing to the person and their family. Anticipating these changes and symptoms, which are described below, and preparing the person and their family members for what to expect may decrease the uncertainty they have at this time.

Social withdrawal

It is usual for a person nearing the end of their life to withdraw and become less concerned about their surroundings. They may begin by losing interest in the newspaper or television, then visitors, and finally in family members and the people most loved. With this withdrawal comes less of a need to communicate with others, even with close family members and carers.

Food

The person may have a decreased need for food and drink, including their favourite foods. This gradual decrease in interest in eating and appetite is one of the hardest things for some family members and carers to accept. You should explain that the person is not starving to death; rather that this reflects the underlying life-limiting illness and their body preparing to die. At this time liquids are preferred to solids and you should follow the person’s lead as to what they can ingest.

Sleep

The person may spend more and more time sleeping, even finding it difficult to keep their eyes open. This is due to the impact of their life-limiting illness on the body’s metabolism. Allow family members and carers to spend more time with the person when they are most alert.

Disorientation

The person may become confused about time, place and the identity of people around them. They may also experience hallucinations, seeing people who are not there, including seeing family members who have already died. While the person themselves may not be distressed, this can be distressing to others. You may gently orient the person if they ask where they are or what is happening, but there is no need to correct the person if they are not distressed.

Restlessness

The person may become restless and pull at the bed linen. These symptoms are also due to a change in their body’s metabolism. Talk calmly with the person so as not to startle them. If the person is a danger to themselves or others, refer the matter to a doctor who can prescribe medication to sedate the person.

Decreased senses

Clarity of hearing and vision may decrease. Use soft lighting in the room and never assume that the person can’t hear you, as hearing is often the last of the five senses to be lost.

Incontinence

Incontinence is often not a problem until death is very near. The amount of urine decreases and becomes darker as death approaches. If required, absorbent pads or a urinary catheter can provide the person comfort and cleanliness.

Physical changes

As death approaches, these changes include decreased blood pressure, fluctuating body temperature, clamminess, decreased circulation with skin colour changes, and changes in breathing and congestion that produce a rattling sound in the lungs and/or upper throat.

Coma

Some individuals may enter a coma before death and not respond to verbal or tactile stimuli.

After death

When somebody dies, their loved ones typically feel much more than physical loss. The deceased person may have played many significant roles. Their death could mean the loss of a spouse, soul mate, partner, confidant and much more. Sometimes family members have resolved difficult issues or reconciled after many years just before the death.

You must know what to do after a death has occurred to be able to offer practical comfort measures to family members, carers and co-workers. If a family member or carer is displaying symptoms of extreme grief inform your manager, a doctor or a nurse so they can arrange bereavement counselling immediately.

After a person's death, it may be your job to:

- give family members the person's personal possessions
- suggest bereavement support and counselling services
- ensure family members understand what needs to be done to meet the person's wishes, such as arranging the type of funeral they want or reading their will.

Support other staff

Members of a palliative care team, especially new or inexperienced members, may require support themselves. They may have become close to the person and the family and may be distressed because the person is in the final stages of their life. They may not want to see the person in pain, or may feel inadequate because their care is not improving the person's condition. They may also feel at a loss about what to say if they have not dealt with dying people before.

Staff may need to be trained or mentored to ensure they act professionally and within policies and procedures at all times. Ensure they understand the specific procedures they should follow and their particular role. It is often a good idea to give staff specific tasks to carry out so they feel their contribution is helping. Make sure they feel comfortable answering any questions and know what queries to refer to you or another member of the palliative care team.

It is helpful for staff to know about the bereavement services offered by the organisation. Information can be given verbally in staff education sessions and more formally through policies and procedures. Printed material with resources available in the community is often helpful for the person to be able to access supports outside the work environment if they have prefer.

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. Always follow organisational policies and procedures when managing the emotional welfare of others.

The supervisor is often the first person a care worker can access if they have any concerns. The supervisor is also able to observe the care worker and may pick up on signs of grief or anxiety that the 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'. 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. These are 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 person, to provide support to family members, carers, and palliative care team members, other persons and volunteers.

A memorial ceremony can be held annually to acknowledge the people who died in the last 12 months; this is a public recognition that each person'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.

Support carers of other people

Carers of other individuals may also be affected by a person's death. If they are professional carers they should be able to explain what has happened to the person they are supporting and maintain a calm and professional atmosphere.

If the carer is a family member who has not experienced death before, they may find it difficult to deal with their emotions. In this case, explain to the carer what will happen to the deceased person's body. This may also be an opportunity to give them information about bereavement, how people react and support services that are available so they can be prepared when their own family member dies.

Self-awareness

It is also important to be aware of your own feelings so you can function professionally as part of the team. You may also be upset about a person or not sure how to approach a situation. You may be particularly busy and have not had time to relax or calm down. Make sure you follow the advice you give team members, remain conscious of your own physical condition and find ways to support yourself.

Example

Prepare the person, family, other staff and self for any distressing end-of-life events

Bruce has worked in a residential aged care facility in a small rural community for 10 years. Dianne had 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 without him being 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.

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Practice task 29

1. List two signs that a person is nearing end-of-life.

2. Explain the responsibilities of the supervisor.

3. What is one of the key responsibilities for a support worker when a person is dying?

Click to complete Practice task 29

Summary

1. As a person enters the final stages of their life, their end-of-life plan should be prepared to document their wishes, particularly their cultural and spiritual needs.
2. ‘End-of-life’ refers to the period where death may be expected to occur within hours or days.
3. When preparing the end-of-life plan, the person and their family and/or carers should be consulted to identify the most important factors for maintaining the person’s dignity, comfort and quality of care before and after death.
4. The palliative care team should be alert for signs that death is imminent and follow organisational procedures for reporting the signs of death. The person’s comfort should remain the ultimate goal and appropriate support provided to carers and family.
5. End-of-life care requires workers to apply effective communication skills to physically and emotionally support family and carers in the final stages of a person’s life.
6. It is critical that effective communication be maintained between members of the palliative care team to ensure awareness of any changes to the person’s needs and preferences. Team members must know exactly what a person has requested in the event that urgent action needs to be taken.
7. When a person dies, workers may also need to provide bereavement support to other people, carers and families.
8. Empathy, sensitivity and a good knowledge of processes, policies and procedures are required to communicate with others before and after a person’s death. Be prepared to support other staff and ensure that your own needs are met.

