

CHCPAL001

Deliver care services
using a palliative
approach



**LEARNER
GUIDE**

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This Learner Guide

CHCPAL001 - Deliver care services using a palliative approach

This unit describes the performance outcomes, skills and knowledge required to provide care for people with life-limiting illness and those within the normal ageing process using a palliative approach, as well as end-of-life care.

This unit applies to workers in a residential or community context. Work performed requires some discretion and judgement and is carried out under regular direct, indirect or remote supervision.

The skills in this unit must be applied in accordance with Commonwealth and State/Territory legislation, Australian standards and industry codes of practice.

No occupational licensing, certification or specific legislative requirements apply to this unit at the time of publication.

A complete copy of the above unit of competency can be downloaded from the TGA website:

<https://training.gov.au/Training/Details/CHCPAL001>

About this Unit of Competency Introduction

As a worker, a trainee, or a future worker, you want to enjoy your work and become known as a valuable team member. This unit of competency will help you acquire the knowledge and skills to work effectively as an individual and in groups. It will give you the basis to contribute to the goals of the organisation which employs you.

It is essential that you begin your training by becoming familiar with the industry standards to which organisations must conform.

This Learner Guide Covers

Deliver care services using a palliative approach

- I. Apply principles and aims of a palliative approach when supporting people
- II. Respect the person's preferences for quality-of-life choices
- III. Follow the person's advance care directives in the individualised plan
- IV. Respond to signs of pain and other symptoms
- V. Follow end-of-life care strategies
- VI. Manage own emotional responses and ethical issues

Learning Program

As you progress through this unit of study, you will develop skills in locating and understanding an organisation's policies and procedures. You will build up a sound knowledge of the industry standards within which organisations must operate. You will become more aware of the effect that your own skills in dealing with people have on your success or otherwise in the workplace. Knowledge of your skills and capabilities will help you make informed choices about your further study and career options.

Additional Learning Support

To obtain additional support you may:

- Search for other resources. You may find books, journals, videos and other materials which provide additional information about topics in this unit.
- Search for other resources in your local library. Most libraries keep information about government departments and other organisations, services and programs. The librarian should be able to help you locate such resources.
- Contact information services such as Infolink, Equal Opportunity Commission, Commissioner of Workplace Agreements, Union organisations, and public relations and information services provided by various government departments. Many of these services are listed in the telephone directory.
- Contact your facilitator.

Facilitation

Your training organisation will provide you with a facilitator. Your facilitator will play an active role in supporting your learning. Your facilitator will help you at any time during working hours to assist with:

- How and when to make contact
- What you need to do to complete this unit of study
- What support will be provided

Here are some of the things your facilitator may do to make your study easier:

- Give you a clear visual timetable of events for the semester or term in which you are enrolled, including any deadlines for assessments
- Provide you with online webinar times and availability
- Use ‘action sheets’ to remind you about tasks you need to complete, and updates on websites
- Make themselves available by telephone for support discussion and provide you with industry updates by email where applicable
- Keep in touch with you during your studies

Flexible Learning

Studying to become a competent worker is an interesting and exciting thing to do. You will learn about current issues in this area. You will establish relationships with other students, fellow workers, and clients. You will learn about your own ideas, attitudes, and values. You will also have fun. (Most of the time!)

At other times, studying can seem overwhelming and impossibly demanding, particularly when you have an assignment to do and you are not sure how to tackle it, your family and friends want you to spend time with them, or a movie you want to see is on television.

Sometimes being a student can be hard.

Here are some ideas to help you through the hard times. To study effectively, you need space, resources, and time.

Space

Try to set up a place at home or at work where you can:

- Keep your study materials
- Be reasonably quiet and free from interruptions
- Be reasonably comfortable, with good lighting, seating, and a flat surface for writing

If it is impossible for you to set up a study space, perhaps you could use your local library. You will not be able to store your study materials there, but you will have a quiet place, a desk and chair, and easy access to the other facilities.

Study Resources

The most basic resources you will need are:

- A chair
- A desk or table
- A computer with internet access
- A reading lamp or good light
- A folder or file to keep your notes and study materials together
- Materials to record information (pen and paper or notebooks, or a computer and printer)
- Reference materials, including a dictionary

Do not forget that other people can be valuable study resources. Your fellow workers, work supervisor, other students, your facilitator, your local librarian, and workers in this area can also help you.

Time

It is important to plan your study time. Work out a time that suits you and plan around it. Most people find that studying, in short, concentrated blocks of time (an hour or two) at regular intervals (daily, every second day, once a week) is more effective than trying to cram a lot of learning into a whole day. You need time to ‘digest’ the information in one section before you move on to the next, and everyone needs regular breaks from study to avoid overload. Be realistic in allocating time for study. Look at what is required for the unit and look at your other commitments.

Make up a study timetable and stick to it. Build in ‘deadlines’ and set yourself goals for completing study tasks. Allow time for reading and completing activities. Remember that it is the quality of the time you spend studying rather than the quantity that is important.

Study Strategies

Different people have different learning ‘styles’. Some people learn best by listening or repeating things out loud. Some learn best by ‘doing’, some by reading and making notes. Assess your own learning style and try to identify any barriers to learning which might affect you. Are you easily distracted? Are you afraid you will fail? Are you taking study too seriously? Not seriously enough? Do you have supportive friends and family? Here are some ideas for effective study strategies:

1. **Make notes.** This often helps you to remember new or unfamiliar information. Do not worry about spelling or neatness, as long as you can read your own notes. Keep your notes with the rest of your study materials and add to them as you go. Use pictures and diagrams if this helps.
2. **Underline keywords** when you are reading the materials in this Learner Guide. (Do not underline things in other people’s books.) This also helps you to remember important points.
3. **Talk to other people** (fellow workers, fellow students, friends, family, or your facilitator) about what you are learning. As well as help you to clarify and understand new ideas, talking also gives you a chance to find out extra information and to get fresh ideas and different points of view.



Using this Learner Guide

A Learner Guide is just that, a guide to help you learn. A Learner Guide is not a textbook. Your Learner Guide will:

1. Describe the skills you need to demonstrate to achieve competency for this unit.
2. Provide information and knowledge to help you develop your skills.
3. Provide you with structured learning activities to help you absorb knowledge and information and practice your skills.
4. Direct you to other sources of additional knowledge and information about topics for this unit.

How to Get the Most Out of Your Learner Guide

Some sections are quite long and cover complex ideas and information. If you come across anything you do not understand:

1. Talk to your facilitator.
2. Research the area using the books and materials listed under Resources.
3. Discuss the issue with other people (your workplace supervisor, fellow workers, fellow students).
4. Try to relate the information presented in this Learner Guide to your own experience and to what you already know.
5. Ask yourself questions as you go. For example, 'Have I seen this happening anywhere?' 'Could this apply to me?' 'What if...' This will help you to 'make sense' of new material, and to build on your existing knowledge.
6. Talk to people about your study. Talking is a great way to reinforce what you are learning.
7. Make notes.
8. Work through the activities. Even if you are tempted to skip some activities, do them anyway. They are there for a reason, and even if you already have the knowledge or skills relating to a particular activity, doing them will help to reinforce what you already know. If you do not understand an activity, think carefully about the way the questions or instructions are phrased. Read the section again to see if you can make sense of it. If you are still confused, contact your facilitator or discuss the activity with other students, fellow workers or with your workplace supervisor.

Additional Research, Reading, and Note-Taking

If you are using the additional references and resources suggested in the Learner Guide to take your knowledge a step further, there are a few simple things to keep in mind to make this kind of research easier.

Always make a note of the author's name, the title of the book or article, the edition, when it was published, where it was published, and the name of the publisher. This includes online articles. If you are taking notes about specific ideas or information, you will need to put the page number as well. This is called the reference information. You will need this for some assessment tasks, and it will help you to find the book again if you need to.

Keep your notes short and to the point. Relate your notes to the material in your Learner Guide. Put things into your own words. This will give you a better understanding of the material.

Start off with a question you want answered when you are exploring additional resource materials. This will structure your reading and save you time.

Introduction



Palliative care is a person and family-centred care provided for a person with an active, progressive, advanced disease who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life.

Sourced from What is palliative care?. © Palliative Care Australia Limited

Palliative care can be given in most healthcare settings. The healthcare settings for this unit include residential, home, and community care.

In essence, palliative care applies the palliative approach. The *palliative approach* specifically refers to the way that care is delivered. For care to adhere to the palliative approach, given care must follow certain philosophies and principles and have specific aims. Some of these are to accomplish the following:

- Improve the client's quality-of-life (QoL) by relieving them of their symptoms
- Provide the client relief through medication, care and support while considering their needs, values and preferences
- Provide support to the carer, family and relevant others affected by the diagnosis

The palliative approach's different philosophies, principles and aims will be discussed in more detail in Chapter 1. Throughout this Learner Guide, you will use the following terms related to palliative care:

Terminology	Meaning
Client	The resident or person receiving care.
Carer	A carer is an individual who provides unpaid, informal support and care to a family member, friend or neighbour who needs assistance because of disability, terminal illness, chronic illness and/or mental illness. The carer may or may not live with the individual.
Family	These are the people closest to the individual and with whom the individual has an ongoing, personal relationship. This may or may not include immediate biological family, a family of acquisition, blended families, same-sex partners and family and friends of choice.
Treating/Care team	This is the group of people involved in the client's care. The team may include doctors, nurses, Aboriginal Health Workers and allied health professionals (e.g. support workers and dieticians).

Based on *End of Life Care and Decision-Making*, used under CC BY 4.0. © State of New South Wales NSW Ministry of Health. For current information go to www.health.nsw.gov.au.

In this Learner Guide, you will learn how to do the following:

- Apply principles and aims of a palliative approach when supporting people
- Respect the person's preferences for quality-of-life choices
- Follow the person's advance care directives in the individualised plan
- Respond to signs of pain and other symptoms
- Follow end-of-life care strategies
- Manage own emotional responses and ethical issues

I. Apply Principles and Aims of a Palliative Approach When Supporting People



Some illnesses are life-limiting or life-threatening. A *life-limiting illness* is an illness or disease that cannot be cured and is expected to shorten one's life. It can be malignant or non-malignant. Often, these lead to further health complications, causing physical pain and psychological distress.

Below are some examples of illnesses that may require palliative care:

Cancer

Dementia

Stroke

Chronic obstructive pulmonary disease

Congestive heart failure

Alzheimer's disease

Kidney failure

These illnesses are irreversible, and the chance of long-term recovery is low. Thus, it is recommended the person is placed under palliative care. Palliative care provides treatment and support to the client and other relevant people around them. Care may start at any point and continue until the person's end-of-life stage.

The Palliative Approach

As a support worker, you are responsible for providing care and support to clients with life-limiting illnesses and relevant others. Knowing the philosophies, principles and aims of a palliative approach will help you do this task.

Philosophy is the stance that serves as a guide for one's conduct. In the palliative approach, the following underlying philosophies guide people who provide palliative care:

Care must address the needs, preferences and values of the client and relevant others.

Care must be person and family-centred.

Care must be accessible to people with a life-limiting illness.

Care affirms life but recognises death as an inevitable part of it.

Based on National Palliative Care Standards. © Palliative Care Australia Limited

Principles are behaviours and attitudes informed by underlying philosophies. In essence, a principle is a philosophy translated into thoughts and actions. The principles of the palliative approach include, but are not limited to, the following:

- Recognising and assessing the needs, preferences and values of the client
- Providing holistic care to address the needs, preferences and values of the client
- Recognising the integral role of the relevant people around the client in planning and decision-making
- Treating clients and relevant people around them with dignity and respect
- Respecting the cultural, spiritual and religious needs of the client
- Supporting the decisions of the client and relevant people during the provision of care
- Supporting the bereaved people following the death of the client

Aim refers to the purpose or the desired outcome. The palliative approach aims to achieve the following:

- Improve the quality of life (QOL) of the person with a life-limiting illness
- Provide support to the relevant people around the person with a life-limiting illness

The National Palliative Care Standards

The *National Palliative Care Standards* are standards for providing palliative care. Palliative Care Australia created these standards. The organisation is the peak national body for palliative care.

The standards list care providers' requirements when delivering palliative care. For this unit, these standards are applied in community and residential care.

Standards 1 to 6 are Care Standards that are necessary for delivering quality care. Here is a summary:

Standard	How to Comply
Assessment of needs (Standard 1)	<ul style="list-style-type: none"> ▪ The assessment focuses on the client's physical, psychological, cultural, social and spiritual needs and relevant others. ▪ The client's needs are reassessed regularly. ▪ The assessment results inform the care plan, and any changes are noted.
Developing the care plan (Standard 2)	<ul style="list-style-type: none"> ▪ The care plan addresses the client's physical, psychological, cultural, social and spiritual needs and relevant others. ▪ The client and relevant others are involved in planning and are updated regularly. ▪ The care plan is updated regularly. ▪ The care plan includes the preferred type and location of care. ▪ The care plan includes instructions for future care (e.g. emergency support and substitute decision-maker).

Standard	How to Comply
Caring for carers (Standard 3)	<ul style="list-style-type: none"> ▪ The carers' needs are assessed and documented. ▪ The carers are involved in planning and provided with information and resources. ▪ The carers are educated on care before and after death.
Providing care (Standard 4)	<ul style="list-style-type: none"> ▪ Care is delivered promptly. ▪ Care addresses the changing needs of the client and relevant others. ▪ Care addresses the client's physical, psychological, cultural, social and spiritual needs and relevant others. ▪ Care that does not fit the goals and preferences of the client is negotiated.
Transitions within and between services (Standard 5)	<ul style="list-style-type: none"> ▪ Prepare for the transition between care settings. ▪ Do referrals to specialists or services to address the client's physical, psychological, cultural, social and spiritual needs and relevant others. ▪ Further support is given for care at home, depending on the client's preferences.
Grief support (Standard 6)	<ul style="list-style-type: none"> ▪ Family and others are given culturally appropriate information and resources. ▪ Support services are regularly provided to family and others before and after death. ▪ Referrals to support groups or professionals (e.g. counsellors, psychologists) are made as needed. ▪ Staff are given education and support about grief, bereavement and loss.

Based on [National Palliative Care Standards](#). © Palliative Care Australia Limited



Standards 7 to 9 are Government Standards outlining quality management and improvement of service providers. Refer to the table below for the summary:

Standard	How to Comply
Service culture (Standard 7)	<ul style="list-style-type: none"> ▪ The service provider provides person-centred palliative care. ▪ The carer supports the needs and preferences of the client reaching the end of life, their family and others.
Quality improvement (Standard 8)	<ul style="list-style-type: none"> ▪ Service providers comply with governance and safety requirements. ▪ Quality service is ensured by improving existing systems, participating in research and engaging in clinical audit reviews.
Staff qualifications and training (Standard 9)	<ul style="list-style-type: none"> ▪ A multidisciplinary team is available to meet the client's physical, psychological, cultural, social and spiritual needs and relevant others. ▪ The staff receives support and supervision. ▪ The staff undergoes training to ensure the delivery of culturally safe care. ▪ The staff are trained in self-care strategies and can access personal support.

Based on National Palliative Care Standards. © Palliative Care Australia Limited

In this chapter, you will learn how to do the following:

- Identify the holistic needs of the person
- Support the person and their relevant others to express needs and preferences
- Communicate with the person and their relevant others about quality-of-life, pain and comfort
- Adjust communication techniques to meet the individual needs of the person and their relevant others
- Respect and support the person's relevant others as integral parts of the care team



1.1 Identify the Holistic Needs of the Person



Every living person has their own set of needs that must be addressed. But for those with a life-limiting illness, these needs are more complex and encompass different life aspects. Needs may even change over time due to their medical condition.

Holistic means that care recognises and addresses the entirety of the person. Palliative care is holistic care. Aside from the symptoms of the illness, other factors (e.g. social and emotional) are also given importance. Recognising holistic needs is crucial. You cannot address needs if you cannot identify them. Holistic needs include the following:

- **Physical needs** – These include the following:
 - Managing pain and other symptoms
 - Promoting comfort
- **Emotional needs** – These include the following:
 - Providing comfort when the person expresses distress
- **Psychological needs** – These include the following:
 - Providing the client with opportunities to talk about needs and worries
- **Social needs** – These include the following:
 - Connecting the client to others and helping them establish deep connections with others
- **Spiritual needs** – These include the following:
 - Providing care in line with the client's beliefs

1.1.1 The Palliative Approach as a Person-Centred Approach

As the name suggests, *person-centred* means putting the person at the centre of care. This means seeing them as a person first and not as a 'case'. The person-centred concept aims to protect the rights and dignity of a person. It focuses on matching services to meet a person's needs and wishes. For example, you will give the person control when using a person-centred approach. You will respect their decision on what kind of treatment they want to receive or where they want to receive care services.

In providing person-centred palliative care, you should do the following:

Give the person control over their care.

Focus on the person's strengths.

Involve the person's family and relevant others.

Tailor your care to the person's circumstances.

Based on What is a person-led approach?, used under CC BY 4.0. © State of New South Wales NSW Ministry of Health. For current information go to www.health.nsw.gov.au.

1.1.2 The Palliative Approach as a Holistic Approach

As mentioned, the holistic approach recognises that the needs of an ill person are not limited to the physical or medical. A life-limiting illness affects both the body and the mind. It may also impact relationships between the sick person and others around them. Given the wide-reaching effect of the illness, a wide-reaching approach is also needed. In other words, palliative care should not be limited to addressing only the person's physical or medical needs. It must also address the person's psychological, emotional, social, cultural and religious needs.

Thus, the scope of palliative care must cover the following:

- The needs of the client, starting from the diagnosis of their illness up until the end of life
- The needs of the relevant people (e.g. the family) during palliative care and after the client's death

The palliative approach's benefits include providing care services that cover the scope mentioned above. This means services holistically address the needs of everyone involved. These services also address the person's holistic needs extending over time, not just during the end of life.

Palliative care services include the following:



Holistic Approach to Address End-of-Life Needs

End of life refers to the period when a person suffers from an irreversible decline due to illness. This period may last for years if the person has a chronic or malignant disease. This period may be brief for those who suffer from acute or unexpected illnesses. End-of-life needs may vary from client to client. However, the same services are offered to them, though tailored to their requirements:



- **Treatment of symptoms**

As mentioned in the introductory chapter, the primary goal of palliative care is to improve the QoL of a person with a life-limiting illness. Most incurable diseases cause a lot of physical pain in a client's physical body, making daily living difficult. Treatment of these symptoms helps ease the pain they are experiencing and improve their QoL.

Understanding what causes the pain is also essential. This helps determine the type of treatment that can be provided to the client. For example, treatment for pain caused by tissue damage (e.g. bones, soft tissues and organs) will be different from pain caused by nerve damage. Depending on the damage, pain treatment can range from a cold compress to anti-inflammatory medicine. For nerve damage, drugs are more commonly used (e.g. topical treatments, anticonvulsants and painkillers).

- **Individualised goals for care**

Palliative care is tailored according to the person's preferences, wishes, values and beliefs. You and your care team need to understand what the client wants regarding their treatment. This can be achieved through proper communication between the client and the care team providing the service.