Learning checkpoint 5

Contribute to the development and implementation of end-of-life care strategies

This learning checkpoint allows you to review your skills and knowledge in contributing to the development and implementation of end-of-life care strategies.

Part A

1. Why is it important for the care plan to be reviewed and communicated to all members of the team?

2. How can changes to the care plan be communicated to different members of the team? List five examples.

3. List five situations where a person is more likely to develop a complex grief reaction following the death of a person.

4. List two ways in which people deal with death that indicate they may need support from the palliative care team.

Part B

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

Case study

Penny is admitted to a residential aged care facility 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, her care worker, contacts the local hospital's palliative care service for support. Penny is also concerned about her spirituality. Penny was baptised a Roman Catholic but had married outside the church and had gradually drifted away. Now, Penny appears distressed about the fact that she has not kept up with her religion and obligations to it. Rhonda asks Penny if she would like the local priest to come and visit her. Penny agrees and after the visit appears more at ease. Penny adjusts her advance care directives to include her funeral plans to have a church ceremony.

Penny gradually loses her appetite and only takes a sip of water or tea. At these times Rhonda needs to sit Penny up and support her with many pillows so that Penny does not choke on the fluids. Rhonda reports this to Gemma her supervisor. Gemma notifies the local doctor and Penny's care plan is amended to food and fluids as tolerated. Penny had requested that she not be fed by artificial means and did not want any invasive procedures such as a PEG tube or intravenous line inserted. Gemma comes out and goes through the care plan with Rhonda. Rhonda asks, 'But won't Penny be hungry?' Gemma provides Rhonda with some printed information on how the body responds to end-of-life situations and this gives Rhonda some comfort, though she still asks Penny is she would like anything to drink.

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

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. Gemma gives Rhonda some printed information on bereavement assistance for support workers in the organisation.

1. Why was it important to include Penny's change of wishes regarding her funeral into her advance care plan?

2. How can Rhonda assist Penny to maintain her dignity at end-of-life?

3. What signs of imminent death did Penny have on discharge from the hospital?

4. How did Gemma and Rhonda provide a supportive environment for Penny?

5. Identify three ways Gemma provided support for Rhonda.

6. Is Rhonda legally obligated to ensure that Penny is fed? Explain your answer.

Topic 6

In this topic you will learn how to:

- **6A** **Identify and reflect on your own emotional responses to death and dying**
- **6B** **Identify and manage impact of emotional responses on yourself and others**
- **6C** **Inform others about available support systems and bereavement care**
- **6D** **Follow organisational policies and procedures in relation to emotional welfare of self and others**
- **6E** **Assist colleagues to debrief and discuss bereavement care**
- **6F** **Identify other strategies and resources available for debriefing**
- **6G** **Evaluate the effectiveness of emotional response strategies**

Identify and manage emotional responses in yourself and others

Caring for people at the end of their lives is an important duty. It may also be exhausting, as you constantly provide support to others, work in situations where suffering and distress are common, and deal with challenging ethical issues.

Workers need to know how to deal with their own reactions and how to respond to individuals who are receiving palliative care. They need to be aware of the type of support available and how they can cope with stress.

Supervisors and coordinators also need to provide support to team members, the person accessing the service and family members, especially after the person has died.

6A

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

A palliative care environment is one in which there may be a lot of suffering, pain, distress, anger and grief. The person may suffer pain before they die, and their family members and friends often place their own demands 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. For these reasons and more, workers must be trained to cope with death and bereavement.

Workers need to maintain a steady, professional manner and display understanding, warmth and empathy towards others. They should also look after their own health and fitness. As there is often little time to grieve or to talk about their own feelings with others, stress levels for workers are often high.

Understand your reaction to dying and death

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 client'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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Emotional responses to dying and death

When considering emotions around death and dying, always remember that everyone is different; some workers may have their own personal losses or experiences to draw upon, while others may have no experience and not understand the impact of death on themselves or others. Likewise, some people are able to remain cool and detached, yet others may experience as much emotion as the person's family members and carers.

A person's culture and background may also affect the way they perceive death and dying. In some cultures people may behave emotionally when dealing with death, whereas in other cultures death is viewed as an integral part of the lifecycle. In some cultures, death may be a taboo subject.

Working in this area can be very rewarding and satisfying; however, discussing end-of-life issues with people with a life-limiting illness is not easy. Taking into account the emotional concerns of the person and their family and/or carers 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.

Reactions to a person's death

Grief and loss may cause you to experience conflicting or bewildering feelings and emotions. Typical reactions include feeling sad, angry, relieved, stressed, tired, confused or guilty. You may cry a lot and have trouble concentrating. Below are some examples of feelings you may encounter after you experience the death of a person you have supported.

Unresolved grief may result in withdrawal from close or meaningful involvement with colleagues and other people accessing the service. In extreme cases, it may contribute to long-term difficulties in personal relationships, inappropriate ways of dealing with emotional stresses, depression or physical illness.

After the death of a person, you may:

- have difficulty shifting from a curative approach to a palliative and supportive role where death is an inevitable and appropriate outcome
- suffer guilt if you feel that a diagnosis was missed or delayed
- suffer trauma if you are unable to relieve the person's difficult symptoms or intense distress for them, their family members and carers
- struggle to confront your own issues and emotions relating to death.

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, feelings of grief may change over time. Grief is a natural reaction and occurs in response to many types of loss, not just death. It is also dependent upon the individual's unique perception of loss.

The worker's grief may also be affected by their relationship with the person who has died; the nature of the person's death; their gender, personality, culture, age or religion; the availability of 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 complex) grief, the symptoms of which are shown below.

Pathological (or complex) grief symptoms may include:

- pangs of severe emotion
- distressing yearnings
- feelings of incredible isolation and emptiness
- great difficulty undertaking tasks that remind them of the deceased.

Social models of grief

Some common models and theories of grief are discussed below.

Freud's model of bereavement

Freud's theory stresses that grieving individuals are searching for an attachment that has been lost; grief is the loss of the attachment. Freud saw melancholia as unconscious, resulting from a subconscious loss and a lowering of self-esteem. In this model, mourning is a normal reaction and the person will return to their reality.

Kubler-Ross grief cycle

This is a linear progression through the stages of denial, anger, bargaining, and acceptance. A person cannot reach the acceptance stage until they have progressed through the other stages. A person can move through the stages at their individual pace and time.

Bowlby's attachment theory

According to this theory, a person experiences distress and emotional disturbances when the attachments that have been developed are broken. This occurs if the person leaves or dies. The experiences include the following:

- Numbing – characterised by a feeling of disbelief
- Yearning and searching – the person acknowledges the loss is real and anger and frustration is common at this phase
- Disorganisation – a acceptance of the reality of the loss occurs
- Reorganisation – the changes made by the person to move on with their life

Lindeman's grief work

In this model, the grieving person experiences emancipation from the bondage of the deceased, meaning that their attachment to the deceased is given away. It allows the person to make new attachments.

Social, emotional, physical and psychological readjustment of the environment in which the person is living occurs during this time, as well as forming new relationships.

Rando's six 'R' model

- Recognise – understand and acknowledge the loss
- React – express and experience the emotions associated with the loss
- Recollect – remember and review the lost relationship
- Relinquish – put the loss behind you
- Readjust – return to normal patterns of living
- Reinvent – form new relationships and commitments

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 for yourself or for members of your team.

Learn to recognise when this type of support is needed and take action to access it so you remain an effective team member. A worker should not continue to work when under extreme stress or when their behaviour impacts negatively on 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

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

Bruce has worked in a residential aged care facility in a small rural community for 10 years. Dianne had been a resident for seven years, until her recent death at age 102. Bruce was very close to Dianne, particularly because she reminded him of his mother, who died without him being able to say goodbye. Following Dianne's death, Bruce grieved openly for her. He cried a lot, kept away 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 30

1. Explain how culture may affect the perception of death.

2. List two symptoms a person may experience with a pathological/complex grief reaction.

3. List two symptoms a person may experience after the death of a person they have been supporting.

Click to complete Practice task 30

6B Identify and manage impact of emotional responses on yourself and others

Caring for people at the end of their lives is an important duty. It may also be exhausting as you constantly provide support to others, work in situations where suffering and distress are common, and deal with challenging ethical issues.

Workers need to know how to deal with their own reactions and how to respond to individuals who are receiving palliative care. They need to be aware of the type of support available and how they can cope with stress.

Supervisors and coordinators also need to provide support to team members, the person accessing the service and their family and/or carers, especially after a person has died.

Reflect on the impact of your responses on yourself and others

Everyone experiences different responses to a person's death; however, the way a worker responds to death and dying has an impact on others around them, such as family members, carers, co-workers and other people accessing the service. Supervisors must provide leadership and create a calm, supportive environment, but this is not possible if you are upset and unable to cope.

Understand the result of your reactions

As discussed previously, you must be able to recognise how your reactions affect your work and others. Here is some more information about the results of your reactions to death and dying.

The impact of unresolved grief on work and personal life

- Your work becomes affected by your feelings when you can no longer perform effectively and are unable to provide necessary support to family and friends.
- Shutting out emotions and withdrawing from other people after a person's death may result in a lower quality of care and prevent effective end-of-life care for others.
- You develop a fear of death and dying.
- Frustration and depression may result from the powerlessness of a person's situation and your inability to help.
- You may be personally affected and grieve as if the person 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 support workers put the persons' needs before their own it is called 'compassion burnout'.

Take action

Learn to recognise your reactions and how to deal with your emotions. Strategies to cope with specific reactions and how they may impact on others are listed below.

Crying

How this may impact on others:

- Team members, people accessing the service, family members and carers may be personally affected, which 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

How this may impact on others:

- You are unable to complete the tasks 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

How this may impact on others:

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

Coping strategies:

- Have a colleague mentor or assist other workers through difficult times and encourage them to recognise their emotions.
- Mentors should be available at all times, even after work hours, in case the worker needs to talk.

Anger

How this may impact on others:

- A worker may take out their anger on other people by swearing, crying or yelling, which creates an unpleasant and upsetting environment.

Coping strategies:

- Allow time to grieve and access support from team members. 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 an individual's life.

Silence

How this may impact on others:

- If you isolate your emotions and withdraw from other individuals following the death of a person, this may result in a lower quality of care and prevent effective end-of-life care for other people.

Coping strategies:

- Seek support from your team and organisation such as bereavement training or debriefing sessions.
- Seek support from counsellors, therapists, psychologists or social workers.

Stress and burnout

How this may impact on others:

- 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 such as a psychologist, social worker or therapist. They will suggest ways to cope such as maintaining your health, evaluating your priorities, giving yourself time out and getting adequate rest and sleep.
- Also, draw on the expertise of external organisations to provide stress-management training and/or professional bereavement support.