For instance, nutrition and hydration are vital in palliative care's early stages. Proper nutrition and hydration will give clients the energy they need and make them healthier. A healthier body reduces the risk of infection and improves the QoL. Nutritional goals are incorporated into the treatment goals, and the client or family are consulted regarding this. Any preferences (e.g. favourite foods) and cultural or religious restrictions are also noted.

Some of the client's nutritional requirements may include the following:

- Adjustment of meal times to ensure the client's appetite is at best
- Consumption of meals that comply with the recommendations of the person's doctor or physician (e.g. avoiding food with high sodium content)
- Provision of tube feeding if the person is suffering from ailments that make it difficult to swallow

Some of the client's hydration requirements may include the following:

Provision of artificial hydration if the person has difficulties swallowing

Consumption of foods with high water content (e.g. fruits and vegetables)

Tracking water intake and urine output to ensure the person is not dehydrated

However, nutritional and hydration requirements may change over time. For example, it is common for the client to stop eating during the end of life. As their illness progresses, the muscles weaken, and swallowing becomes difficult. The client's refusal to eat or drink can cause family concerns. They may think that their loved one is not getting proper nutrition. Some may insist on feeding. It is explained to the family that aggressive feeding may cause their loved one discomfort. They are reassured that during this time, the focus of nutrition is to provide comfort and better QoL on the last days of the client's life. Easing hunger and thirst is important, but not at the cost of the client's comfort.



Here are some measures you can take to address the nutrition and hydration requirements of your client:

- Offer small amounts of food and fluid regularly, but do not force them
- Moisten the lips and mouth using swabs dipped in fluid every one to two hours
- Give the client some ice chips to stay hydrated if unconscious
- Talk to the family about the possibility of using artificial hydration if it makes the client more comfortable

■ Additional support

The other needs of the clients, families and carers are also assessed. This ensures that the care provided follows their wishes, values and preferences. For example, the cultural and religious needs of the clients and relevant others are considered. This may include incorporating cultural or religious practices in their care, like serving particular foods, singing, ceremonies or healing.

Support is also given for any psychological and emotional impacts experienced by the client and relevant others during palliative care. Knowing that a person has a life-limiting illness can be distressing for the client and their loved ones. In particular, the news of the diagnosis can be a hard blow. They may refuse to accept the situation or have difficulty coping with it.

Refer to the table below for the possible psychological and emotional impacts:

Person	Possible Psychological Impact	Possible Emotional Impact
Client	<ul style="list-style-type: none"> ▪ Depression ▪ Anxiety ▪ Fear 	<ul style="list-style-type: none"> ▪ Anger ▪ Denial ▪ Shock
Family	<ul style="list-style-type: none"> ▪ Depression ▪ Anxiety ▪ Fear 	<ul style="list-style-type: none"> ▪ Guilt ▪ Helplessness ▪ Shock
Carer	<ul style="list-style-type: none"> ▪ Depression ▪ Anxiety 	<ul style="list-style-type: none"> ▪ Helplessness ▪ Sadness
Friends, Colleagues and Others	<ul style="list-style-type: none"> ▪ Depression ▪ Anxiety ▪ Fear 	<ul style="list-style-type: none"> ▪ Shock ▪ Denial ▪ Sadness

The care journey will not be easy in most cases, especially as the end of life draws near. It can be difficult for everyone who may need support to move forward.

- **Coordinated care**

Palliative care services help organise the delivery of care. The care team can bring in specialists or try different diagnostic and treatment interventions. Care may also be delivered in multiple settings (e.g. home care, nursing homes, hospice care) as per the client's wish. All these will depend on the needs and preferences of the client. The trouble and stress of undergoing different processes within different healthcare setups in palliative care are minimised.

Below are other types of needs of people dealing with a life-limiting illness:

- **Physical** – Assistance in maintaining good personal hygiene
- **Emotional** – Feelings of assurance through words of affirmation and physical affection
- **Psychological** – Opportunities to boost independence and self-confidence (e.g. expression through art or pursuing passion/interests)
- **Social** – Interaction with people who have similar interests/hobbies
- **Spiritual** – Opportunities to observe and celebrate religious traditions and celebrations

Holistic Approach to Address Needs Extending Over Time

In palliative care, addressing the client's holistic needs is not limited to just the end of life. Remember that palliative care also involves the client's family and relevant others. Often, holistic needs do not end when the client's life has ended. These needs extend after death and revolve around the loved ones that remain. Recognising these needs is the first step towards providing everyone with the appropriate support.



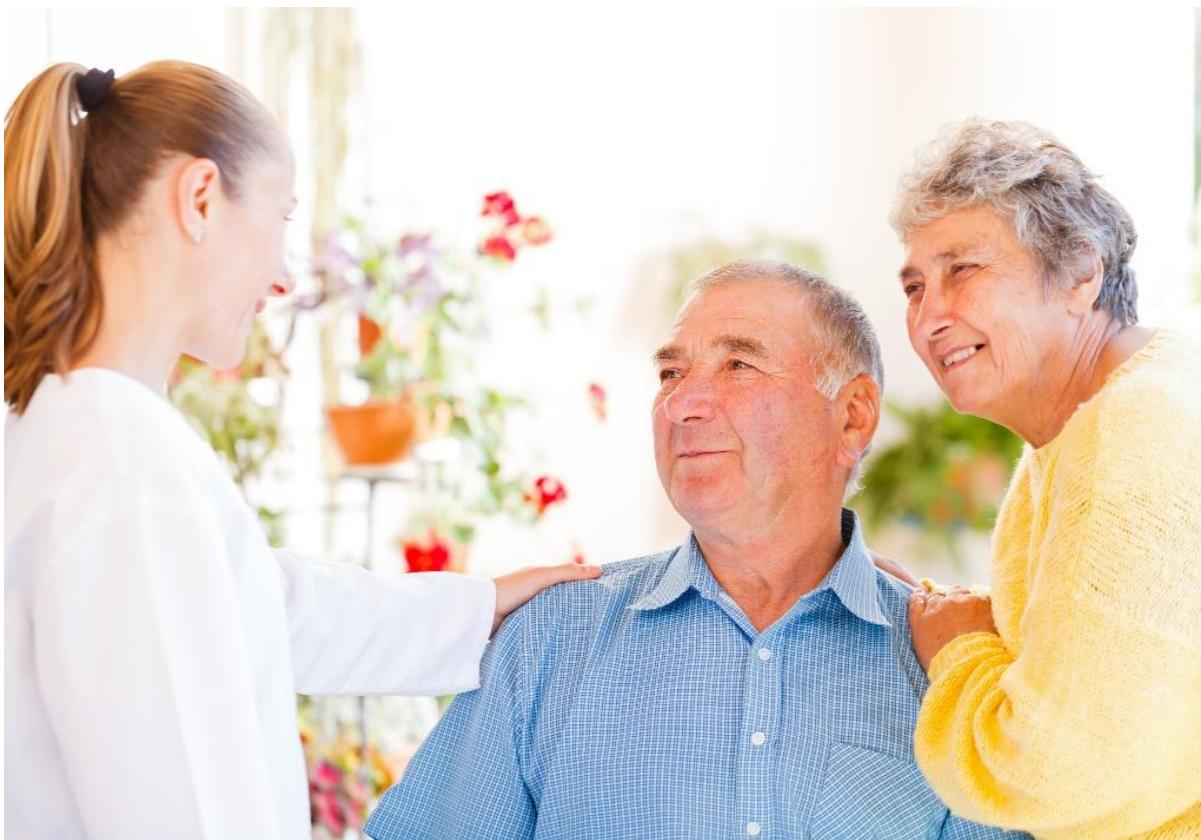
Care services addressing needs extending over time include care after death and support for the bereaved. In providing care after death, you will consider the spiritual needs of the client and their loved ones. In providing support for the bereaved, you will consider their emotional needs.

Checkpoint! Let's Review



1. Holistic means that care recognises and addresses the entirety of the person. Palliative care is holistic care.
2. Person-centred means putting the person at the centre of care. This means seeing them as a person first and not as a 'case'.
3. The person-centred concept aims to protect the rights and dignity of a person. It focuses on matching services to meet a person's needs and wishes.
4. A life-limiting illness is an illness or disease that cannot be cured and is expected to shorten one's life.
5. A life-limiting illness can be malignant or non-malignant. Often, these lead to further health complications, causing physical pain and psychological distress.

1.2 Support the Person and Their Relevant Others to Express Needs and Preferences



You must demonstrate support for the person's needs and preferences. This helps the person to be more comfortable with you and other care team members. Seeing your support will encourage them to be open to the things they expect in palliative care service. It also allows care team members to identify these needs and preferences accurately. Thus, they can adjust the care provided to suit the client.

It would be best if you also recognised the needs and preferences of your client's carer, family and other people important to them. The client's carer may or may not be related to them but oversees taking care of them at home. On the other hand, the client's family refers to immediate family members like their spouse or children. Lastly, other people identified by the client refer to their friends or anyone outside their family with whom they have a close bond. Responding to these people's concerns or suggestions helps build their trust in you and your organisation. This also improves the relationship between them and the care team.

The case study below demonstrates support for the person's needs and preferences:

Client Needs and Preferences

Thanh migrated to Australia 40 years ago. She is originally from Vietnam. Following her second stroke, Thanh had difficulties doing her daily tasks. Although reluctant, she chose to stay in a residential aged care facility to receive assistance with daily living.

Sera, the support worker, noticed that Thanh still insists on bathing and feeding herself even if it is hard for her to move independently. Sera found out that Thanh is worried asking for assistance will make her look too demanding. In addition, she has concerns about modesty and feels embarrassed to be assisted with bathing. Thus, she tries to do things on her own.

Sera gently explained that helping Thanh is part of her job. Sera added that when Thanh expresses her needs, she can help her better. Thus, Thanh can spend her days worry-free. Sera also mentioned that they could adjust Thanh's care following her preferences. This includes her concerns with bathing.

As seen in the case study, some client needs are more recognisable than others. For instance, it is easy to recognise when your client is low on medications or has not yet eaten their meal. But not all needs are as easy to identify. Clients may hesitate to voice their needs and preferences due to their cultural upbringing or personal attitudes. For example, they may think they are being a bother or that their request is difficult to fulfil.

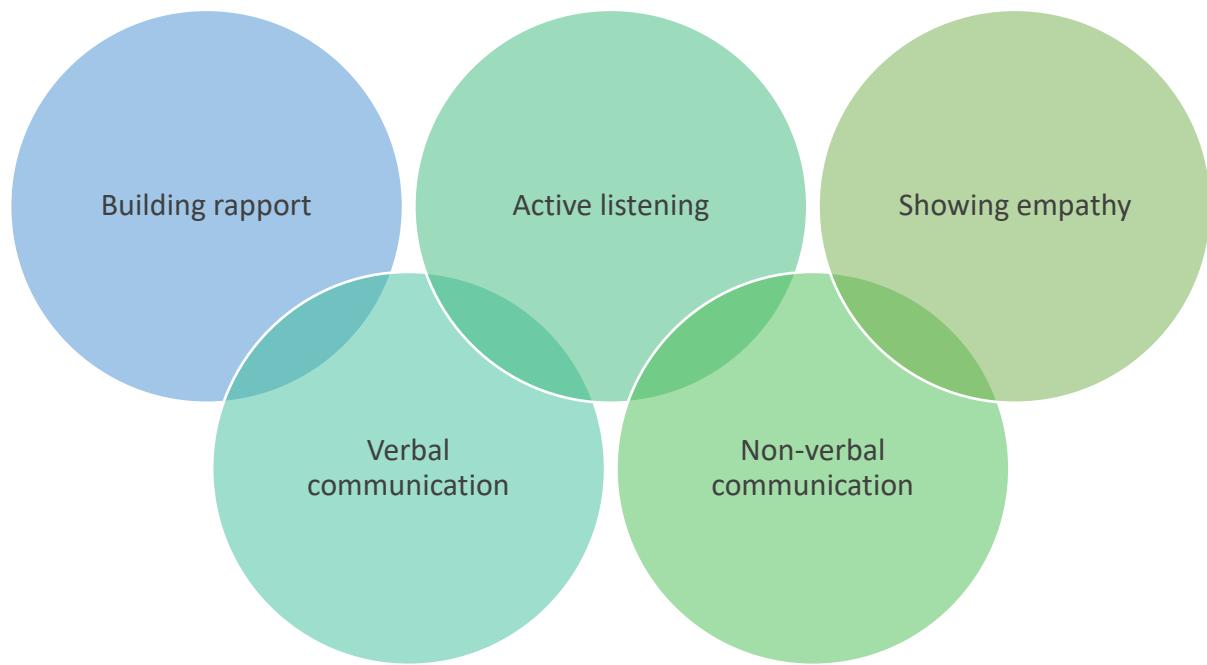
As a support worker, your job is to create a safe environment where everyone can express their needs and preferences. You must know what your clients need. Not knowing will make it difficult for you and your care team to address these needs and preferences. There can be barriers that prevent them from being open (e.g. cultural differences, personal attitude). However, using the appropriate communication strategies will help you overcome them.



1.2.1 Effective Communication



Before you can begin to apply communication strategies, examine the breakdown of the elements of effective communication below:



The three elements on top (building rapport, active listening and showing empathy) can be expressed through the two elements below (verbal and non-verbal communication). These five elements are interconnected and essential in effective communication. You will see how this process works in more detail below.



The first and most important step to opening communication lines is building rapport. *Rapport* is a harmonious relationship between individuals or groups of people. You can build rapport in simple but effective ways by using the following techniques:

- **Addressing people using their names**

When you address people by their names, it implies attentiveness and interest. On the first meeting, remember the names and faces of your client and the people around them. This might not be easy initially, but visual cues and markers may help you. For example, you can identify who is who by distinguishing features (e.g. hair colour, height or jewellery). On your next encounters, try to call them by their names. You might be surprised to learn how many people appreciate being remembered. It is especially meaningful in your line of work, where you encounter many people daily.

- **Mirroring the speech and expression of the person you are talking to**

Another way of expressing attentiveness is through mirroring. Like the name suggests, *mirroring* is copying the speech, expression or mannerisms of the person you are talking to. You must match your speech or expression to your conversation partner. It would not be right to smile when someone shares a sad story. Likewise, it would be awkward to remain very polite when someone is telling a good joke. Paying attention to these little things shows that you are attuned to others.

- **Using non-verbal language**

Body language is equally as important in communication. Remember, your words will not appear sincere when your body language does not reflect them. Some common examples of body language include eye contact, facial expressions, posture, gestures and giving space. In conversations, you can show you are listening by tilting your body towards the person, making eye contact and nodding from time to time.

Generally, aim to match your body language to your client's (e.g. being relaxed when they are). However, you also must be mindful when mirroring body language. Do not mirror those that may be seen as rude (e.g. crossing arms or rolling eyes) or showing disinterest (e.g. tapping your foot). Consider their comfort level when approaching them too. Be mindful of differences in cultural upbringing or personal attitudes. Some might find eye contact or proximity uncomfortable.

- **Doing active listening**

Active listening is listening to both what is and is not being said. It is also listening without judgment. When listening to the other person, dedicate your full attention to them. Do not interrupt them during their speech, especially with your stories. Remember that you are here to listen actively, not talk. Let them share their thoughts and experiences. Show that you are paying attention by using the non-verbal language mentioned above. You can also show that you understood their point by paraphrasing or repeating what they said in your own words. You can use lines such as, 'You are saying that...' or, 'From what I understood...'.



Match their tone of voice and expression and take note of and respond to any changes. Often, these indicate a shift in the mood or topic. Ask follow-up questions to show you care and want to know more about their experience. You can do this by asking, 'How did it feel when...' or, 'Can you tell me more about...'.

Most importantly, listen without judgment. The client and everyone involved may still be coming to terms with the reality of the diagnosis. This can be an emotional time for them. What they need is someone who will listen to them. Sometimes, they want to vent their frustrations or worries. It would certainly not be helpful to criticise how they feel. Hold your biases at bay and practice empathy. *Empathy* is understanding and feeling others' emotions. Imagine yourself in their situation and aim to validate their feelings. Some sample phrases are, 'It must have been hard for you,' and 'I can imagine how hard it was.'

- **Making a connection by finding shared interests**

You can also build rapport by finding shared or common interests. Talking about your shared interests will help you connect with your client and the people around them. You can ask them about their hobbies and favourite shows or food. The possibilities are endless.

- **Being genuine in your interactions**

Do not forget to be genuine in all your interactions with your clients and those around them. This genuineness is reflected in your words and body language. Your genuineness will be recognisable by everyone you encounter. Remember to be your best self. When you are authentic in approaching others, you will find that they will be the same.

Remember, trust is also present between the two parties once rapport is established. The presence of trust indicates that you have successfully created a safe space for your client and other relevant people. They are reassured their needs and preferences can be expressed and even listened to.



Refer to the table below for other communication strategies to build trust with the person and relevant others:

Individual	Communication Strategy
Person	Showing transparency by promptly informing the person of any updates regarding any changes to their care plan
Carer	Promptly informing the person's carer of any updates in the person's care plan
Family	Asking for feedback from the family regarding your ideas on the care strategies for the person
Others Identified by the Person	Remembering the names of the person's friends and address them by their names

Multimedia



Adjusting your communication strategies based on who you are talking to is important. An older person may have different communication needs. You may have to make adjustments to communicate effectively. The video below offers some valuable tips on how you can do this:

[How to Communicate Effectively With the Elderly](#)

1.2.2 Reporting Information to Supervisor

In this context, *information* refers to the client's and their relevant others' needs and preferences that you previously identified. After identifying this information, you must report this to your supervisor. Your supervisor will then relay this information to the other care team members. Thus, reporting information to your supervisor ensures the following:



- Everyone in the care team is updated about the client's and relevant others' needs and preferences
- Care provided will remain in line with the client's and relevant others' needs and preferences

Some of the information you have to report may include the following:

- The needs and requirements of clients not within the support worker's job role (e.g. providing psychological counselling, diagnosing medical conditions, prescribing medication)
- The client's needs and preferences regarding their care
- The client's changing needs (e.g. increasing pain requiring a higher dosage of pain medication)

Organisations will have different policies and procedures for reporting information to your supervisor. Ensure access to these policies and procedures.



Lotus Compassionate Care

Lotus Compassionate Care is the simulated organisation that provides services in disability support, home and community support, and residential care referenced in our learning resources.

Their policies and procedures are published on their site. You can access them through the link below:

[Policies and Procedures](#)

(username: newusername password: new password)

Checkpoint! Let's Review



1. You must demonstrate support for the person's needs and preferences. This encourages the people involved in care to express these needs and preferences.
2. It also allows care team members to identify these needs and preferences accurately. Thus, they can adjust the care provided to suit the client.
3. The person, family, carer and others feel valued when supported. This improves the relationship between them and the care team.
4. Like the name suggests, mirroring is copying the speech, expression or mannerisms of the person you are talking to. You must match your speech or expression to your conversation partner.



1.3 Communicate With the Person and Their Relevant Others About Quality-of-Life, Pain and Comfort



One of the aims of palliative care is to improve the quality of life (QoL) of the person with a life-limiting illness. In healthcare, *quality-of-life* refers to how a person perceives they are healthy, comfortable and able to enjoy life given their health status.