Example

Identify and manage impact of emotional responses on yourself and others

Grace has recently commenced working in a palliative care facility. At a morning tea break, she tells Jen, another worker, that she is scared of experiencing and seeing her first death as she has never experienced the death of anyone before, or even been to a funeral. Grace has been assigned to care for John, who is in the final stages of early onset dementia at the age of 53. To prepare Grace, Jen explains what may happen and the feelings and emotions Grace may experience. Jen also explains the type of support that is available if she needs it.

After three weeks of caring for him, John passes away. At first, Grace feels all right about John's death, but two days after returning to work Grace finds that she is often crying after work and has difficulty concentrating on other tasks at home. Grace also finds that she is extremely fearful of other people she is supporting dying and spends a lot of time checking them, which causes delays with completion of her work duties. Grace's colleagues are becoming impatient with her, as it is a rule that all staff leave the shift together. With Grace constantly behind with her work responsibilities, other members of staff have to pick up care for the people that Grace is allocated to support.

Grace goes to her supervisor to talk about the experiences that she is having. The supervisor refers Grace to an external counsellor to assist Grace to talk through her emotions. Jen is appointed as a mentor until Grace feels that she can manage her emotions and work role responsibilities.

Practice task 31

1. Identify three ways unresolved grief can impact on work and personal life of the support worker.

2. What are three behaviours a support worker might experience after the death of a person?

3. What coping strategies could a support worker employ if they experience stress and burnout as a result of the death of a person they have been supporting?

Click to complete Practice task 31

6C Inform others about support systems and bereavement care

Palliative care work relies on a team approach and strong mutual support for each other. Therefore, you, your team and the person's family and/or carers should be provided with opportunities to prepare for and acknowledge a loss, together with access to adequate bereavement assistance and support when required.

Remember, everyone is different and some people require more support than others when grieving; even team members who have experienced many deaths may still require access to support services.

Choose support that is appropriate and that makes individuals feel comfortable. To prepare family members as early as possible for the imminent death of their loved one, assess how much and what type of support they need.

Support for grieving family and/or carers

A helpful social model for understanding grief is the theory described in *Continuing bonds: new understandings of grief* by Klass, Silverman and Nickman (1996). The continuing bonds theory suggests that grief is the period when you:

- find ways to adjust your life without the person
- redefine your relationship with the person who has died
- maintain the bonds of attachment to the person.

Some ways to continue bonds with a person who has died:

- Talk to them, either out loud or in your head.
- Write them letters or keep a journal.
- Keep photographs of the person around.
- Include the memory of the person in special family events.
- Imagine their responses to your decisions.
- Talk about them to people.
- Live your life well.
- Finish a project they were involved with.
- Take a trip that they always wanted to take.
- Keep something that belonged to the person.

Support for parents whose child has died

The grief a parent feels is often very intense. It is not expected that a parent will outlive their child. All the normal supports that are offered to people following the death of a person need to be in place along with some additional information and supports.

Information about why and what caused the death of a child is often required for the parent of the child.

Here are some causes of death in children.

Death following an illness

The illnesses that lead to death in children are usually oncological conditions such as cancer or leukaemia. Other causes include life-threatening and life limiting conditions.

Cancer and leukaemia

Cancer Australia estimates that 650 children will be diagnosed with cancer in Australia in 2015. They found that death rates children with cancer had decreased by 60% over the last 30 years. It has also been found that survival rates of cancer have increased, but that death due to brain cancer has remained the same.

Life-threatening conditions

These include the following:

- Acquired brain injury due to a motor vehicle accident or near-drowning
- Meningitis
- Encephalitis
- Premature births
- Chronic illness such as asthma

Australia Institute of Health and Welfare 2010 report found the following:

- The perinatal death rate of babies born to Indigenous Australian mothers in 2007 was twice that of other babies (20.1 compared with 9.8 per 1,000 births).
- Death rates among children and young people halved in the two decades to 2007, largely due to fewer deaths from transport accidents.
- More children are being vaccinated against major preventable childhood diseases, with 91% (the target level) being fully vaccinated at two years of age – but only 82% of five year olds are covered
- Land transport accidents and intentional self-harm accounted for two in every five deaths (42%) among young Australians (aged 15–24) in 2007.

Acquired brain injury

Brain Injury Australia found that one third of deaths occurred from injuries sustained in motor vehicle accidents and near-drownings.

Admissions to hospital involved the following reasons for children:

- About one in five people admitted to hospital due to injury in 2001–02 were children.
- Falls were the most common cause (43%).
- Transport accounts for fewer cases (14%) but these tend to be severe.
- The special vulnerability of toddlers to injury is indicated by the prominence of drowning and pedestrian injuries in this age group.
- For older children, the prominence of injuries related to cycling and falls reflects the exploratory and adventurous character of this stage of life.

Meningitis

Meningitis is when the membrane covering the brain and spinal cord becomes inflamed either due to a viral infection or a bacterial infection.

Signs and Symptoms

- Fever
- Vomiting
- Seizures (fits)
- Headache
- Irritability and high pitched cry (especially in babies)
- The soft spot on the top of a baby's head, called the fontanelle, may bulge and look very full
- Tiredness or drowsiness (lethargy) or hard to wake
- Stiff neck in older children
- Dislike of bright lights (photophobia)
- Rash which may vary in appearance but may look like red/purplish spots which do not turn white when you push on them (nonblanching)
- Babies may hold their head back or arch their back

Most people recover from meningitis, although it may take a long time if appropriate care and treatment is given.

Encephalitis

Encephalitis is an inflammation of the brain.

Signs and symptoms:

- Fever
- Headache
- Poor appetite
- Loss of energy
- A general sick feeling
- Severe headache
- Nausea and vomiting
- Stiff neck
- Confusion
- Disorientation
- Personality changes
- Convulsions (seizures)
- Problems with speech or hearing
- Hallucinations
- Memory loss
- Drowsiness
- Coma

In infants, signs to check for are:

- vomiting
- a full or bulging soft spot (fontanelle)
- crying that doesn't stop or that seems worse when an infant is picked up or handled
- body stiffness.

Support for staff

There are a number of things you and your organisation can do to support staff, but be aware that not everyone may feel the need to participate and this should be respected. See below for examples of strategies for providing internal support.

Grief time

Allow your team grief time. This includes permission to cry, to be angry, not expecting them to return to work immediately, offering time to discuss how they feel and letting them know you are available to listen.

Debriefing sessions

Arrange debriefing sessions in which everyone is encouraged to talk about the person, the care that was given, how they feel and to recall positive experiences.

Continuous improvement

Conduct stress-management or bereavement training. These are often part of a quality assurance and continuous improvement program.

Workplace activities

Provide workplace activities to improve physical or mental wellbeing such as exercise classes, aromatherapy or yoga.

Family visits

Arrange for team members to make follow-up visits to bereaved family members and carers so they have time to discuss their grief away from the work environment.

Health professionals

Draw on the expertise of health professionals within the organisation such as psychologists, social workers, therapists and pastoral workers.

Mentors

Have a colleague act as a mentor or support person to help other workers through difficult times and to encourage them to acknowledge their emotions.

Support for family members and/or carers

Family members and carers must be supported as they, too, face issues and concerns about death and dying.

Bereavement support may be simply offering your time to listen, or you may need to suggest specialist services. You may arrange for the person's spiritual advisor to speak with the family, and some families appreciate a get-together of all those involved to celebrate the person's life.

External support available

There are a number of professional bereavement support services available to you as well as to family members and/or carers. These include professional counsellors, psychologists or clergy. These people can explain the grief process and the common stages people go through when coping with death.

There may also be virtual support groups available online, which provide the opportunity for support through chat rooms or telephone conference groups. Find out what services are available in your area and collect information about services they offer. Palliative Care Australia is a useful source of information on community resources.

You can access their website at http://aspirelr.link/palliative-care

Example

Inform others about support systems and bereavement care

Grace has been caring for John, who recently died at the age of 53. Grace attends counselling with a psychologist, which is helpful in resolving her feeling about the death of John. Afterwards, she is no longer fearful that other people she is supporting will die unexpectedly.

Grace attends John's funeral and is warmly welcomed by John's family. Grace is given a reduced workload on her return to work, which assists her to resolve her work issues in a positive manner. The supervisor holds an education session for all staff members regarding the emotional impact a person's death can have on families and/or carers, and also on the support worker. Brochures are given to all staff at the meeting with information on available supports. Jen shows Grace an article in the facility's newsletter about John. It includes pictures of John in healthier times and lists his life achievements. Grace and Jen attend the yoga classes that the facility provides as a means of reducing work stress, and find this a relaxing and positive activity.

Practice task 32

1. List two health professionals who may be contacted to assist staff after the death of a person they have been supporting.

2. Explain the term 'grief time'.

3. List three activities a workplace can implement to support the staff.

Click to complete Practice task 32

6D Follow organisational policies and procedures in relation to emotional welfare of self and others

All organisations engaged in palliative care have guidelines, policies and procedures based on legislation and industry standards to support the emotional welfare of staff, family members and individuals when dealing with end-of-life issues. Palliative Care Australia's *Standards for Providing Quality Palliative Care for all Australians*, Standard 8, requires that 'formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services'.

Be familiar with your organisation's policies and procedures and provide your team with access to them. You have a duty of care to the people you support, their family and/or carers and your co-workers to uphold legislation and industry standards in the workplace. To achieve this, you may be required to conduct training to ensure everyone knows their responsibilities.

A coordinator is also responsible for the emotional welfare of the people they care for and work with. People coping with loss, bereavement and stress may require support in different ways, so different options must be made available.

A Guide to policies and procedures relating to palliative care

Follow organisational policies and procedures when managing the emotional welfare of others.

Ask for clarification of anything you don't understand to ensure what you do is legal and ethical. Some of the broad policy areas are outlined below.

Confidentiality and privacy

Confidentiality and privacy must be ensured at all times.

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

Bereavement support

Bereavement support must be provided when needed.

- Offer 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.

The person's family

The person's family must be supported.

Explain to the family what a palliative approach means.

- At all times promote a caring attitude – sensitivity, empathy and compassion – and demonstrate concern for the family and all aspects of the family's emotional circumstances.
- Provide information and emotional support to the family.
- Ensure person-related decisions 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 the family.

Dignity and quality of life

The person's dignity and quality of life must be maintained.

- Relieve suffering and discomfort as advised.
- 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, spiritual and cultural needs 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.

Spiritual support

Spiritual support must be provided when requested.

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

Care plans

Care plans and person's preferences must be followed at all times.

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

Advance care directives

Advance care directives must be implemented when required.

- Follow advance care directive instructions 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.

Cultural issues

Cultural issues must be understood and the person's wishes followed.

- 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.

Psychological support

Provide psychological support when necessary.

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

Intimacy issues

Social support, intimacy and sexuality issues must be addressed.

- Provide social interaction, continuing personal contact and a strong support network for the person.
- Understand family relationships so you can be nonjudgmental and accept the family's situation.
- Understand the importance of touch for the person.

Aboriginal and/or Torres Strait Islander culture

Issues specifically relating to Aboriginal and/or Torres Strait Islander people must be understood and addressed.