Pain and comfort levels are factors that greatly affect QoL. *Pain* is a distressing sensation in the body that physically and mentally hurts a person and causes discomfort. Pain negatively affects a person's wellbeing and functioning. For example, pain may hinder them from doing their daily tasks. It may also prevent them from enjoying life. Thus, higher pain levels cause deterioration in a person's QoL.

Comfort is the absence of pain or distress. When people are comfortable, they can do what they need to do. They are also more likely to enjoy life and live satisfactorily. Thus, higher comfort levels improve QoL.

The pain levels of a person with a life-limiting illness must be reduced, and their comfort levels promoted to improve their QoL. To know about their pain and comfort levels, you must communicate with the client and relevant others about these. The elements of effective communication discussed in Section 1.2.1 will still apply here.

In addition, communication can also include the following:

- Asking about the client's pain and comfort levels during your interactions with the client and relevant others
- Asking follow-up questions when a client hesitates to talk about their pain and comfort levels
- Asking follow-up questions when a client shows signs of being in pain
- Cultivating an open dialogue with the client by letting them know that managing pain, promoting their comfort and improving their QoL are priorities

Barriers to Reporting Pain and Comfort Levels



As mentioned, some client needs are more recognisable than others. This is because these needs can be identified objectively using your senses. It is easy to recognise when your client is low on medications because you can see or count how many more are left. Likewise, you know your client has not yet eaten because they have a schedule for their meals. On the other hand, pain and comfort levels rely on subjective reports from the client.

Because pain is subjective, the only person who knows best about how it feels is the one experiencing it. Self-reports are often used to assess a person's pain levels. However, some barriers prevent clients from communicating their pain truthfully and accurately. When pain is not accurately assessed, pain management strategies may not be effective. This will affect the client's comfort levels and decrease their QoL.

Barriers are things that block communication. Communication barriers hinder truthful reporting of pain and comfort levels. The barriers to reporting pain are often personal. Older clients are less likely to truthfully and accurately report their pain due to the following reasons:

- They believe that pain is a part of the ageing process.
- They do not want to be a burden.
- They do not have the right words to describe their pain.
- They come from a culture or generation that believes pain must be endured.
- They fear that strong medications may have adverse side effects.
- They think that increasing pain is a sign of a worsening condition.

If the client still feels reluctant to share, you can also seek information from the carer, family and other people around them. Sometimes, clients feel more comfortable disclosing to them instead of the health personnel. Keep the client's wellbeing in mind when approaching these relevant others.

Reporting Information to Your Supervisor

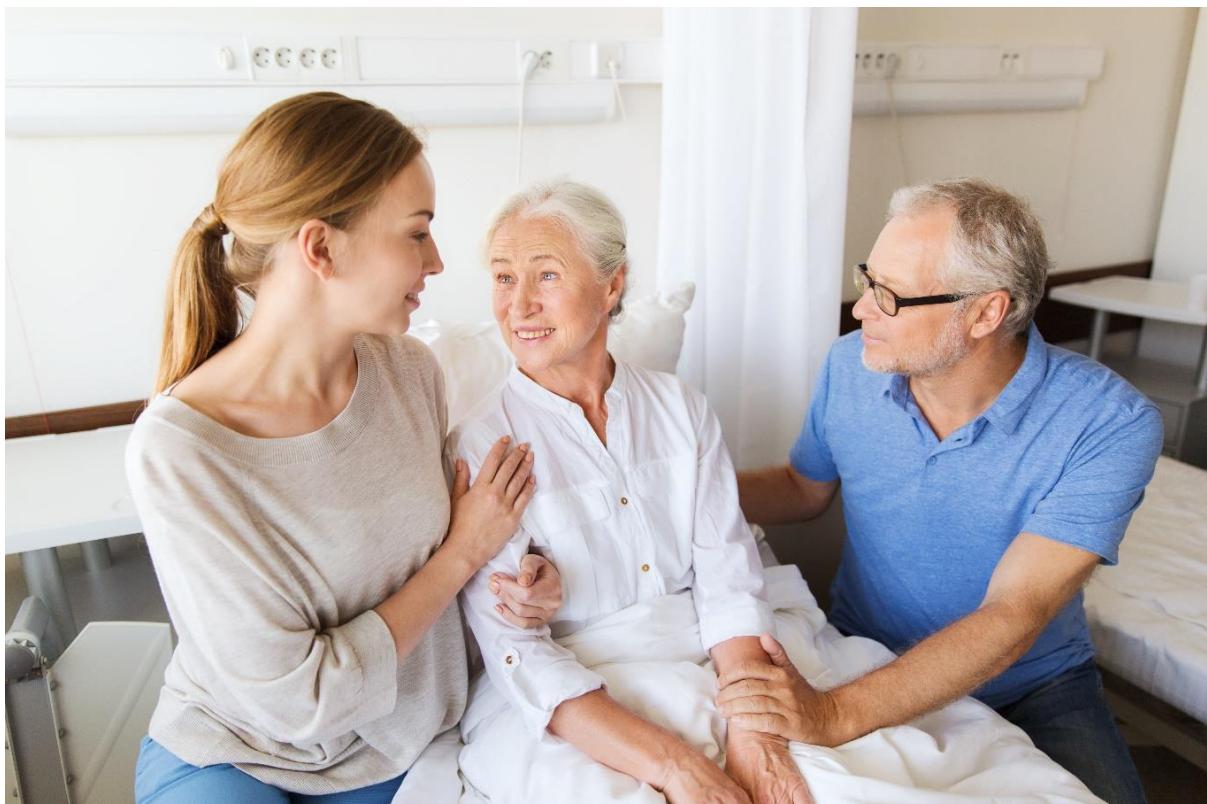
As discussed in the previous subchapter, you must report your findings to your supervisor once you have information on the client's pain and comfort levels. Your supervisor will relay this information to the other care team members. Organisations will have different policies and procedures for reporting information to your supervisor. Ensure access to these policies and procedures.



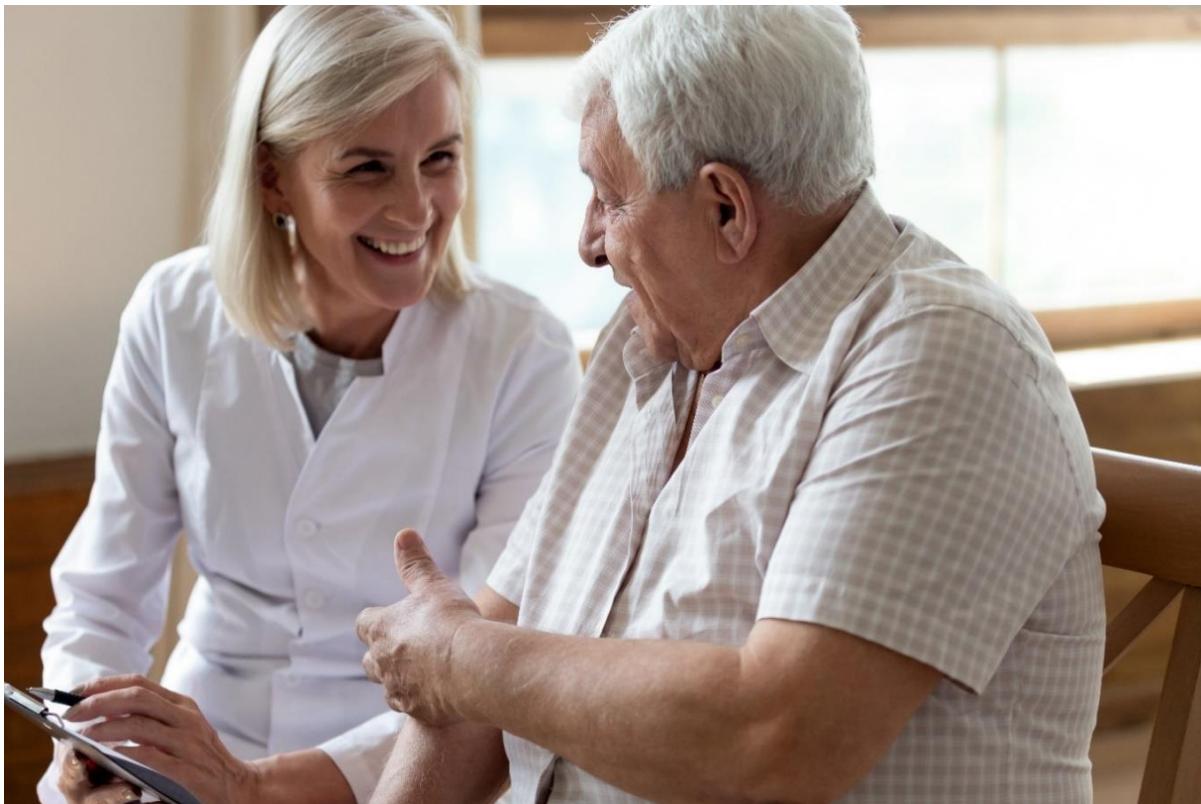
Checkpoint! Let's Review



1. One of the aims of palliative care is to improve the QoL of the person with a life-limiting illness.
2. In healthcare, QoL refers to how a person perceives they are healthy, comfortable and able to enjoy life given their health status.
3. Pain is a distressing sensation in the body that physically and mentally hurts a person and causes discomfort.
4. Comfort is the absence of pain or distress. When people are comfortable, they can do what they need to do.
5. Higher pain levels cause deterioration in a person's QoL.
6. Higher comfort levels improve a person's QoL.



1.4 Adjust Communication Techniques to Meet the Individual Needs of the Person and Their Relevant Others



In Subchapter 1.2, you learnt the different elements necessary for effective communication. You also learnt techniques to help clients and their relevant others express their needs. In this subchapter, you will learn more about adjusting these communication techniques to meet the client's individual needs and relevant others.

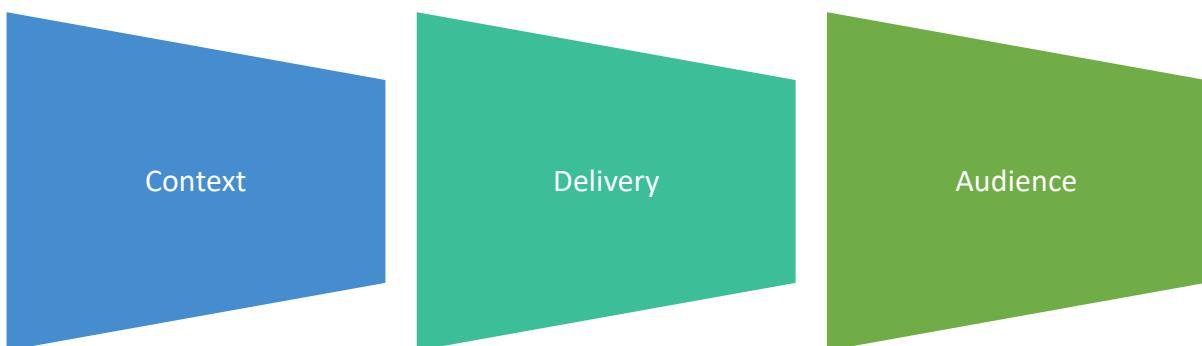
In palliative care, you are working closely with different people. Each of them is unique, with different personalities and attitudes. Because each person is different, you must adjust communication techniques depending on who you talk to. *Adjustments* are changes made to improve something. Adjustments to communication techniques ensure the following:

- Communication remains effective, regardless of the context and the interlocutor
- Misunderstandings are minimised
- Both parties understand each other
- The client and relevant others can better express their needs such that these needs are supported and met

Recall the following communication techniques from Subchapter 1.2:

- Addressing people using their names
- Mirroring the speech and expression of the person you are talking to
- Using non-verbal language
- Active listening
- Making a connection by finding shared interests
- Being genuine in your interactions

The effectiveness of these communication techniques would also depend on how you adjust them to suit your purpose. Consider making adjustments according to the following factors:



- **Context**

Context refers to the circumstances (e.g. setting, time and topic) surrounding the conversation. Adjusting communication techniques based on context ensures communication fits the current circumstances. For example, laughing, a non-verbal language, is inappropriate when death is the context of the conversation.

Below are some ways of adjusting communication techniques according to context:

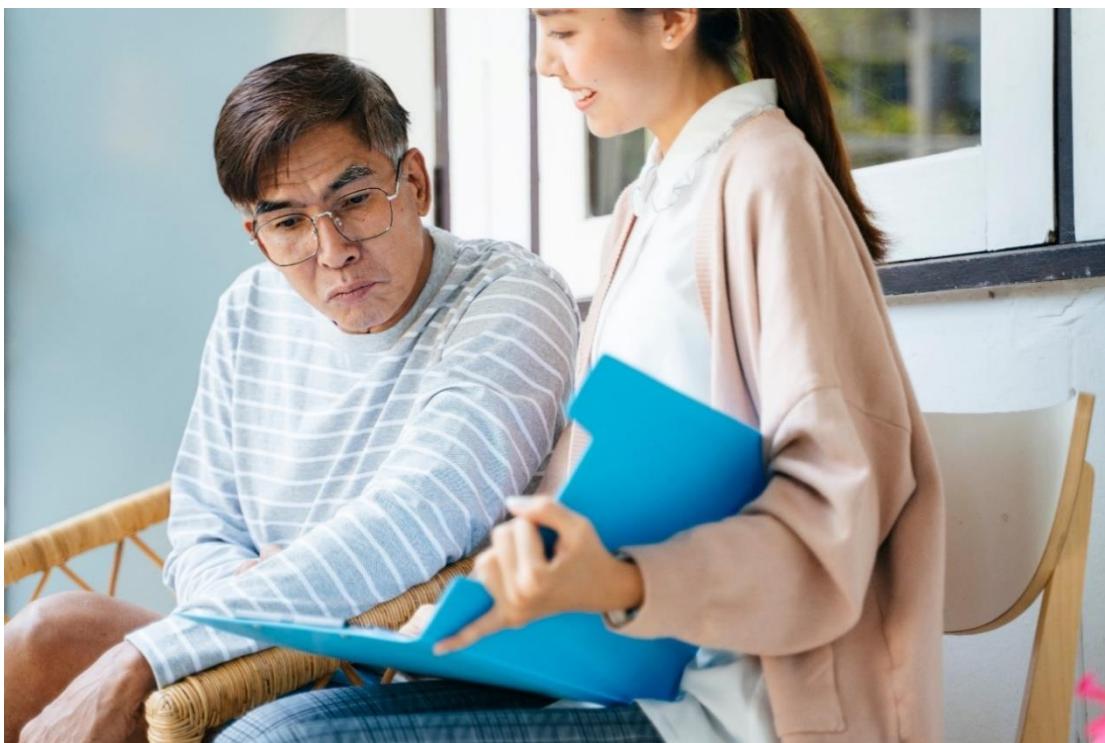
- **Talk in a private and comfortable space.** You must ensure the other person is comfortable talking about their needs. Consult in an area where they can sit comfortably and speak freely without being heard by others.
- **Set the context of the conversation.** State your purpose whenever you approach them. If you consult with them regarding their needs, let them know at the beginning of your conversation.
- **Communicate with the concerned person at an appropriate time.** For example, if they are upset, it is better to let them calm down first. Once they are calm, you can pick up the conversation again.

- **Delivery**

Delivery refers to the way the words in a conversation are given. Delivery may also involve non-verbal cues (e.g. tone of voice) or terms used in communications. Adjusting the delivery of communication techniques ensures the message conveyed is understood clearly.

Below are some examples of adjusting the delivery of communication techniques:

- **Use words that are easy to understand.** Avoid medical jargon, which can be difficult to understand for the layperson.
- **Say what needs to be said, but with kindness and understanding.** Being honest helps lessen misunderstandings.
- **As much as possible, avoid using euphemisms during conversations.** Although the topic of death can be uncomfortable for some, open conversations allow for better preparation in palliative care (e.g. using the term ‘passing away’ instead of ‘dying’).
- **Use non-verbal language to reinforce your message.** For example, simply altering your tone of voice can introduce warmth and empathy into the conversation.



▪ Audience

In communication, the *audience* is the other person you are talking to. As mentioned, you will work with people with unique personalities and needs. Adjusting communication techniques according to your audience ensures communication remains relevant.



Below are examples of adjusting communication techniques according to your audience:

- **Consider the audience's communication needs.** For example, when talking to a person with a hearing impairment, modify the speed and volume of your speech. It would be best if you speak slower and louder.
- **Consider the audience's personal circumstances in your communication.** You must adapt to these so that communication remains effective. In conversations with the family, you may find that some members may not be comfortable disagreeing in the presence of another member. With this, you might need to talk to that family member individually to know more about their thoughts.
- **Learn more about your audience and how they communicate.** This ensures that you can use appropriate communication techniques and tweak these as needed. For example, some may be more comfortable using informal language.

Checkpoint! Let's Review



1. Because each person is different, you must adjust communication techniques depending on who you talk to. Adjustments are changes made to improve something.
2. Adjusting communication techniques based on context ensures communication fits the current circumstances.
3. Delivery may also involve non-verbal cues (e.g. tone of voice) or communication terms. Adjusting the delivery of communication techniques ensures the message conveyed is understood clearly.

1.5 Respect and Support the Person's Relevant Others as Integral Parts of the Care Team



In the previous subchapters, you may have noticed how the carer, family and relevant others are always included in the care process. Because the palliative approach is person-centred, care involves other people important to the client.

Throughout palliative care, family and relevant others remain an integral part of the care team. They can serve as a bridge between the care team and the client to communicate needs. They can also be a valuable source of information (see discussion in Subchapter 1.3).

Respecting Other Members of the Care Team

Respect is often related to a person's rights, decisions and feelings. There are also concrete ways to give respect. For example, respecting someone as an integral part of the care team means they are involved every step of the way. Depending on the client's individualised plan, the family, carer or relevant others may have to be consulted on some matters. They may also have to make decisions later on behalf of the client. This is especially true during end-of-life care. They may also identify gaps or errors in the care delivery, which can be important in improving the client's QoL. However, the previously mentioned things would not be possible if they were not given the information and support needed.

Aside from responding to the concerns of the client's family, carers and relevant others, you can demonstrate respect through the following actions:

- **Get to know the client's family, carers and relevant others.**

Take the time to talk to the important people in the client's life. They can provide insights about your client, such as their personality and behaviour. They can also tell you information that you can use to form a stronger bond with your client.

Establishing a friendly approach when talking to these people shows that you respect their role in ensuring the client will get the optimal service they need.

- **Be sensitive in your words.**

You can demonstrate respect to the client's family, carers and relevant others using language that does not imply discrimination. For example, you can use gender-neutral terms when addressing a client's spouse. Use 'partner' instead of husband or wife.

In addition, these people may have cultural, traditional, or religious beliefs that might differ from the principles of palliative care. You can show respect by listening to their concerns. However, remember that the client's wellbeing is the most important. Be patient in explaining the purpose of treatments involved in palliative care and assure them that the client is safe under your care.

- **Share information.**

Keep the client's family, carers and relevant others updated with the client's condition. Sharing information with them means acknowledging their role in ensuring that the client is well taken care of. Aside from providing updates about the client's health, you can also share anecdotes about their behaviour. In turn, their family or relevant others can suggest tips on communicating better with the client.