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

Example

Follow organisational policies and procedures in relation to emotional welfare of self and others

Anisha visits her grandmother Sushila at her aged care facility every Sunday morning. Sushila has advanced dementia and is expected to live only a few months longer. She no longer recognises Anisha and sometimes screams for her to leave her room when she visits.

One Sunday, the support worker, Dora, notices that Anisha looks very upset when she leaves her grandmother's room. Dora asks Anisha if she can help. Anisha responds by telling her how upsetting it is that her grandmother doesn't recognise her anymore. Dora takes Anisha to a quiet area and sits with her.

Anisha says, 'I don't feel like there's anyone to talk to. I can't talk to my mother about this as it upsets her too much and my brothers and sisters are too young to understand.'

Dora waits until Anisha has finished speaking and then suggests that she talk with the bereavement counsellor on staff to help her deal with her feelings about her grandmother. Dora offers Anisha some brochures about the benefits of counselling and says she may like to bring her mother along as well. She also suggests that Anisha visits on Sunday evenings as Sushila is usually more settled and receptive to visitors at this time.

Practice task 33

1. How can a support worker offer bereavement support?

2. What are three things a support worker needs to know regarding advance care directives?

3. How can a support worker demonstrate culturally safe care?

Click to complete Practice task 33

6E Assist colleagues to debrief and discuss bereavement care

Bereavement care means ensuring colleagues are emotionally strong enough to continue working in a professional capacity. The death of a person can be devastating, so support and information must be made available as soon as possible. Support can include debriefing with colleagues, utilising collaborative team relationships and specific bereavement workshops. Palliative care teams that function well have four characteristics, which are described below.

Well-functioning palliative care teams:

- allow opportunities for reflection and debriefing
- create an emotionally open work environment
- support each other
- have a shared culture of care and accumulated wisdom about how to support bereaved people, family members and carers.

Return to work

Because everyone reacts differently to death, you will find that some people may want to resume work straightaway, while others may need more time before they can move on. Identify team members' concerns, fears, ideas, skills and experiences by asking them questions such as those below.

Useful questions for understanding team member reactions to death

- In general, how effectively do they deal with grief?
- What strategies for managing loss and grief have been successful in the past?
- What training have they had to deal with bereavement and what further training would they like?
- Do they have any questions they need answered?
- How does grief impact on their lives at work and at home?
- Do they recognise grief when they feel it?
- What do they fear the most about the death of a person or people?
- What is most upsetting to them when a person dies?

Strategies to acknowledge a person’s death

Strategies that organisations use to acknowledge a person’s death and provide a means of closure include:

- arranging for staff to sign a sympathy card for the person’s family and carers
- attending the memorial service or funeral
- encouraging staff to look after themselves by getting enough sleep, exercising, taking a proper lunch break and not taking work home
- providing a mentor for the colleague to help them reflect and discuss end-of-life issues and issues surrounding death.

Grief and bereavement

The terms grief and bereavement are often used interchangeably, but they have two distinct meanings. Bereavement is the experience of losing someone close, such as an immediate family member or spouse, and the period of adjustment that follows their death. Grief refers to how bereavement or loss affects an individual personally. Grief is a highly personal and individual experience, and includes a wide range of emotions, thoughts and behaviours. Although people who are bereaved and grieving may experience many common feelings and reactions, it is important to remember that individual responses to grief differ, and some people may develop complex grief reactions.

It is important that you are aware of and recognise the common features of grief and bereavement. People experiencing grief and bereavement not only experience emotional reactions, but may also experience psychological and physical reactions, such as:

- sadness – this is a deep sense of psychological and emotional pain at the loss of someone close, which gradually fades in intensity, although it may never go away altogether.
- longing and yearning – these feelings may last for months or years after a loved one’s death.
- somatic complaints – these are physical conditions associated with grief, including sleep disturbances, aches and pains and susceptibility to illnesses such as colds and flu.
- gradual integration of the loss – this occurs when a bereaved person is able to adapt to their loss and merge it into their life.

The stages of bereavement

Support workers should be familiar with the stages of bereavement so they can recognise that what they are experiencing is a usual part of the process. Coordinators must also have a good understanding, as it may be their job to advise or reassure less-experienced staff members that their feelings are valid.

The stages and phases of bereavement follow the process shown here.

The stages and phases of bereavement

Denial – the person finds it difficult to accept what has happened.

Anger – the person is angry that their loved one has died.

Finding a reason – the person searches for a reason for the death.

Depression – the reality of death starts to sink in, causing sadness and depression.

Acceptance and adjustment – the person understands that a loved one has gone and begins to move on with life.

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 and express their emotions by talking about how they feel about the person, including 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 incidents involving people receiving palliative care. Finally, a discussion of the person's funeral and ways to celebrate the person's life may be explored.

Critical stress debriefing

One effective debriefing method is critical incident stress debriefing. This is usually led by trained peers, counsellors or a healthcare professional who is not actively involved in the specific palliative care case. This structure of debriefing provides the healthcare professionals with a safe and supportive environment in which to share their feelings and emotions in relation to a specific palliative care case, and involves the following seven steps.

Critical incident stress debriefing

1. Introduction – the specific situation is described so participants know why they are meeting.
2. Fact phase – the type of death and what happened is described.
3. Thought phase – participants describe the thoughts they had prior to, during and after the death.
4. Reaction phase – participants talk about their reactions and the emotions they felt or still feel.

5. Symptom phase – the team leader talks about the possible signs of emotional, physical and social stress that the group members may be feeling.
6. Teaching phase – the team leader identifies participants who may require further counselling.
7. Re-entry phase – the team leader invites discussion about suggestions for coping and closes the session positively.

Example

Assist colleagues to debrief and discuss bereavement care

Sarah has been off work for the last three weeks following the sudden death of David, the person she has been supporting for the last six months. Gary, her supervisor, is concerned about Sarah since running into her down the street the other day and noticing that she has lost weight and looks tired and sad.

Gary rings Sarah to see if Sarah would mind if he went around to see her at home. Sarah and Gary have worked together for the last 12 years and are also friends outside of work. Gary goes over after work and they have a coffee. Gary asks Sarah how things are going.

‘I’m sad all the time, nothing seems worthwhile,’ says Sarah.

‘When do you think you will come back to work?’ says Gary.

‘I’m not sure, I don’t think I can stand going back and seeing David’s empty room.’

‘Sarah, you have had other people die previously. What did you do then?’

‘Nothing special; David’s death just seems to have affected me more than usual,’ says Sarah.

‘Would it help if you went to some counselling sessions?’ says Gary.

‘Yes, I would like to talk about what happened to David with someone who can help me understand why I feel so down.’

Practice task 34

1. Explain two of the seven phases of critical stress debriefing.

2. How can debriefing assist in stabilising a workplace?

3. List three questions that you might ask to gain an understanding of a team member's reaction to grief.

Click to complete Practice task 34

6F 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. These are 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.

Opportunities to 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 person, to provide support to family members, carers, palliative care team members, other people and volunteers.
- A memorial ceremony can be held annually to acknowledge the people who died in the last 12 months; this is a public recognition that each person'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

Identify other strategies and resources available for debriefing

John has taken on the responsibility of manager for the local aged care residential facility with a staff of 30 permanent workers. On commencement, John notes that the staff have not completed a formal appraisal for the last three years.

On mentioning this to the supervisors of the different sections, John becomes aware that the appraisal system is not well understood. John decides to implement some learning for the supervisors about the benefits of appraisals and how they can be used to support staff working in the facility.

The supervisors are asked to identify what other strategies or resources the facility could use to support the staff. The supervisors think it would be a good idea to develop a questionnaire for the staff to identify other strategies. On the questionnaire, the staff feel it will be good to have both work-focused opportunities to debrief and more social opportunities, such as yoga or group walks, to debrief informally.

Practice task 35

1. Explain the importance of relaxation for staff.

2. Identify two things that can occur if a person suffers from burn out.

3. Identify three forms of relaxation techniques

Click to complete Practice task 35

6G Evaluate effectiveness of emotional response strategies

The strategies you use to emotionally support staff and people's families and/or carers must be regularly reviewed so you can identify how effective they are. Organisations should constantly strive to find better ways of undertaking work. The coordinator should determine whether the bereavement care program for staff is working, how families have responded to the support they received and whether the support services and networks promoted are successful. This may be done on an informal or a formal basis, as detailed below.

Informal reviews

- You can determine whether the strategies in place are working by observing staff members after subsequent deaths. Are they more professional? Do they support the person's family well by listening to them and offering comfort with empathy? Do they wait until the family has gone before they express their own emotions?
- Talk with staff members at a quiet time to ascertain how they are coping. A coordinator who has a good working relationship with staff can establish how honestly they respond to questions about feelings and emotions.
- You may include an informal discussion about bereavement, loss and grief at a staff meeting to allow colleagues the opportunity to talk freely about these topics in general rather than specific terms.
- Speaking to families after a death must always be done sensitively. Often, it may be more appropriate to wait until after the funeral to then contact them to finalise the situation and to determine if anything could have been done better.

Formal reviews

- Your organisation may have a formal review process to evaluate the effectiveness of emotional response strategies. This may be a survey that families complete, with questions that evaluate the type of support they were offered, the information they were provided, specific support that wasn't available and an evaluation of staff support. The coordinator may also formally interview families and carers and record the findings.
- A vital part of any evaluation is to analyse complaints and other feedback the organisation receives. Results can be categorised into areas such as services provided by staff (whether it was professional, timely and prompt), information provided (whether it was sufficient, appropriate and relevant) and support services provided by external providers such as counsellors, psychologists, social workers or clergy (whether this was suitable for the situation, effective and met people's needs).
- Analysing the data may determine whether people need to be given more information, when they want to be given the information, which external providers offer professional services that your organisation should continue to recommend, and whether staff require any additional training in bereavement care.

Debriefing and team meetings

- 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; allowing time to cry.
- A formal debriefing provides the health care professionals with a safe and supportive environment in which to share their feelings and emotions in relation to a specific palliative care case.
- Debriefing is usually in response to a specific milestone such as the death or a critical incident. Team meetings allow staff to express emotions and concerns on an ongoing basis in an atmosphere that is supportive of the team member.

Surveys

Surveys can be used both internally and externally to identify and review support strategies provided by an organisation. Analysing the data may determine whether people need to be given more information, when they want to be given the information, what external providers offer professional services that your organisation should continue to recommend and whether staff require any additional training in bereavement care. Here is an example of a survey that could be used to internally identify and review support strategies provided by an organisation.

Services questionnaire			
Item	☑ **or** ☒	**Effectiveness** (0 = not effective 10 = very effective)	**Priority**
Spiritual, religious and cultural standards			
Support available 24 hours a day for anyone who needs it			
Bereavement support standards			
Bereavement support for family members, carers and significant others is available			
Bereavement support groups offered			
Active follow-up is available			
Memorial services are conducted for staff and family members, carers and significant others			
Psychosocial and emotional standards			
Referral and support is available 24 hours a day			
Crisis response teams are present for significant losses			

Support is available for professional care workers			
Support groups for people, family members and carers are available; information about support groups is given and they are encouraged to participate in at least one group meeting			
Support groups offered during day and evening hours			
Support groups held at locations convenient for people, family members and carers			
Waiting time to join a support group is less than two weeks			
Virtual support groups are available; for example, chat rooms and also telephone conference groups			
Accurate support information clearly conveyed			
Questions answered honestly and promptly			
Routine feedback from people, family members, carers, care leaders and workers, bereaved family and community partners is obtained			
Quality improvement standards			
Research to continue developing new ways to improve care is developed and findings are applied			

Example

Evaluate effectiveness of emotional response strategies

Joan is the supervisor at the local aged care facility. There have been four deaths in the facility over the last two months and Joan is aware that the staff have been affected by the loss of these residents that they provided support for.