Ensuring That Family and Relevant Others Are Informed and Supported

Remember to involve the family and relevant others in the client's care. You must ensure they are continuously informed and supported during their involvement. To be *informed* means having access to the client's care information. Keeping them informed also encourages them to be continuously involved in the client's care.



Shared information related to the client's care includes the following:

- Illness prognosis
- Progress of the client's condition
- Effectiveness and possible side effects of pain medications
- Contents of the client's individualised care plans and advance care directives
- Name of the care staff members caring for the client
- Changes that might have taken place while they were away
- Changing needs and preferences of the client

To ensure the family and relevant others are informed, you must do the following:

- Discuss how to best share the information needed by the family and relevant others with your supervisor.
- Ask the family and relevant others if they have questions or clarifications about the information shared with them.
- Encourage the family and relevant others to approach you or anyone from the care team when they have other questions about the client's care.

On the other hand, to be *supported* means that the family and relevant others are given the support that addresses their needs and preferences. Different kinds of support can be given in various ways by different professionals. For example, medical support is provided by physicians, specialists and other health professionals. Meanwhile, psychological support involves consultations with psychologists or psychiatrists.

To ensure the family and relevant others are supported, you must do the following:

- Encourage the family and relevant others to share their needs and preferences with you or anyone from the care team. Use appropriate communication techniques to encourage them to express these (see Subchapter 1.2).
- Continuously engage with the family and relevant others to know if any changes to their needs and preferences exist.
- Discuss with your supervisor how to best support the identified needs and preferences of the family and relevant others.
- Support the family and relevant others as stated in your job role.



Checkpoint! Let's Review

1. Respecting someone as an integral part of the care team means they are involved every step of the way.
2. The family and relevant others can serve as a bridge between the care team and the client to communicate needs.



Learning Activity for Chapter 1

Well done completing this chapter. You may now proceed to your **Learning Activity Booklet** (provided along with this Learner Guide) and complete the learning activities associated with this chapter.

Please coordinate with your trainer/training organisation for additional instructions and guidance in completing these practical activities.

II. Respect the Person's Preferences for Quality-of-Life Choices



In the previous chapter, you learnt how to apply the principles and aims of a palliative approach in your work. You also learnt how to use communication techniques to support your client's and their relevant others' needs.

This chapter will further discuss how you use these techniques to respond to their preferences related to quality-of-life choices. *Quality-of-life choices* refer to decisions made by your client related to their quality of life. These decisions may involve the type of care they receive or where they will receive it. Respecting the client's preferences for QoL ensures the client remains at the centre of palliative care.

You will also know how to consider your clients' different values and beliefs when working with them. You must know how to sensitively approach these differences to provide the best care for them.

In this chapter, you will learn how to do the following:

- Create a supportive environment to share information regarding changing needs and preferences
- Respect the person's individuality, values and beliefs
- Identify needs and issues outside the scope of job role
- Communicate in a manner that shows empathy and provides emotional support

2.1 Create a Supportive Environment to Share Information Regarding Changing Needs and Preferences



Life-limiting illnesses are often chronic and progressive. These are irreversible, and further health complications are expected in the long run. There will likely be changes in care depending on the stage of illness. You must identify these changing needs and preferences so that the care team can address them appropriately.

In the previous chapter, you learnt how to establish rapport. You also learnt how rapport enables everyone to share their needs and preferences. Although not explicitly stated, you have already created a supportive environment. Now, you have to foster this supportive environment where everyone can continuously share any changes in these needs.

Some of the client's changing needs in palliative care may include the following:

- Changing levels of care to address the physical symptoms of the illness
- Psychological needs associated with the effects of the illness (e.g. depression)
- Emotional needs related to the effects of the illness (e.g. illness prognosis)
- Spiritual needs (e.g. Finding solace in one's faith)
- Changing levels of assistance with tasks as the illness progresses (e.g. feeding)

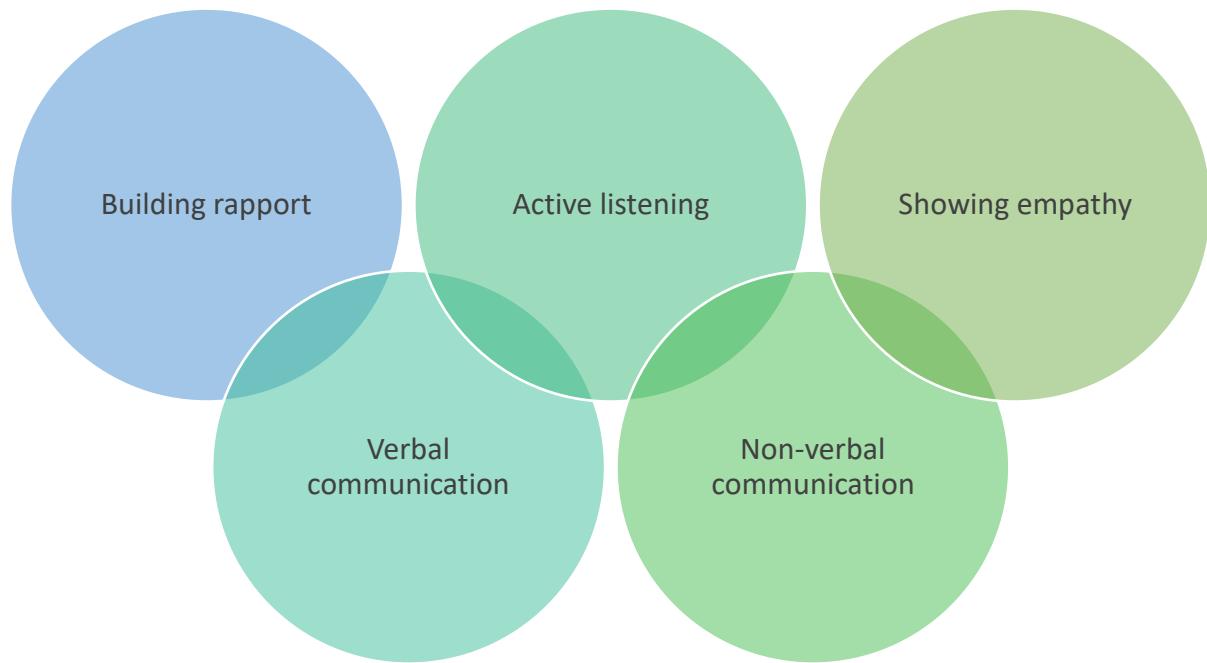
Some of the client's changing preferences in palliative care may include the following:

- Where they want to receive care
- What food do they like to eat
- Which services would they like to receive

Creating a Supportive Environment

A supportive environment encourages everyone to express their needs and preferences freely. Knowing these needs and preferences will be easy for you and your care team to respond to them. There may be barriers that prevent your client and others from being open (e.g. cultural differences, personal attitude). However, using the appropriate communication strategies will help you overcome them.

Below is a quick refresher on the elements of good communication:



Verbal and non-verbal communication can show you are actively listening. You can also express your empathy through these. You may refer to Subchapter 1.2 for further guidance. Adjust your techniques according to the person's cultural background or other needs.

Below are other communication strategies you can use to demonstrate support:

Individual	Communication Strategy
Person	Asking the person politely whether they need assistance with a task or not
Carer	Setting one-on-one meetings to share services and resources for self-care
Family	Checking in regularly with them to see how they are doing through consultations, quick messages or simple phone calls
Others Identified by the Person	Showing consideration of any suggestions or feedback they share by actively listening to them and noting them down

Another way to demonstrate support is by empowering the people in your care. Below are communication strategies you can use to empower them:

Individual	Communication Strategy
Person	Using positive words, such as, 'You can do it!' to encourage the person to accomplish tasks they find challenging
Carer	Acknowledging the challenges the carer shared and using positive words to motivate them (e.g. 'Thank you for taking care of the person well. I appreciate you for your work'.)
Family	Showing positivity through positive body language (e.g. appropriate eye contact or firm posture) to assure the family that everything is well taken care of
Others Identified by the Person	Using positive words to thank them and motivate them to continue putting efforts to support the person (e.g. 'I appreciate all the things you do to help your friend under our care.')

You have previously built rapport with your clients and their relevant others. In doing this, you have also established trust. Trust is a prerequisite to creating a safe and supportive environment. They trust you to hear and respond to their needs and issues. If there are any changes to their requirements and preferences, they will also be willing to share these with you. With your relationship established, it is just a matter of doing what you can to nurture this environment. Continue practising the communication techniques you previously learnt to give support.



Checkpoint! Let's Review

1. A supportive environment encourages everyone to express their needs and preferences freely. Knowing these needs and preferences will be easy for you and your care team to respond to them.
2. You have to foster this supportive environment where everyone can continuously share any changes in these needs.



2.2 Respect the Person's Individuality, Values and Beliefs



Individuality is the number of traits and characteristics that make a person unique. Often, a person's individuality is influenced by their values and beliefs. *Values* refer to what a person sees as essential to their life. Values often guide a person's behaviours. *Beliefs* refer to what a person accepts as true. Beliefs involve things that may or may not exist or things that may or may not be based on facts.

Respect refers to considering other people's individuality, values and beliefs. It considers their feelings, rights and wishes. You will encounter many unique people with different values and beliefs in your line of work. These should not hinder you from providing the best care you can for the client. Respect a client's individuality, values and beliefs to provide person-centred palliative care. It also has the following benefits:

- It improves the client's QoL.
- It improves the relationship between the client and the support staff caring for them.
- It ensures the client is given the care that does not discriminate based on personal differences.
- It distracts clients from their medical problems or condition.
- It reduces the risk of client depression and other emotional problems.

There are concrete actions to take to respect the client's individuality, values and beliefs. To show respect towards the client's individuality, you must do the following:

Acknowledge the client's uniqueness.

Respond in a way that is acceptable and meaningful to them.

Provide support that fits the client.

- **Acknowledge the client's uniqueness.**

To acknowledge someone means to accept the person for who they are. There is no attempt to change the person; rather, their individual traits and characteristics are cherished. You can show acknowledgment of the client's uniqueness by:

- Showing the client that you are interested to know more about them
- Allowing the client to express themselves without judgement
- Avoiding comparison with others

When you accept clients for who they are, it boosts their morale and wellbeing. It also builds their trust in you, which improves your relationship and positively affects support provision.

- **Respond in a way that is acceptable and meaningful to them.**

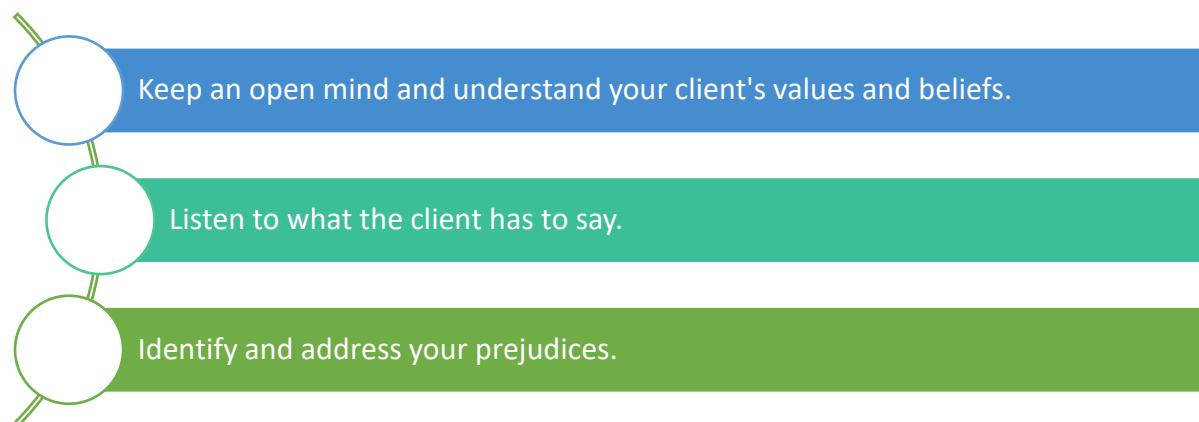
In every interaction, you must approach the client acceptably. To be acceptable means being mindful of how you present yourself to them. For one, use the appropriate language and address them appropriately. You must also adjust your approach based on their traits and characteristics. For example, an introverted client may prefer not to talk much more than an extroverted one.

When you approach the client in acceptable ways, your interactions with them are more meaningful. This would make the client feel they are more than just a patient.

- **Provide support that fits the client.**

The person must always remain at the centre of support provision. This means adjusting the support you provide to fit the client's needs and preferences. Every step in support provision must consider what is important for the client. A one-size-fits-all approach will not work, as each of your clients will have unique characteristics and, therefore, unique needs.

Here are the ways you can show respect towards the client's values and beliefs:



- **Keep an open mind and understand your client's values and beliefs.**

Replace value judgements with curiosity. Telling someone their values and beliefs are wrong may come off as condescending. It also shuts down the conversation. Instead, seek to understand what makes the client consider certain matters important or true. Ask questions to know more about them. For example, ask, 'What makes this matter important to you?' Genuine curiosity will encourage your client to share more about themselves.

- **Listen to what the client has to say.**

Asking is not enough; you must also listen to what the client says. Listen actively with the intent to understand, not contradict. When the client is aware that you are hearing the words and the content of what they are sharing, they will feel respected.

Listening will also help you understand more about the values and beliefs important to your client. When you have come to understand these things, you will later understand the life they live and the choices they make, including those related to their care (e.g. end-of-life decisions).

- **Identify and address your prejudices.**

Differences in values and beliefs may affect the way you interact with others. For example, you may have a certain perspective of someone who believes in things you do not. These biases may be unconscious and may reflect in your care services unknowingly. An example is when support workers believe the client cannot make sound decisions independently due to their illness. With this belief, support workers may consult other people more (i.e. family members and relevant others) regarding the client's needs. This may lead to impaired decisions in the planning and implementing appropriate care strategies for the person.

Actions influenced by unconscious biases are often harmful, hurtful and disrespectful to the other person. Thus, it would be best if you examine your biases.

To examine your unconscious biases, ask yourself these questions:

- How do I feel about people with values and beliefs different from mine?
- Do I consider values and beliefs different from mine as valid?
- Do I feel uncomfortable with any of my client's values or beliefs?
- Do my values and beliefs affect how I support my client?
- What do I feel when I judge others with values and beliefs different from mine?
- What would I feel if I were judged according to my values and beliefs?

You will meet people with different values and beliefs as a support worker. These values and beliefs make each one of them unique. It would be best if you treated these differences with respect. Please show respect for other people's individuality by trying to learn more about them. You can politely ask them to talk about themselves. Encourage them to tell you if you disrespect their individuality, values, or beliefs.



Checkpoint! Let's Review



1. Individuality is the number of traits and characteristics that make a person unique. Often, a person's individuality is influenced by their values and beliefs.
2. Values refer to what a person sees as essential to their life. These often guide a person's behaviours.
3. Beliefs refer to what a person accepts as true. These involve things that may or may not exist or things that may or may not be based on facts.
4. Respect refers to considering other people's individuality, values and beliefs. It considers their feelings, rights and wishes.
5. You will encounter many unique people with different values and beliefs in your line of work. These should not hinder you from providing the best care for the client.



2.3 Identify Needs and Issues Outside the Scope of Job Role



Your role as a support worker focuses on providing individual support to older people in palliative care. The specific scope of your role depends on where you are working. Understanding what you should do to perform your role properly is important. If you do not know the limitations of your role, you may overstep your boundaries.

Ensure to read and understand the role details when applying for a job in aged care. There are different roles in palliative care in aged care work, and each role comes with various tasks. Different employers may also have varying job descriptions for each role.

Scope of Job Role

Your *scope of job role* is the limitation of your role based on your position and training. This means the scope of your responsibilities in the palliative care sector. You can find out your scope of practice by looking at your job position in your employee handbook. You can also check your company's policies regarding your role.

Going beyond your scope of practice can lead to negative consequences. You may accidentally cause harm to an older person if you do something outside of your work role or training. That is why it is important to know your responsibilities and limitations.

Consider the example of a job post below:

Support Worker



Role

The successful candidate will work part-time (two to three days a week). The role involves visiting client homes in the Carlton area. Each home care worker is assigned to visit three homes for six hours per home each week. The company will provide transportation for each home visit. The successful candidate will work with a care team to provide high-quality care.

Key Responsibilities

- Provide support in the client's daily activities at home
- Assist with hygiene and personal care
- Assist with meal preparation
- Chaperone the client when going outside the home environment
- Report any issues or changes in the condition of the client or their home

Qualifications

- Possesses a Certificate III in Aged Care or Individual Support (Ageing)
- Possesses Senior First Aid and CPR Certificates
- Possesses a driver's license

If you apply for this role, you should recognise what the position requires. You will be responsible for basic assistance with chores and meals. You may also provide basic first aid since the post says you need a certification. You should also know how to drive since you will accompany them when they leave their house.

Based on the job description, what you are not allowed to do are the following:

- Suggest and administer medication
- Make decisions on behalf of the person
- Stay with the person for full-time care without approval

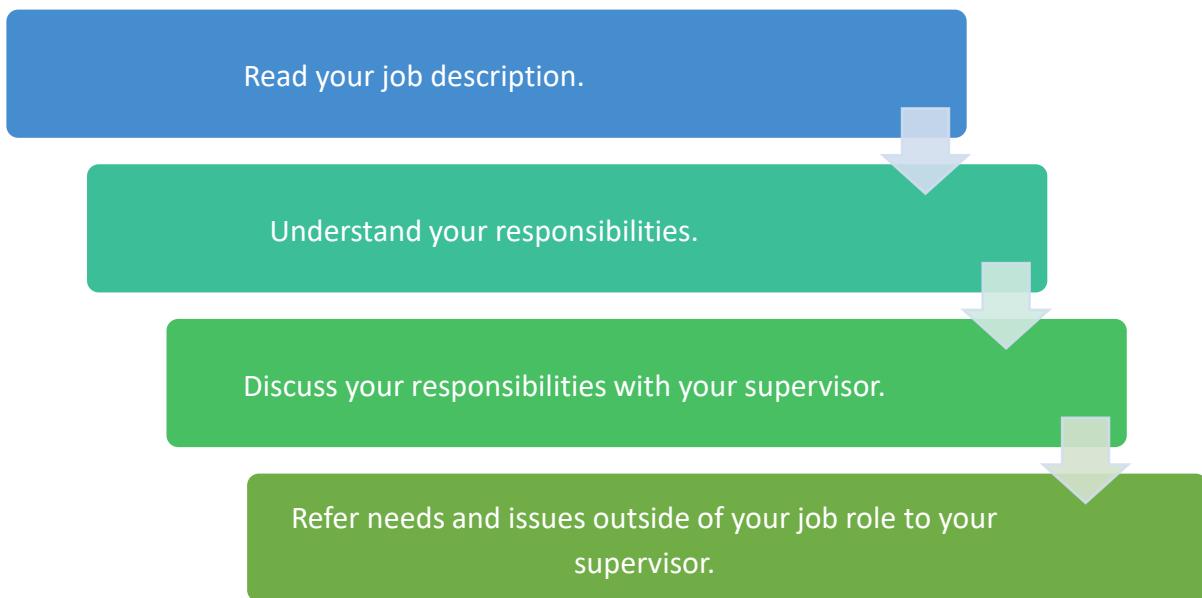
Confirming Work Role Responsibilities

Once you understand your job role, you must confirm it with your supervisor by discussing your work role with them. This ensures you agree on your responsibilities. You can ask your supervisor for any questions and clarifications you might have. If you do not confirm the scope of your role, you cannot confirm if your interpretation is correct.

You might make assumptions about responsibilities that you are not qualified to perform.

It would be best if you had this discussion as soon as you get hired. Your supervisor will likely describe your responsibilities in detail. This should include your work hours, job responsibilities and expectations. You should listen carefully and ask for clarifications if needed. You might get new responsibilities that you should also confirm at any point.

It is also crucial you discuss what you expect from your role. This helps clarify what you hope to get from your job. Agreeing on these will ensure that expectations are clear from both sides. This graphic summarises the process of understanding and confirming your job role:



Referring Needs and Issues to Your Supervisor

Now that you understand what you can and cannot do, you know what needs and issues you can and cannot address. You now have a grasp of the boundaries of your work.

For needs and issues that fall outside the scope of your practice, you must refer these to your supervisor. To *refer* can mean any of the following:

- To direct someone to another person for help, clarification or guidance
- To approach another person for help, clarification or guidance

In this context, it would be best to refer the needs and issues outside your role's scope to your supervisor. You must refer these concerns to your supervisor to ensure you do not accidentally cause harm to your clients. It also ensures the appropriate personnel or professional addresses the client's needs and issues. Some examples of needs and issues outside of your role's scope include, but are not limited to, the following:

Pain medication concerns

Symptom treatments

Psychological counselling provisions

Medical condition diagnosis

Medication prescriptions

Organisational Reporting Policies and Procedures

Reporting lines differ between organisations. This means reporting procedures also differ depending on where you work. It would be best if you learned your job's reporting policies and procedures. Typically, reporting policies and procedures would include the following:

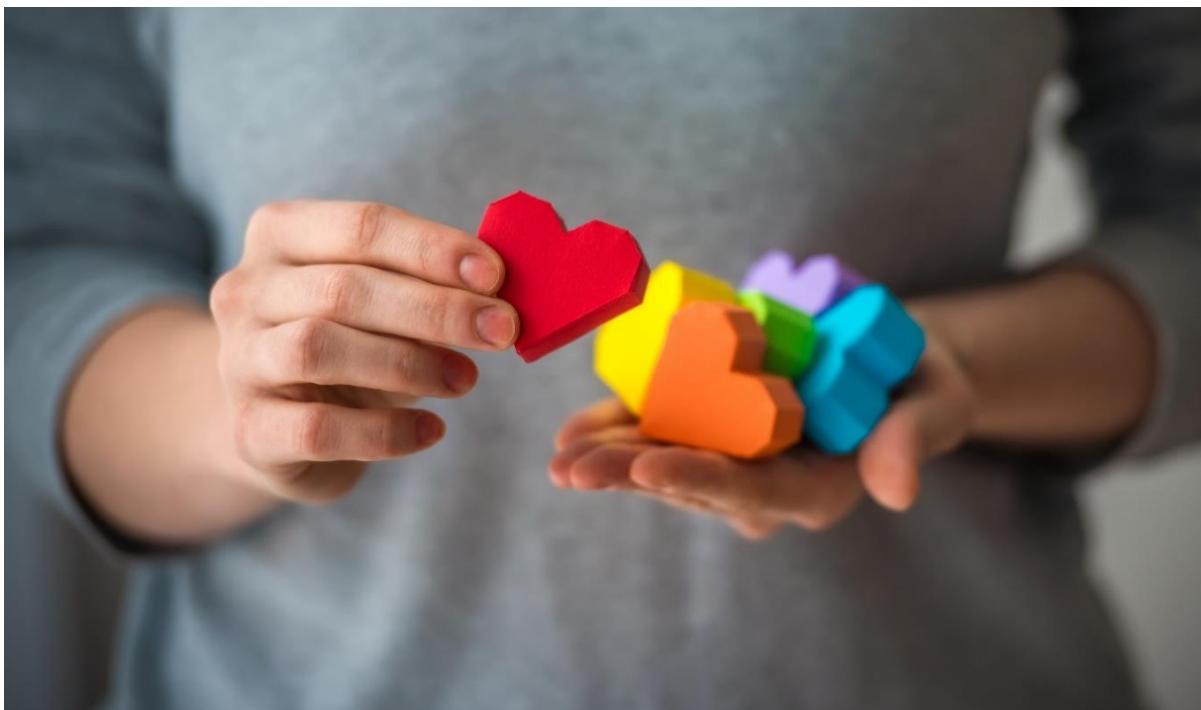
- How to identify the limits of your role
- To whom should you refer a concern or issue outside your role
- Steps in referring a concern or issue outside your role
- Steps in confirming that concern or issue outside your role has been referred to correctly



Checkpoint! Let's Review

1. If you do not know the limitations of your role, you may overstep your boundaries.
2. Your scope of job role is the limitation of your role based on your position and training. This means the scope of your responsibilities in the palliative care sector.

2.4 Communicate in a Manner That Shows Empathy and Provides Emotional Support



The diagnosis of a life-limiting illness can be difficult to accept for both the diagnosed and their loved ones. In particular, the emotional impact of the diagnosis can take a toll on them. Because the illness cannot be cured, it may feel like death is always hanging over them. In addition, the diagnosis of a life-limiting illness may lead the person to feel negative emotions, such as anxiety, depression and a sense of helplessness or despair. This further negatively affects their relationship with their family and relevant others as they tend to think and act as if their lives have no more purpose.

Every person will react differently to the news of the diagnosis. Some may respond with anger, others with denial. Most will feel shocked, followed by grief. The client and their loved ones may also start worrying about the future (e.g. the financial burden associated with the illness). They may also deal with concerns about treatment and prognosis.

During this time, the client and their relevant others will make many decisions regarding client care. The client's preferences will often dictate their choices, impacting their QoL. However, making decisions during this time can be difficult for everyone involved, especially if they have not yet accepted their circumstances. The client and relevant others will need understanding from you and everyone on the care team. The life-limiting illness has dramatically impacted their lives. You must understand that they will need emotional support to get on their feet again.

As a support worker, you must communicate with the client and relevant others to show empathy and provide emotional support. In this context, communication revolves around the client's preferences for their QoL choices. Giving the client and relevant others emotional support will help them make the best choices for client care, improving the client's QoL.

Empathy is understanding and feeling the other's emotions. Empathic communication was extensively discussed in Section 1.2.1. This involves active listening. To perform this, you must do the following:

- You must listen to both what is said and what is not being said. This means listening to the other person's content and emotions, tone of voice and body language. These can help you fully understand their concerns.
- You must listen without judgement. Non-judgement allows the person to feel heard and valued. It also encourages them to share their preferences and other concerns regarding QoL choices
- You dedicate your full attention when listening to the other person. Doing so lets the other person know you are present in the conversation and really willing to listen to what they have to say.

You can also use the following communication strategies below:

Individual	Communication Strategy
Person	Listening to what the person has to say rather than doing most of the talking
Carer	Showing an understanding of the carer's thoughts by paraphrasing or repeating what they said in your own words
Family	Asking follow-up questions to know more about their experiences, thoughts and feelings (e.g. 'How did it feel when...' or 'Can you tell me more about...').
Others Identified by the Person	Asking follow-up questions to know more about their experiences with the person and how they feel about the person's situation (e.g. 'How did it feel when...' or 'Can you tell me more about...').

Other ways to show emotional support during communication include the following:

- Let the client and relevant others know you are always there to listen.
- Encourage the client and relevant others to ask questions or share their concerns about their preferences and QoL choices.
- Check on the client's and relevant others' emotional wellbeing regularly. This can be as simple as asking them how they are doing during conversations.



Multimedia



Knowing more about the older person helps you establish a deeper connection with them. See the video below of an example on how you can connect with your client:

[Leah's story \(The lasting power of music therapy\)](#)



Checkpoint! Let's Review



1. Giving the client and relevant others emotional support will help them make the best choices for client care, improving the client's QoL.
2. Empathy is understanding and feeling the other's emotions.



Learning Activity for Chapter 2

Well done completing this chapter. You may now proceed to your **Learning Activity Booklet** (provided along with this Learner Guide) and complete the learning activities associated with this chapter.

Please coordinate with your trainer/training organisation for additional instructions and guidance in completing these practical activities.

III. Follow the Person's Advance Care Directives in the Individualised Plan



The previous chapter discussed the holistic needs of your client and their families. You learnt how good communication is an essential first step to identifying their needs. In this chapter, you will learn how to address these needs concretely. You learn about laws, legislation, and standards you must adhere to when providing care services. You will also learn about the processes and steps you need to follow. You will become familiar with important documents, like advance care directives and individualised plans, when providing end-of-life care. *End-of-life care* is given to a person approaching the end of life. It aims to support their needs and improve their QoL in their remaining days.

Advance Care Directive

Nobody knows what the future holds, so some people choose to prepare for what may happen. They plan their current or future health care through an advance care directive. An *advance care directive* is a legal document that serves as the client's 'living will.' This is important, especially if the person has a life-limiting illness. As their illness progresses, it may be difficult for them to decide for themselves later. When the time comes that the client cannot decide for themselves, the advance care directive is used to guide their treatment. This ensures that the preferences and wishes of the client under care are considered.

The purpose of an advance care directive is to provide details on a person's values, life goals and preferred outcomes. It contains details on the treatment and the care a person would prefer or refuse if they have a life-threatening illness or injury.

An advance care directive does the following:

- Outlines the medical treatment and care plan the client wants when they lose their capacity for decision-making, including the client's decision to refuse a particular treatment in the future
- Enables the client to appoint an attorney for health and personal matters, including a substitute decision-maker on their behalf
- Details the client's wishes, preferences and instructions for their health care, end-of-life arrangements and/or other personal matters
- Includes information the support workers must know, including their physical, cultural or spiritual needs

The client can also provide specific instructions in their advance care directive. This will concern the QoL they want to receive. They may state if life-sustaining measures must be withheld or withdrawn. This is considered if a person has the following:

A terminal illness with no known cure or chance of recovery

A severe and irreversible brain damage that makes them unable to communicate

A severe illness or injury that has no chance of recovery

Based on [Advance health directive](#), used under CC BY 4.0. © The State of Queensland 2022

You may get a copy of the client's advance care directives from any of the following people:

- The client's family
- The client's friend/s
- The client's carer/s
- The client's doctor
- The client's healthcare facility's staff
- The client's enduring guardian/person responsible

Service care providers must follow a client's advance care directives. The care team refers to this document when making the client's individualised plan towards end-of-life care. It would be best if you familiarise yourself with these advance care directives. Doing this will help you provide your client with the best and most up-to-date care. Advance care directives are typically uploaded on the My Health Record website. Care is easily coordinated among health professionals because the data is accessible to them.



Further Reading

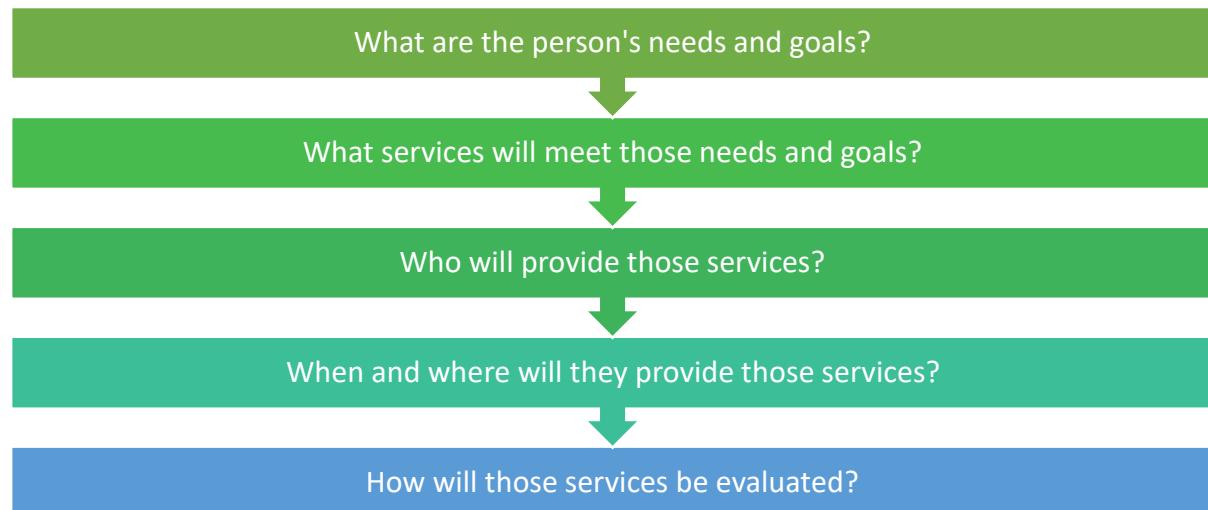
My Health Record makes it easier for the care team to see the client's current health or other relevant information about their care. During care, you will frequently refer to or update this website's information:

[My Health Record](#)

Individualised Plan

Individualised plans dictate the services that a client in palliative aged care receives. The care team prepares an individualised plan together with the client. If the client cannot help prepare the plan, an assigned advocate can represent them.

The care team must consider the following sequence of questions when creating a plan:

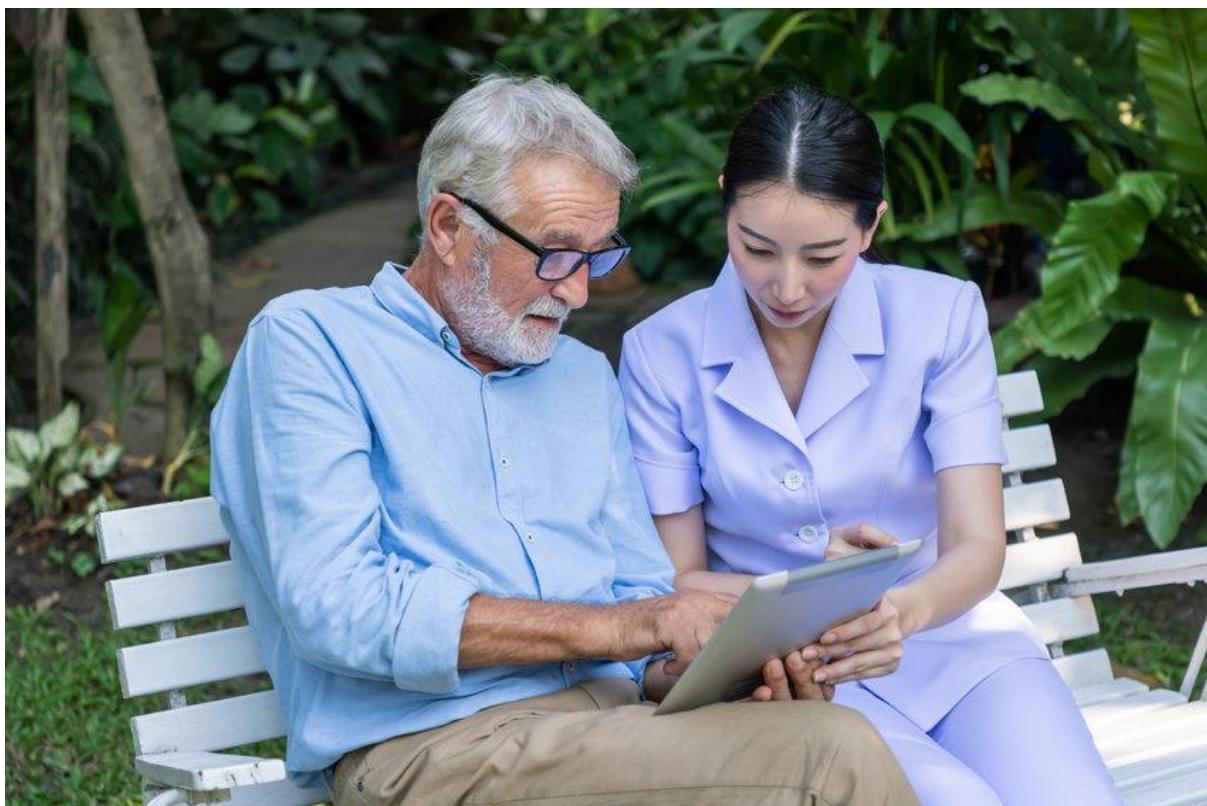


Individualised plans are important because they are tailored to each person. It is especially useful in palliative care since the same illness can be experienced differently by different people. It ensures the client is not just receiving generic services that do not fit their needs. It also enables them to decide when and how to receive the services.

The client's needs might change throughout treatment. You have to keep track of these changes and report them appropriately. Knowing these changes will help you and your care team provide the best possible care for your client. The rest of this chapter will teach you how to do your job respectfully and efficiently.

In this chapter, you will learn how to do the following:

- Interpret and follow advance care directives
- Comply with end-of-life decisions in the individualised plan
- Report the person's changing needs and issues in end-of-life care
- Monitor and refer the impact of the person's end-of-life needs, issues and decisions
- Support the person's right to choose the location of their end-of-life care



3.1 Interpret and Follow Advance Care Directives



Service care providers are legally and ethically obliged to follow a client's advance care directives. The care team refers to this document when making their client's individualised plan. As a support worker, you must follow these advance care directives.

3.1.1 Advance Care Directives in the Individualised Plan

An individualised plan is created by the client (or their representative) and the care team. It addresses the needs specific to a person. On the other hand, the client can write advance care directives once they turn 18. It is a legal document that provides a direction for their health care when they can no longer decide. It also details their preferences in receiving care aligned with their values and beliefs.

When making the individualised plan, the care team has to ensure it is in line with the advanced care directives of the clients. Their preferences for receiving care must come first.

State and Territory Laws on Advance Care Directives

Advance care directives are supported by common law and statutory law. *Common law directives* follow the common law (i.e. rulings made by court judges). *Statutory law advance care directives* are created and governed by state legislation. The scope and content included in statutory advance care directives vary in every state or territory. Further information about these statutory laws and regulations for each state/territory can be found on the links below:

State or Territory	Links
Australian Capital Territory	Medical Treatment (Health Directions) Act 2006
New South Wales	Advance care planning laws in New South Wales
Northern Territory	Advance Personal Planning Act 2013
Queensland	Powers of Attorney Act 1998
South Australia	Advance Care Directives Act 2013
Tasmania	Guardianship and Administration Act 1995
Victoria	Medical Treatment Planning and Decisions Act 2016
Western Australia	Guardianship and Administration Act 1990

Further Reading



You can read more about each state's process for creating an advance care directive through the link below:

[Create your plan](#)

Lotus Compassionate Care



Access and review Lotus Compassionate Care's sample individualised plans through the link below:

[Client Records](#)

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Interpreting and Following the Advance Care Directives in the Care Plan

You must interpret and follow the client's advance care directives as a support worker. *Interpret* refers to showing your understanding of something. In this context, you must show you understand what is written in the advance care directives. Interpretation of the advance care directives follows these general steps:

1. Understand what is written in the plan.
2. Confirm your understanding with your supervisor and with the client.

After interpretation comes implementation. You must follow what is written in the advance care directive. To *follow* means to take steps according to the instructions or directives. To follow the advance care directive, you must do these:

1. Identify the directives in the document relevant to your job role.
2. Confirm with your supervisor the directives you identified and the support services related to these directives.
3. Prepare the necessary equipment or documents in preparation for support provision.
4. Inform the client of the support services that will be given to them concerning their advance care directive.
5. Confirm with the client when and where you will provide the support services.
6. Provide the client with the support services they need.