The education program is currently under review and Joan feels that it is a good time to see if additional areas of support in the form of education are required. Joan is unsure what other support the staff require so decides to hold an informal debriefing session for the staff to attend. The staff are very open and honest and welcome the opportunity to grieve for their loss in a supportive environment.

Joan has prepared a short survey for the staff members to complete. The survey asks the staff if there are any areas of education that they would like to be provided with. On the collation of the responses, Joan determines that the staff would like some more education on death and dying. Two staff members have requested the opportunity to undertake training in the area of counselling.

Practice task 36

1. List the three ways to assess the effectiveness of emotional response strategies.

2. List two positive aspects of an informal debriefing.

3. Identify two things surveys can identify to assist in improving services.

Click to complete Practice task 36

Summary

1. Understanding their own feelings about death and dying contributes to a worker or coordinator maintaining a professional approach to their job role.
2. All workers must learn to recognise when they need bereavement support and then take action to receive it.
3. While everyone has a different response to death, the way a worker responds to a person's death can have a significant effect on others around them, such as family, carers, other people receiving support and co-workers. Workers must learn to deal with their emotions.
4. A supervisor is responsible for maintaining a supportive team approach to the grieving process and must be familiar with the range of support offered internally in the workplace and also by external organisations.
5. All organisations involved in palliative care are guided by legislation and standards. Organisational policies and procedures assist workers to deal with end-of-life issues.
6. The supervisor is responsible for providing staff bereavement care that offers the opportunity to debrief and deal with the emotional stresses of providing palliative care.
7. Formal and informal reviews should be offered to family and/or carers, and also to the palliative care team to evaluate the effectiveness of bereavement, loss and grief strategies.

Learning checkpoint 6

Identify and manage emotional responses in self and others

This learning checkpoint allows you to review your skills and knowledge in identifying and managing emotional responses in yourself and others.

Part A

1. What two of the supervisor's responsibilities for supporting family and/or carers when a person is dying?

2. Explain two policies and procedures that are followed in palliative care for the support of the family.

3. List four questions a supervisor could ask to assess the individual team member's reaction to death.

4. List four strategies that can be used to assist the debriefing of staff members.

5. What are the reasons for completing an informal review? What is one consideration that support workers should be aware of?

Part B

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

Case study

Mrs Gibson is 45 years old. After being diagnosed with breast cancer she had a total mastectomy but the disease recurred. As a result, she was admitted to hospital for treatment. She has increased shortness of breath and chest swelling following chemotherapy, and suffers from pneumonia.

Her hospital stay is marked by increased pain, chest swelling, periodic seizures, a second pneumonia and progressive weakness. At all times, she is bed-bound and artificially fed. Her pain is relatively well-controlled but the chest swelling is uncontrollable. Communication is possible to some extent through hand signals.

Decisions are made after lengthy explanations to Mrs Gibson and her husband, who is her designated healthcare agent. Mrs Gibson elects a ‘do not resuscitate’ option. She also asks not to be sedated as she wants to remain in control. She wants her feeding tube to be withdrawn when the end is near and it is no longer effective. She also asks that no visitors be allowed as she wants them to remember her when she was well, and not see her as she is now.

In the final weeks of her life, Mrs Gibson’s condition further deteriorates and she is often unconscious. Her ability to communicate markedly decreases. In response to her enormous suffering, palliative care staff recommend that she be sedated. Although her husband supports the decision, several palliative care workers are concerned that such an intervention goes against her wishes. John, who is the primary support worker, has formed a strong relationship with Mrs Gibson’s husband, Roger, who is roughly the same age as him. Roger is very distressed by his wife’s suffering and he is the person who has legal responsibility now that Mrs Gibson is no longer able to speak for herself. Roger is aware that Mrs Gibson does not want to be sedated but he also knows that Mrs Gibson does not want to experience unnecessary pain or discomfort. Mrs Gibson’s feeding tube is withdrawn, in accordance with symptom control, comfort measures and her wishes.

John feels emotionally very close to Roger and his wife and talks about this to his supervisor. His supervisor gives him some contacts for counselling services if John feels the need to access additional support. John is also reminded that he needs to take care of himself, take time out to relax, eat and sleep and also maintain good exercise habits to ensure his own health and wellbeing. John’s supervisor reminds him that he is available to talk to regarding his work if John wishes to do so.

Mrs Gibson is completely unresponsive in the last five days of her life. When Mrs Gibson’s closest friend comes to visit, a worker feels so sorry for her that she lets her into Mrs Gibson’s room for a few minutes. Roger, who is at lunch when the visitor arrives, feels extremely upset when he finds the visitor in his wife’s room on his return. Roger asks John to assist him to make a formal complaint. John lets the supervisor know what has occurred.

The next day Mrs Gibson dies peacefully while Roger is present. Roger is distraught and will not leave his wife’s room. John comes in early in response to the request by the supervisor and sits with Roger. After several hours Roger allows John to call the funeral director to come and take Mrs Gibson to the funeral parlour.

John and Roger pack all of Mrs Gibson’s personal effects for Roger to take home and ensure that the clothing that Mrs Gibson requested for her burial is given to the funeral director.

1. How did John look after his own health and wellbeing?

2. If John was not aware of his feelings and need for support, he might have experience unresolved grief. Give three examples of the effect of unresolved grief on a support worker.

3. What could John's supervisor do to assist other members of the palliative care team to discuss and debrief?