Each organisation has its policies and procedures for following advance care directives. Remember to consult your organisation manual or ask your supervisor for any questions and clarifications. You must interpret and follow the advance care directives according to legal and ethical requirements. These requirements will be discussed in more detail below.

3.1.2 Legislation on Aged Care

There are several laws created to protect the welfare of older people. These laws are important in managing the quality of care services that older people receive. This section will discuss the following legislation relevant to palliative care in aged care:



Aged Care Act 1997

The *Aged Care Act 1997* is the framework for government funding for aged care services. It also states what care providers must meet to get government assistance. Aside from funding and regulation, the *Aged Care Act 1997* also ensures providers prioritise the rights of their clients. Part of a client's rights is to receive quality care. Below is a summary of what the relevant chapters within this Act contain:

Chapter 2

- Contains the obligations of an approved provider
- Contains the classification of care recipient

Chapter 3

- Contains the details about government subsidy
- Contains the process of receiving government subsidy
- Contains the conditions for receiving subsidy

Chapter 4

- Contains the responsibilities of approved providers

*Based on content from the Federal Register of Legislation at 7 November 2021.
For the latest information on Australian Government law, please go to <https://www.legislation.gov.au>.*

Aged Care Quality Standards

The *Aged Care Quality Standards* contains the requirements care providers must meet. The *Aged Care Quality and Safety Commission* created these standards. This commission protects the rights, safety and wellbeing of older Australians.

All aged care providers must meet these standards. The standards cover the rights of older people. These include their right to receive care according to the best practice. Care providers must ensure palliative care is incorporated within aged care. The tables in the next pages provide a summary of the standards.

Standard	What it is About
Dignity and choice	<ul style="list-style-type: none"> ▪ Treat people with respect. ▪ Value people's culture and diversity. ▪ Support people to make decisions for themselves. ▪ Help people live their best lives.
Ongoing assessment and planning	<ul style="list-style-type: none"> ▪ Consider risks to people's wellbeing when providing care. ▪ Assess people's conditions when planning for care. ▪ Evaluate the organisation's services for effectiveness. ▪ Inform people about their care and services.
Personal and clinical care	<ul style="list-style-type: none"> ▪ Provide people with the best care to meet their needs. ▪ Monitor people's condition and respond to changes. ▪ Control health risks related to infection. ▪ Refer people to appropriate services when needed.
Services and support for daily living	<ul style="list-style-type: none"> ▪ Provide services such as food, home assistance and recreation. ▪ Support people to participate in their community. ▪ Ensure meals provided are healthy and enough for each person. ▪ Ensure provided equipment is safe and updated.
Organisation's service environment	<ul style="list-style-type: none"> ▪ Ensure the environment is safe, welcoming and comfortable. ▪ Provide accessible furniture and equipment. ▪ Provide people with opportunities to move freely.
Feedback and complaints	<ul style="list-style-type: none"> ▪ Encourage people and their carers to give feedback and express complaints. ▪ Give people ways to express their opinions. ▪ Resolve any complaints from people. ▪ Improve services based on people's feedback.

Standard	What it is About
Human resources	<ul style="list-style-type: none"> ▪ Hire enough workers to provide care for every person. ▪ Ensure workers are respectful and caring towards people. ▪ Train workers to have the required qualifications to work in aged care. ▪ Evaluate workers regularly to ensure good performance.
Organisational governance	<ul style="list-style-type: none"> ▪ Create a safe and inclusive organisational culture. ▪ Manage the organisation well. ▪ Establish good risk management plans.



Further Reading

You can read more about the Aged Care Quality Standards in the fact sheet through the link below:

[Aged Care Quality Standards fact sheet](#)

Quality of Care Principles 2014

The Quality of Care Principles 2014 regulates the quality of aged care providers. This is where you can find the *Aged Care Quality Standards* discussed above. These standards are listed in Part 5 of the Quality of Care Principles 2014. Other details of this document include the following:

Part 4

- Contains the laws for flexible care services
- States that care may be provided in a residential or home setting
- States that one must comply with Aged Care Quality Standards

Part 5

- Contains the Aged Care Quality Standards
- States that care provided must comply with these standards

*Based on content from the Federal Register of Legislation at 7 November 2021.
For the latest information on Australian Government law, please go to <https://www.legislation.gov.au>.*



Voluntary Assisted Dying (VAD) Laws

Clients in the late stages of advanced disease, illness, or medical condition can ask for voluntary assisted dying (VAD). This process refers to administering a VAD substance to clients suffering from unbearable pain. From the term itself, VAD must be the client's own choice. You, nor any other health professionals, cannot pressure them to ask for this process.

VAD is done through the following options:

Self-administration

- In this method, a client takes the VAD medication by themselves with the help of health practitioners.

Practitioner administration

- In this method, a client receives the VAD medication from a health practitioner.

States in Australia have their own VAD laws. Services relevant to VAD are currently available in Victoria, Western Australia, and Tasmania. Other states, including South Australia, Queensland, and New South Wales, will start implementing VAD by 2023.

However, Northern and Australian Capital Territories still consider this practice illegal. This is because territories follow federal laws regarding assisted dying. The federal government's Euthanasia Laws Act 1997 prevents the territories from performing VAD.

In the palliative care industry, clients suffering from pain are provided with medical treatment and support services for their physical and psychosocial needs. It has no intention of hastening the death of a client. However, even with access to palliative care, some people may prefer to die due to suffering too much from their illness.

If a client wishes for VAD, they must first meet the legal conditions and follow the processes to become eligible for it.

For example, a client's decision to ask for VAD must be voluntary, consistent and fully informed. If you have a client with a mental health condition that affects their decision-making ability, they will not qualify for VAD.

Only doctors can perform assessments and administer a VAD substance to a client. As a support worker, your role is only limited to providing information. You cannot, under any circumstance, do the following:

- Perform a VAD assessment on the client
- Help a client get access to any VAD medication
- Personally suggest VAD to a client or to any of their family members
- Withhold information about VAD when a client asks about it

You must consult your supervisor to clarify any information about VAD.

The full details of the VAD laws in Australian states can be accessed below:

State	VAD Law
Victoria	Voluntary Assisted Dying Act 2017
Western Australia	Voluntary Assisted Dying Act 2019
Tasmania	End-of-Life Choices (Voluntary Assisted Dying) Act 2021
South Australia	Voluntary Assisted Dying Act 2021
Queensland	Voluntary Assisted Dying Act 2021
New South Wales	Voluntary Assisted Dying Act 2022



Further Reading

Click the link below to check the differences in the VAD laws per state in Australia:

[Voluntary Assisted Dying](#)

3.1.3 Legal and Ethical Requirements

Support workers must consider the legal and ethical requirements when providing support. *Legal requirements* are responsibilities that must be performed following legislation. The organisation applies the legal requirements. *Ethical requirements* are the standards and principles set by the organisation. Ethical requirements are based on principles, values and beliefs that people must act upon as members of the bigger community. There are legal responsibilities that may not be ethical and ethical requirements that may not be legal.

Consider the case study below:

Kelly's Dilemma

Kelly has been diagnosed with chronic liver disease. She has been receiving palliative care services at home, where she lives with her only daughter, Linda. Aside from Kelly, Linda also provides support for her own family.

Kelly needs to take pain medications to manage the symptoms of her illness. She knows her medicines are expensive. She has seen how this causes financial constraints and stress to her daughter. Kelly wants her daughter to save up for her family's future instead.

One day, Kelly shared with you, her support worker, that she wishes to stop her treatment. 'The medicines are so expensive! Do I have to drink them if I will die anyway? I'd rather die without burying my daughter in debt if I will die anyway!'

You know that stopping the treatment will worsen the symptoms of her condition. However, you also see how Kelly does not want to become a burden to her daughter.

To help Kelly and Linda, you must first be familiar with the organisations and agencies in your community that offer support services relevant to palliative care. You can refer them to appropriate financial assistance services. You can also advise Linda on where she can get cheaper or even free medicine.

These are the legal and ethical considerations that the care team, including the support worker, must understand when working in palliative care:

Dignity of risk

Duty of care

Human rights

Privacy, confidentiality and disclosure

Work role boundaries, responsibilities and limitations

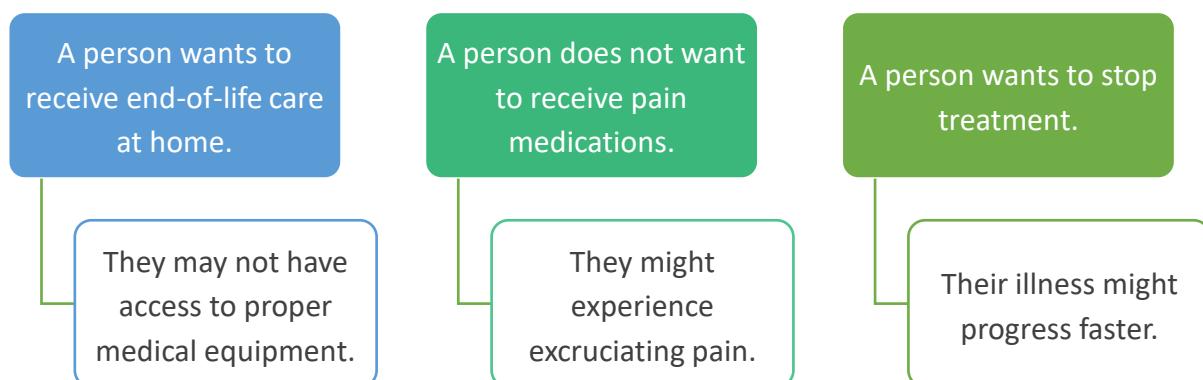
Dignity of Risk

According to the Aged Care Quality Standards, the *dignity of risk* is the person's right to decide on their own regarding the care provided for them, including their right to take risks. It accepts that people can choose what they do and how they live. It acknowledges that these choices come with possible risks. It means respecting the autonomy and independence of a person receiving palliative care and allowing them to make choices for themselves.

Support workers have a duty of care to ensure their clients are safe and free from risks. Risks are associated with any activity, including providing support and treatment that clients undergo. Below are ways to uphold the client's dignity of risk:

- Inform and help the person understand the risks of their choices.
- Consult with the person to develop solutions to address these risks.
- Manage risks that come with the person's decisions.

Here are some examples of client choices and the risks involved:



Family members, carers and even you may find the choices and decisions made by the client may put their health and life at risk. However, you must respect their dignity by helping them carry out their choices despite the risks. Instead, you and the care team can help minimise the risk involved with the person's choices.

Duty of Care

Duty of care is the legal obligation of a person to take reasonable care of their client, colleagues and relevant others to ensure their health, safety, and welfare. It lists what you should do as a support worker. Your duty of care relates to the *Charter of Aged Care Rights*. The Aged Care Act 1997 requires the Charter of Aged Care Rights. You must perform your duties to ensure your client enjoys their rights.

The rights of your client based on the Charter of Aged Care Rights include the following:

- Right to safe and high-quality care and services
- Right to be treated with dignity and respect
- Right to have their identity, culture and diversity valued and supported
- Right to live without abuse and neglect
- Right to be informed about their care and services in a way they understand
- Right to access all information about themselves, including information about their rights, care and services
- Right to have control over and make choices about their care, and personal and social life, including where the choices involve a personal risk
- Right to have control over, and make decisions about, the personal aspects of their daily life, financial affairs and possessions
- Right to their independence
- Right to be listened to and understood
- Right to have a person of their choice, including an aged care advocate, support them or speak on their behalf
- Right to complain free from reprisal and to have their complaints dealt with fairly and promptly
- Right to personal privacy and to have their personal information protected
- Right to exercise their rights without it adversely affecting the way they are treated



Further Reading

The duty of care listed above helps uphold these rights. You can read more about the Charter of Aged Care Rights at the link below:

[Charter of Aged Care Rights](#)

Your duty of care as a support worker includes the following:



Duty of care also considers that any situation has unforeseen harm or risk. Therefore, if these unforeseen risks happen, you must set preventive actions. This means that support workers must always follow work health and safety policies and procedures when performing their duties and responsibilities.

To perform your duty of care, you must ensure you reduce the risks to your clients as much as possible. You can develop ways to honour their dignity of risk while still protecting their wellbeing.

Here are some ways to reduce the risks:

- **They may not have access to proper medical equipment.**
 - Discuss the possibility that your client may not have access to the necessary medical equipment. Ask if they are willing to talk to the palliative care team about other options available close to their home.
- **They might experience excruciating pain.**
 - Ask your client why they refuse to take medications. If they are experiencing adverse side effects or have misconceptions about the drug, refer them to your supervisor.
 - Ask if they would be open to trying complementary therapies like massage or meditation to manage their pain.

- **Their illness might progress faster.**

- Ask your client why they refuse to receive treatment. Give reassuring facts if they have any misconceptions about palliative treatment, but do not argue with them. Listen without judgement and validate their emotions.
- Respect their wishes and provide support in other ways (e.g. emotional and/or psychological). You may connect them with other members of the care team as required.

A support worker may be found in breach of the duty of care when they fail to appropriately act upon any harm, present or unforeseen, that had occurred to a client. This failure will make the support worker liable for negligence. Support workers are accountable for the services they provide. They may face consequences and sanctions if they fail to meet their duty of care. They are also responsible for reporting any breaches of the duty of care they become aware of by the organisational procedures.

All staff, including support workers, must familiarise themselves with the policies and procedures of the workplace, the standards and codes of practice as they provide their services to the client. They should also consider the scope of their roles and responsibilities.

Support workers must comply with the relevant standards outlined in the Aged Care Act 1997 and the Quality of Care Principles 2014 at all times. These set out the responsibilities of support providers to their clients. These also include the guidelines for quality care and adherence to the duty of care.



Human Rights

Human rights are rights that every person should enjoy. They have always been part of different legislation. The aged care laws aim to protect older people's rights. These rights include the following:

- **Right to healthcare**

Older people have the right to receive quality healthcare. Governments must have laws that address the following aspects to meet this right:

Availability

- There should be enough medical goods and services in all areas.

Accessibility

- Medical goods and services should be non-discriminating and affordable.
- Medical goods and services should be physically accessible.
- Information about medical goods and services should be easy to find.

Acceptability

- Medical goods and services must meet the needs of a diverse population.

Quality

- Medical goods and services must be safe, effective and efficient.

- **Right to information**

Older people have a right to access information about their care. This includes information about their service options and medical records. The government has set up an aged care information website called My Aged Care to address this. They provide access to services funded by the government. The website also has useful links for providers, workers and carers.



Further Reading

My Aged Care is the government's official website for finding suitable aged care needs. Access the website through the link below:

[Welcome to My Aged Care](#)

- **Right to autonomy**

Autonomy means having control over one's decisions. Older people have a right to make decisions in matters directly affecting them. This includes decisions over their care, health and home. The government ensures this by having laws that protect their freedom over their care. This is addressed in the first standard of the *Aged Care Quality Standards*. Section 3.1.1 also discussed specific legislation about advanced care decisions.

- **Freedom from discrimination**

Discrimination is the unjust, unfair, and prejudicial treatment of people based on age, sex, race, background or disability. Australia has several anti-discrimination laws to protect the rights of its citizens, including the following:

Legislation	Purpose
Age Discrimination Act 2004	This legislation protects people from age discrimination in employment, access to goods and services, education, and the implementation of Commonwealth laws and programs.
Disability Discrimination Act 1992	This legislation aims to eliminate discrimination against people with disabilities.
Racial Discrimination Act 1975	This legislation aims to promote equality before the law for everyone regardless of race, colour or national or ethnic origin.
Sex Discrimination Act 1984	This legislation protects people from unfair treatment based on their sex, sexual orientation, gender identity, intersex status, marital or relationship status, and pregnancy and breastfeeding situation.

Older people have the right to protection from discrimination. An example of discrimination is withholding care based on the client's values and beliefs. Culturally diverse older people may also face discrimination based on their culture. Discrimination may lead to an older person not receiving support for their diverse needs. To ensure that older people's diverse needs are met, aged care systems use the *Aged Care Diversity Framework*.

The framework aims to:

- Ensure everyone factors in diversity in the design and provision of aged care
- Identify and address barriers preventing people from getting the necessary care
- Support governments, representative groups and aged care providers to remove the barriers identified
- Support older people and carers to take an active role in improving aged care

Here are the important details you must remember from various legislation about discrimination:

■ **Disability discrimination**

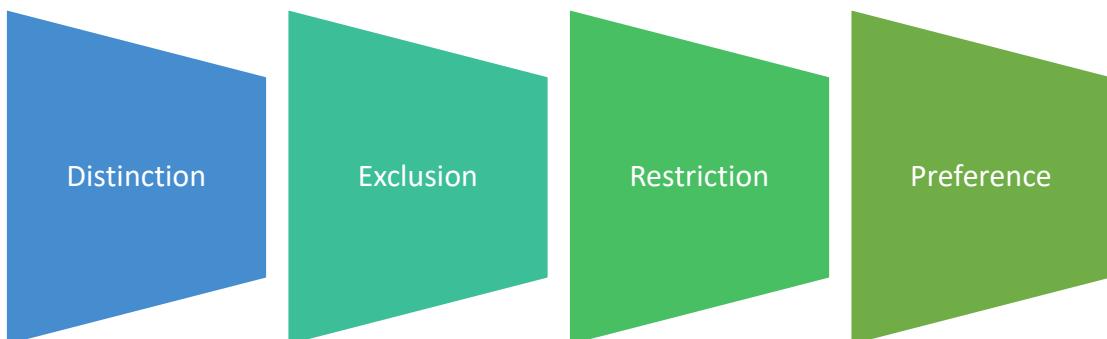
Be familiar with the nine disabilities covered in the Disability Discrimination Act 1992:

<input type="checkbox"/>	Physical disability	
<input type="checkbox"/>	Intellectual disability	
<input type="checkbox"/>	Sensory disability	
<input type="checkbox"/>	Neurological disability	
<input type="checkbox"/>	Psychosocial and learning disability	
<input type="checkbox"/>	Physical disfigurement	
<input type="checkbox"/>	Diseases and/or illnesses	
<input type="checkbox"/>	Medical conditions	
<input type="checkbox"/>	Work-related injuries	

- **Racial discrimination**

Part 2, Section 9 of the Racial Discrimination Act 1975 outlines four acts that are considered unlawful for a person to do based on someone's race. This refers to a person's colour, descent or national or ethnic origin.

The four acts are as follows:



- **Sex discrimination**

Ensure you treat people equally to avoid committing any of the three types of discrimination based on the Sex Discrimination Act 1984. This includes the following:



Further Reading

You can read more about Australia's anti-discrimination laws through the links below:

[Age Discrimination Act 2004](#)

[Disability Discrimination Act 1992](#)

[Racial Discrimination Act 1975](#)

[Sex Discrimination Act 1984](#)

Privacy, Confidentiality and Disclosure

Privacy is the right of people to keep their information to themselves. This means they have control over what information they share. *Confidentiality* is the responsibility of keeping a person's information private. This means any information shared will be safe from unauthorised access. This includes any record about older people and their families in aged care. The care provider must ensure to keep these records private. Outsiders must not gain access to these records without the person's consent in care.

Examples of protected information include the following:

Personal records

Medical and vaccination records

Financial and insurance information

Services received records

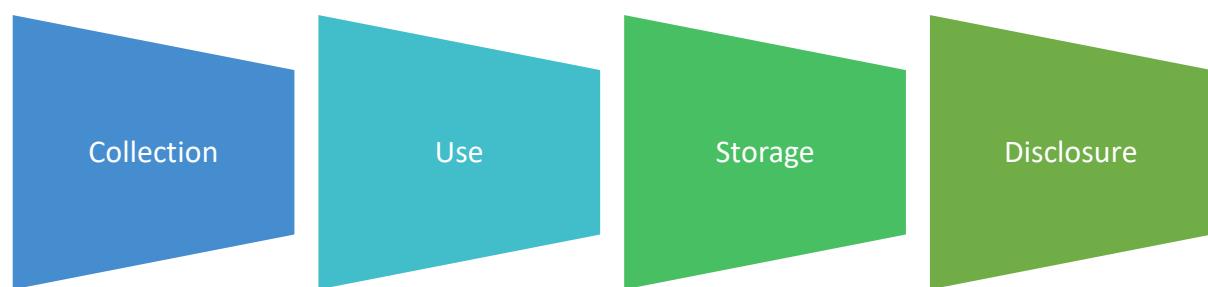
Reported instances of abuse records

Criminal records

Contact records of the person, their family or representatives

The Privacy Act 1988 is legislation that protects people's private information. It applies to Australians of all ages. It contains the 13 Australian Privacy Principles. These are the principles that care providers must follow to ensure confidentiality.

Below are the activities that the Privacy Act 1988 cover about handling an individual's personal information:



The Act includes exceptions where disclosure of private information is acceptable. People receiving aged care are covered under exceptions for 'health services'. According to Part 3, Division 2 (16B) of the Act, exceptions include situations where:

Information is necessary to provide medical care

Information may affect public health and safety

Information is necessary to keep the person safe

A representative has given consent, if person is unable

*Based on content from the Federal Register of Legislation at 18 October 2021.
For the latest information on Australian Government law, please go to <https://www.legislation.gov.au>.*

Refer to the table below to access the different versions of this Act:

State or Territory	Links
Australian Capital Territory	The ACT provisions are within this legislation: Privacy Act 1988
New South Wales	Privacy and Personal Information Act 1998 No 133
Northern Territory	Information Act 2002
Queensland	Information Privacy Act 2009
South Australia	SA does not currently have specific legislation regarding the protection of privacy, but it has the following circular: Privacy in South Australia
Tasmania	Personal Information Protection Act 2004
Victoria	Privacy and Data Protection Act 2014
Western Australia	Freedom of Information Act 1992

You must also follow the Australian Privacy Principles. You must respect your client's right to privacy. Support workers must go through a process of authorisation to access records. These records should not be available for anyone to find online.

The Australian Privacy Principles are as follows:

- Open and transparent management of personal information
- Anonymity and pseudonymity
- Collection of solicited personal information
- Dealing with unsolicited personal information
- Notification of the collection of personal information
- Use or disclosure of personal information
- Direct marketing
- Cross-border disclosure of personal information
- Adoption, use or disclosure of government-related identifiers
- Quality of personal information
- Security of personal information
- Access to personal information
- Correction of personal information

Your responsibilities to maintain privacy and confidentiality include the following:

Strictly following the organisation's records policy

Not keeping a personal copy of your client's records

Not sharing information about your client to anyone outside the organisation

Not uploading your client's records anywhere else online

A support worker must not share the client's personal information with other people at work. Unauthorised disclosure of client and staff information, such as personal and medical information, can put the client and the staff at risk. The support worker must maintain this information if the client wishes not to discuss their condition with their family. A support worker must maintain the privacy, confidentiality and disclosure of the clients they care for, including their families and carers, at all times.

Clients can identify family members who can access their personal information and records. If the client cannot do so, a guardian will be appointed. The guardian makes decisions on personal matters on behalf of the client. These include lifestyle choices and financial and legal matters.

Work Role Boundaries, Responsibilities and Limitations

There are boundaries set in the support worker-client relationship. Both parties must respect and adhere to this. Support workers must always maintain a professional working relationship with their clients. They must never go beyond this. Support worker violates this when they become too involved in a client's matters (e.g. family or financial). Another is when they enter into a romantic relationship with a client.

As a support worker, you support the client and relevant others. However, it would be best if you were not overly involved or attached to clients and their families. You should always follow the client's advance care directives, no matter how much you or the family disagrees with the consequences of the decision. You should also report any ethical issues or concerns with the client or others to their supervisor.

You may develop a close interpersonal relationship with the client, their family and their friends as you provide care and support. Your role gives you direct access to the client's information and may include their private lives. It is your responsibility to treat clients with dignity and respect. You also have to develop and maintain their trust and confidence. In this, you should be bound by the ethical standards set by the organisation when performing your responsibilities.

The table below shows examples of legal and ethical considerations for these:

Aspect	Legal Consideration	Ethical Consideration
Work role boundaries	Aged care workers must be careful when performing physical steps (i.e. care processes involving touching the person) to prevent cases of harassment.	An aged care worker must develop and maintain professional relationships with their clients, which means not getting too involved with their client's personal lives (e.g. finances)
Work role responsibilities	Aged care workers must closely supervise their clients, following their organisation's duty of care protocols.	Aged care workers must respect and consider their client's decisions by allowing them to experience an acceptable level of risk.
Work role limitations	Aged care workers must acquire permission or consent first before applying restrictive practices.	Aged care workers must not share false information or unfounded assumptions with their clients, such as making a medical diagnosis that only a health specialist can do.

When providing support and care for the client, support workers must not do the following:

Share personal matters with clients during work hours

Do all the work for their clients

Engage in a non-professional relationship with clients, their friends and family members

Visit clients outside of shifts

Accept money or expensive gifts from clients or their family members

Advise the client on matters outside your work role

Be involved with the clients' purchase or consumption of alcohol or illegal substances

Setting the limitations in your role will prevent possible conflicts of interest in your work.

Multimedia



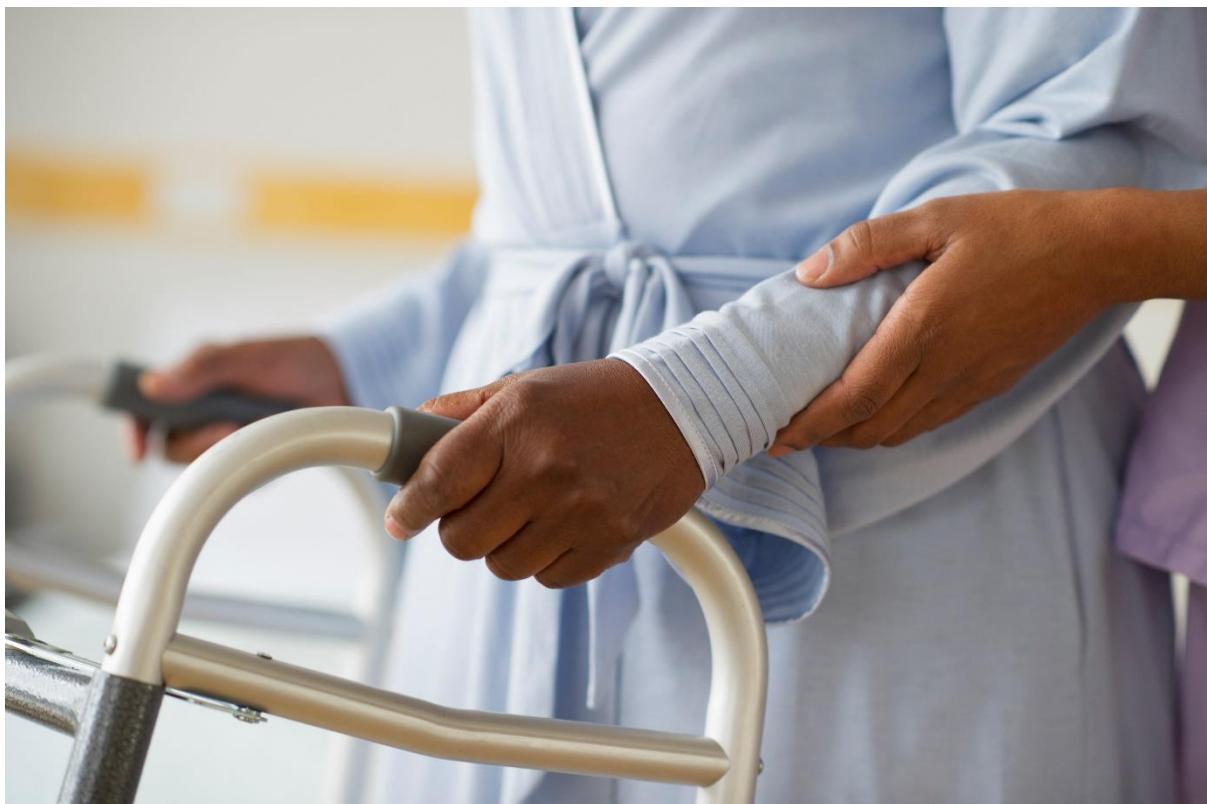
Professional boundaries can vary according to the nature of your job and the age or needs of your clients. The following video provides information on professional boundaries between support workers and clients in a home care setting:

[Professional Boundaries for Caregivers](#)

Checkpoint! Let's Review



1. Service care providers are legally and ethically obliged to follow a client's advance care directives.
2. The care team refers to this document when making their client's individualised plan.
3. The client can write advance care directives once they turn 18. It is a legal document that provides a direction for their health care when they can no longer decide.
4. Advance care directives also detail their preferences in receiving care aligned with their values and beliefs.
5. According to the Aged Care Quality Standards, the dignity of risk is the person's right to decide on their own regarding the care provided for them, including their right to take risks.



3.2 Comply With End-of-Life Decisions in the Individualised Plan



You learnt that the palliative approach is person-centred. A person-centred approach considers the client under care as the expert of their own lives. They can decide what type of support must be provided for them. Complying with their end-of-life care decisions shows that you respect their capacity to decide for themselves.

During the end of life, the client may have impaired functioning and increased symptoms. They will need higher levels of care to address these. Decisions are often made regarding the type of care the client wishes to receive at their end of life. Sometimes the family (or even you) may disagree with your client's decisions. However, it would be best if you respect these decisions. You have to trust that the client knows the risks associated with them. It can be difficult, but laws and legislation are in place to protect the rights and wellbeing of the people involved. Ensure you follow these legal requirements when carrying out your client's end-of-life decisions.

3.2.1 Laws About Medical Decisions

Some states and territories have laws related to aged care. Their laws are still based on or similar to federal legislation. Some states and territories use federal legislation and do not make their own. All states and territories use the laws discussed in Section 3.1.2.

There are specific laws in some states and territories about making medical decisions. These decisions usually relate to end-of-life care. The laws enable older people to make decisions for their medical care in advance. These include consent to medical procedures, such as surgery. These decisions also include consent to ventilation and resuscitation. For end-of-life care, older people may also include their decisions regarding organ donation.

Here are the laws and regulations about medical decisions for each state or territory:

State or Territory	Links
Australian Capital Territory	Medical Treatment (Health Directions) Act 2006
New South Wales	Guardianship Act 1987 No 257
Northern Territory	Advance Personal Planning Act 2013
Queensland	Powers of Attorney Act 1998
South Australia	Advance Care Directives Act 2013
Tasmania	Guardianship and Administration Act 1995
Victoria	Medical Treatment Planning and Decisions Act 2016
Western Australia	<p>WA does not currently have specific legislation regarding the protection of privacy, but it has the following directives:</p> <p style="text-align: center;">Advance Health Directives</p>

There are laws in Australia that ensure the rights of people to consent when it comes to medicine. These laws apply to all people, including older Australians. There are a lot of medical practices involved in aged care. Therefore, it is important to know the consent laws related to giving medical care.

3.2.2 Substitute Decision-Making

When the client cannot decide on their own due to severe health conditions, an appointed person by the client can substitute for decision-making.

Power of Attorney

Power of attorney is power assigned to someone that allows them to make medical decisions for another person. An older person can choose someone they trust to consent on their behalf when they can no longer do it. This power is usually given to a family member, close friend or advocate. When someone has this power, they can consent to medical procedures for someone else. An example is when a person has severe dementia. Refer to the table for these specific laws:

State or Territory	Links
Australian Capital Territory	Powers of Attorney Act 2006
New South Wales	Powers of Attorney Act 2003 No 53
Northern Territory	Powers of Attorney Act 1980
Queensland	Powers of Attorney Act 1998
South Australia	Powers of Attorney and Agency Act 1984
Tasmania	Powers of Attorney Act 2000
Victoria	Powers of Attorney Act 2014
Western Australia	Guardianship and Administration Act 1990

The appointed substitute decision-maker may also be indicated in the advance care directive. Ensure checking this to know who to approach when medical decisions need to be made.



Checkpoint! Let's Review

1. Complying with their end-of-life care decisions shows that you respect their capacity to decide for themselves.
2. Power of attorney is power assigned to someone that allows them to make medical decisions for another person.

3.3 Report the Person's Changing Needs and Issues in End-of-Life Care



Many changes occur during the end-of-life stage as the client suffers an irreversible decline in their health. As the client's illness progresses, their needs will continuously change. Issues identified in the early stages of diagnosis will also change. To continue providing care that fits the client's current condition, you must report their changing needs and issues.

To report is to give a verbal or written account of your observations. Reports can be given through verbal communication (e.g. meetings) or accomplished forms (e.g. official documents). Reports are essential in the documentation process, as these serve as official accounts of the palliative care provision. Reports will also serve as document references when updating the client's individualised plan.

Some of the client's changing needs during end-of-life care may include the following:

- Higher levels of care to address the physical symptoms of the illness
- Psychological needs (e.g. addressing feelings of anxiety or depression)
- Emotional needs (e.g. addressing fear and concerns about the end of life)
- Spiritual needs (e.g. finding solace in one's faith)
- Task needs (e.g. feeding)

Some of the client's changing issues during end-of-life care may include the following:

- Experiencing increasing levels of physical pain
- Experiencing intense emotions (e.g. anger, hopelessness)
- Experiencing the psychological impact of the illness
- Experiencing a loss of dignity as their health deteriorates
- Planning for the inevitable death
- Having medical interventions

Consider how the support worker reported and responded to the changing needs and circumstances in the client's care in the case study below:

Changing Needs and Circumstances in Mike's Care

Mike is diagnosed with middle-stage Alzheimer's disease. He suffers from moderately severe cognitive decline and requires assistance to meet his daily needs. To better address Mike's needs, his family sought palliative care services.

Jenna is the support worker assigned to assist Mike. She enjoys working with Mike, who is a very jolly and enthusiastic person. Although Mike sometimes forgets information like the date and time, he can still perform daily tasks like feeding and dressing up independently. However, after a month in the service, Jenna noticed that Mike seemed to be having personality and behavioural changes. For one, he shows increased agitation, especially when he wanders and finds himself lost. He also started to have delusions, which made him worried. Mike shared, 'I heard someone knocking on my door last night. I think they are trying to steal my things! What if they break into my room and harm me? I think that person will come again tonight!'

Jenna reported these changes in Mike's needs and circumstances to her supervisor. She also supports Mike in other ways. Jenna calms him down when he feels agitated by gently touching his arm and reassuring him she is there. She also asks him if he needs to go somewhere and tells him she will help him get there. When Mike shares his worries, Jenna listens.

Like Jenna, you must report any observed changes in the client's needs and issues. You must do this to keep track of any changes in the client's care and update the care team. Afterwards, make the necessary updates in the individualised plan. To report the client's changing needs and issues through verbal and written means doing the following:

Record observations about the client's needs and issues regularly. Consistent recording allows you to track any changes to these needs and problems.

Ensure to note any observed changes to the client's needs and issues.

Ensure the information recorded is accurate and complete.

- Aim to be objective by using language that describes what was seen, observed or heard. Use terms that are easily understood.
- Submit the report to the appropriate person on time. Alternatively, communicate your findings to the right person promptly.

Your organisation may have its template for reporting. In addition, there may also be organisational policies and procedures you must follow when reporting the client's changing needs and issues. Ensure to follow all of these.



Checkpoint! Let's Review

1. Many changes occur during the end-of-life stage as the client suffers an irreversible decline in their health. As the client's illness progresses, their needs will continuously change.
2. Issues identified in the early stages of diagnosis will also change. To continue providing care that fits the client's current condition, you must report their changing needs and issues.
3. Reports can be given through verbal communication (e.g. meetings) or accomplished forms (e.g. official documents).
4. Reports are essential in the documentation process, as these serve as official accounts of the palliative care provision.
5. Reports will also serve as document references when updating the client's individualised plan.
6. Reporting any observed changes in the client's needs and issues helps you keep track of any changes in the client's care and update the care team.

3.4 Monitor and Refer the Impact of the Person's End-of-Life Needs, Issues and Decisions



As mentioned in the previous subchapter, a client's needs during the end of life will continuously change following the progression of their illness. To recall, the examples of client needs during the end of life include the following:

- Higher levels of care to address the physical symptoms of the illness
- Psychological needs (e.g. addressing feelings of anxiety or depression)
- Emotional needs (e.g. addressing fear and concerns about the end of life)
- Spiritual needs (e.g. finding solace in one's faith)
- Task needs (e.g. feeding)

The client can also experience other issues during the end of life. These issues are often consequences of the client's condition. These issues include the following:

- Experiencing increasing levels of physical pain
- Experiencing intense emotions (e.g. anger, hopelessness)
- Experiencing the psychological impact of the illness
- Experiencing a loss of dignity as their health deteriorates
- Planning for the inevitable death
- Having medical interventions

These needs and issues during end-of-life care also affect the clients' decisions for themselves. These decisions often involve transitions. In palliative care, *transitions* are the changes caused by deterioration or improvement in the client's health condition. Transitions include changes in the following areas:



The client decides their end-of-life care for the following areas:

- Place where care is given**
 - At home
 - At a residential aged care facility
- Level of care received**
 - Informal care (no doctors or professionals)
 - Professional palliative care
- Goals of care**
 - Palliative care (to relieve symptoms)
 - No care

During the end of life, the client's needs, issues and decisions can impact the family, carers and others. For example, these people may have difficulty addressing the client's needs. They may also not know how to deal with the issues. The client's decisions may also be hard for the family and others to accept in some instances.

You must monitor the impact of the client's needs, issues and decisions on the family and relevant others. Unmonitored impacts, especially negative ones, are detrimental to client relationships and relevant others. These may also negatively affect the wellbeing of the people involved. Monitoring impacts ensures any concerns of the family and relevant others will be identified and referred to the proper personnel.

Monitoring is a process of observation, checking and recording of data over some time. Monitoring is usually done to check for changes in something. To monitor the impact of their needs and decisions on the family and relevant others, you must do the following:

- **Observe** – Note the family's and relevant others' responses to the client's needs, issues and decisions during end-of-life care.



- These people may show physical signs (e.g. fatigue, losing weight).
- There may also be strains in relationships between the client and their relevant others. This can include miscommunications, disagreements or fights.
- Aside from observations, you may also approach these people directly and ask how they are doing. You may find that other things are affecting them, which may not be noticeable at first glance.
- **Check** – Look for any changes in the family's and relevant others' responses to the client's needs, issues and decisions over time. The client's needs, issues and decisions can change during end-of-life care. These changes can have an impact on others. For instance, transitions can take a toll on them.
- **Record** – Note all initial observations and any subsequent changes over time. Keeping records is important because these will allow you to see how the observed impacts changed over time. Remember to create these records according to your organisation's policies and procedures.

Referring to the Appropriate Member of the Care Team

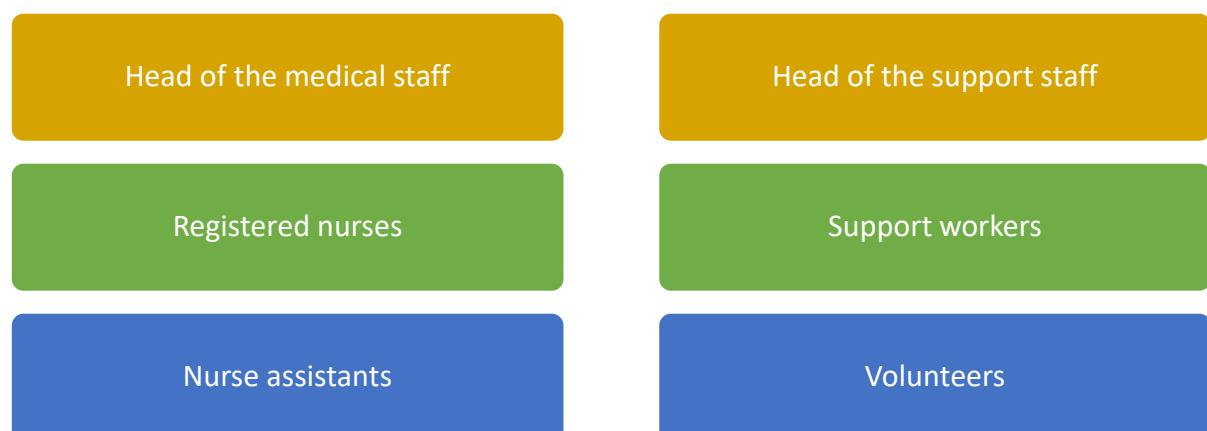
Concerns will become more obvious during your monitoring. You can address some of these needs (e.g. providing emotional support). However, some concerns will fall outside your job scope (e.g. medical interventions). Hence, it would be best if you referred to the appropriate care team member for support. To *refer* may mean:

- To direct someone to another person for help, clarification or guidance
- To approach another person for help, clarification or guidance

Before referring to the appropriate care team member, you must first know about your organisation's reporting line. A *reporting line* refers to the structure of an organisation. This tells you to whom you will report within your workplace. It is also known as an organisational chart. You must know the reporting line of your organisation to identify whom to refer a concern. Below is a simplified example of a reporting line in an aged care setting:



In this chart, you can see to whom each role reports. Under the bottom row, there are still different hierarchies, such as the following:



Further Reading



You can read more about the different roles of workers in the aged care sector through the link below:

[Who's who in aged care](#)

You can use the reporting line to refer the concern or issue to the correct person if there is a concern or issue outside of your work role. You can direct the individual to the correct person. You can also seek the correct person for guidance and clarification. The referral process will vary according to the circumstances of the concern and your organisational policies and procedures. In general, you refer by doing the following steps:

Identify the concerns or impacts that fall outside your scope of role.

Coordinate with your supervisor regarding the concerns and impacts you identified.

Identify the care team member that can best address these concerns or impacts (e.g. a doctor for pain medication issues).

Relay the concern with the appropriate care team member.

Set a consultation between the care team member and concerned family or relevant others as needed.



Checkpoint! Let's Review

1. In palliative care, transitions are the changes caused by deterioration or improvement in the client's health condition.
2. A reporting line refers to the structure of an organisation. It is also known as an organisational chart.

3.5 Support the Person's Right to Choose the Location of Their End-of-Life Care



Care providers must recognise clients' needs, preferences and wishes approaching the end of life. These needs and preferences are written in the advance care directives and are also reflected in the individualised plan. You must follow the wishes of the client as indicated. This shows respect and support towards their needs and preferences. This also shows respect towards their autonomy and capacity to make their best decisions.

Instructions for end-of-life care are typically included in the advance care directives. It is also incorporated into the individualised plan. These instructions may consist of how and where to deliver care services. This includes providing end-of-life care services in the client's preferred location. End-of-life care services may be provided in the following places:



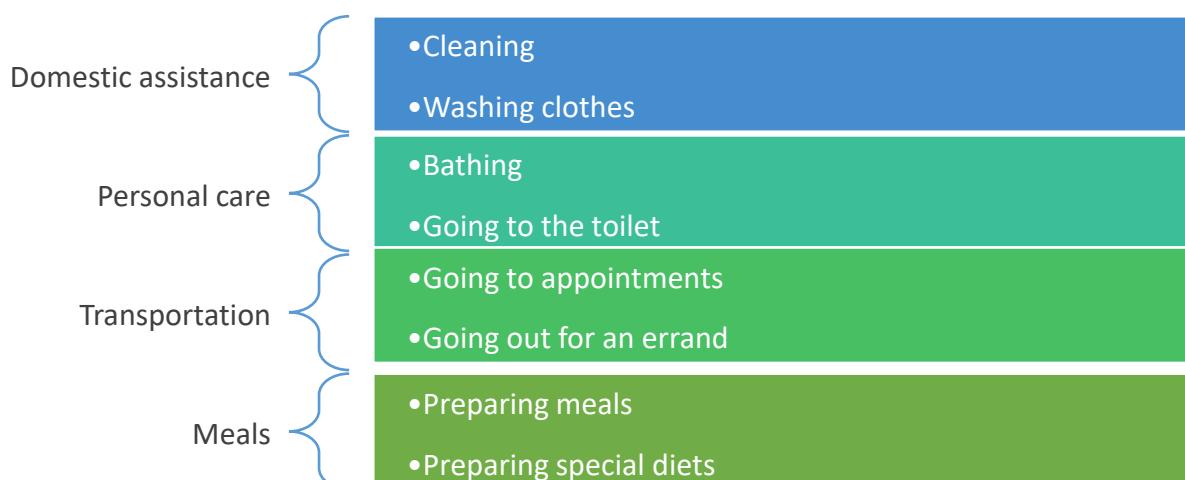
This unit applies to support workers in residential or community contexts. As such, the focus will be on providing end-of-life care at home and a residential aged care facility.

3.5.1 End-of-Life Care at Home



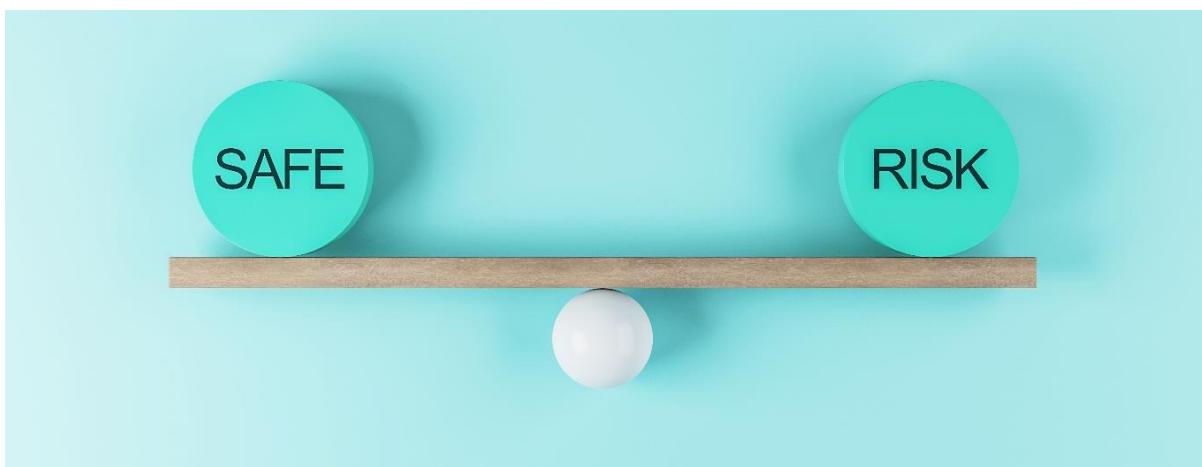
The priority of clients at the end of life is to spend as much time with their loved ones as possible. At home, it can be possible to have a friend or family member by their side at all times. This can be a source of comfort for them. Unlike in the hospital or hospice, where they are constantly monitored, home care can feel more relaxed and less clinical. They may still access medical care and support at home according to their wishes. This may help them gain a sense of control over the last part of their life.

As a support worker, your role requires you to provide the best possible care for your client, wherever they may be. Your job responsibilities may include providing the following:



You may check your job description for your other responsibilities. When providing care, you may also refer to your organisation's policies and procedures. Remember to acknowledge your client's dignity of risk but keep your duty of care towards them in mind.

3.5.2 End-of-Life Care at a Residential Aged Care Facility



Some clients spend most of their days in a residential aged care facility. The facility might have become their home if they had lived there for quite some time. It can comfort them to be surrounded by familiar staff as they approach the end of life.

Residential aged care facilities provide continuous care and assistance for older people. They usually have a range of chronic or life-limiting illnesses. Some clients may need ongoing care only an aged care facility can provide. As a support worker, your role requires you to provide the best possible care for your client, wherever they may be. Your job responsibilities may include providing the following:

Support with daily activities

Personal care and hygiene (e.g. bathing, going to the toilet)

Transportation (e.g. chaperoning, going to appointments)

Meals (e.g. assisting the preparation of meals or special diets)

Medication reminders

You may check your job description for your other responsibilities. When providing care, you may also refer to your organisation's policies and procedures. Remember to acknowledge your client's dignity of risk but keep your duty of care towards them in mind.



Checkpoint! Let's Review

1. Care providers must recognise clients' needs, preferences and wishes approaching the end of life. You must follow the wishes of the client as indicated.
2. As a support worker, your role requires you to provide the best possible care for your client, wherever they may be.
3. Remember to acknowledge your client's dignity of risk but keep your duty of care towards them.



Learning Activity for Chapter 3

Well done completing this chapter. You may now proceed to your **Learning Activity Booklet** (provided along with this Learner Guide) and complete the learning activities associated with this chapter.

Please coordinate with your trainer/training organisation for additional instructions and guidance in completing these practical activities.

IV. Respond to Signs of Pain and Other Symptoms



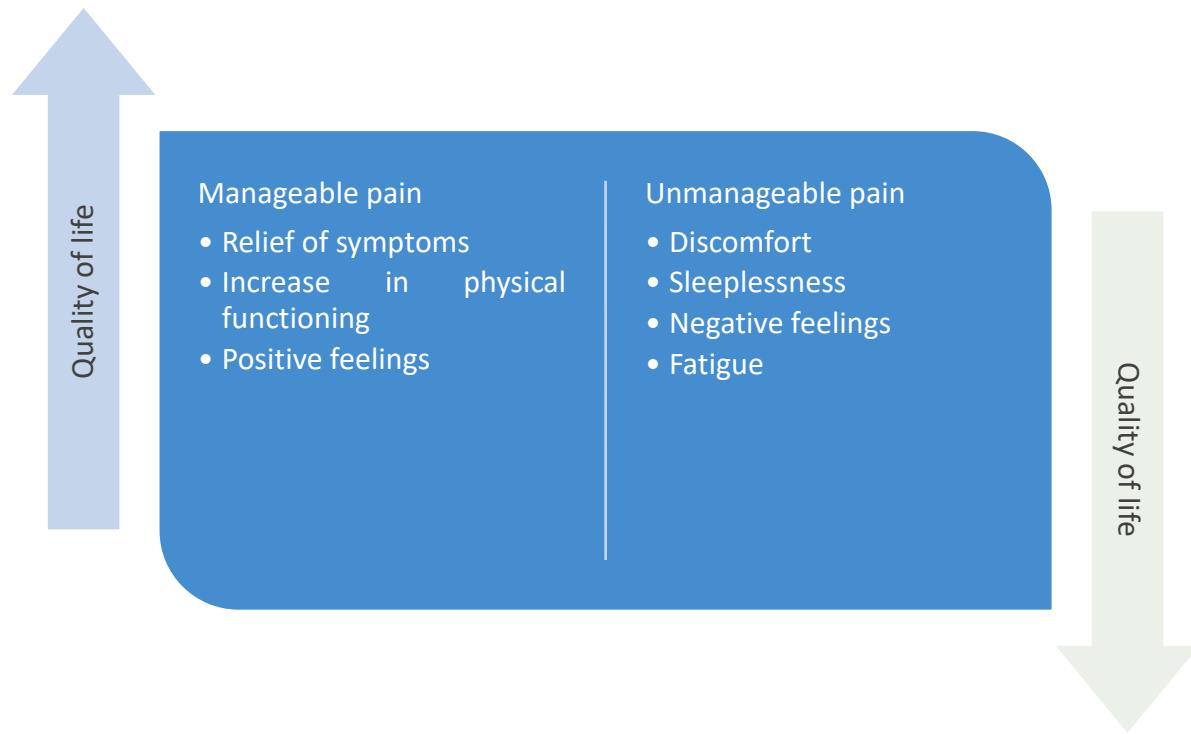
Previously, you learnt how to address your client's needs. These are indicated in their individualised plan and advance care directives. These needs encompass those that may emerge during the end-of-life stage. Thus, the discussion is more general. In this chapter, the focus is on one aspect of palliative care: pain management.

Pain is a distressing sensation in the body that can range from mild discomfort to agony. It is a common symptom felt by a person with a life-limiting illness. Pain can be *acute* (felt for a short time) or *chronic* (lasts for weeks or longer). It can also be *localised* (felt on only one body part) or *widespread*. The pain experienced by a client depends on the stage of their illness and its cause.

Pain has physical and emotional components which influence each other. Emotions can affect pain tolerance. For example, positive emotions can reduce feelings of pain. Meanwhile, negative emotions add to the feeling of pain. Pain also influences emotions. Chronic pain can make one feel resentful, frustrated or stressed.

Pain management refers to different strategies used to prevent, reduce or stop the pain. Pain management is important because it negatively impacts the client's QoL in many ways when pain is not properly managed.

See the figure below on how manageable and unmanageable pain affects the client's QoL:



Aside from pain, the client may also experience other symptoms associated with their illness. These symptoms can also be a side effect of their pain medication. Some symptoms include nausea, constipation, breathlessness and fatigue. The client's symptoms must be relieved to ensure a better QoL. Providing comfort towards the end of life is a priority.

In this chapter, you will learn how to do the following:

- Observe, document and report the person's pain and other symptoms
- Implement pain management and comfort strategies
- Document effectiveness of pain management strategies
- Identify and report concerns about the use of pain-relieving medication

4.1 Observe, Document and Report the Person's Pain and Other Symptoms



As mentioned, improving a client's QoL is one of palliative care's aims. Pain is one of the factors affecting QoL. In its progressive stage, a life-limiting illness can bring intolerable pain. The client's pain must be managed, and comfort levels must be monitored regularly to improve their QoL. This is where pain management comes in.

Pain management is integrated into the client's individualised plan. Pain management outlines the strategies the care team must follow to lessen the pain and other symptoms of the client. Pain management has these crucial aspects, which will be discussed accordingly:

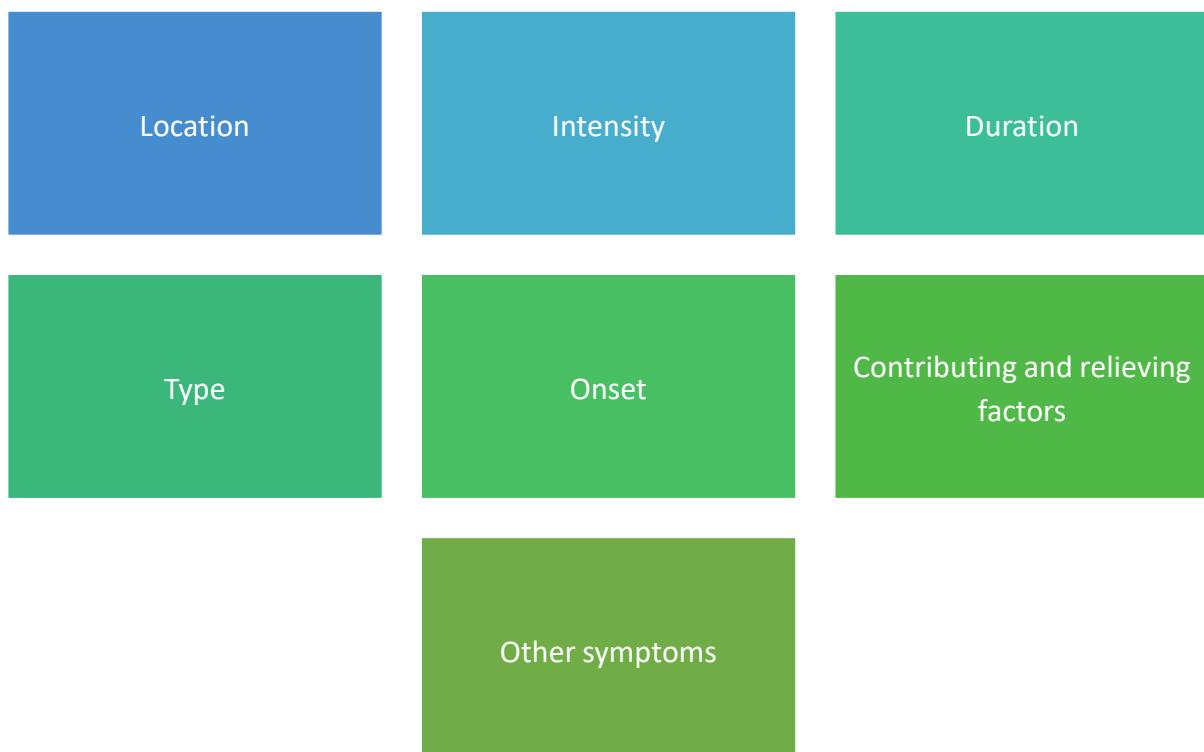
- Observation, documentation and reporting of the client's pain and other symptoms (Subchapter 4.1)
- Coordination with the care team members regarding the client's pain and other symptoms (Subchapter 4.1)
- Implementation of pain management strategies (Subchapter 4.2)
- Documentation of the effectiveness of pain management strategies (Subchapter 4.3)
- Education regarding pain (Subchapter 4.4)

Observing Pain and Other Symptoms

The client is the person who knows best about the pain they are experiencing. Care workers often rely on self-reports to measure the pain levels of their clients. The client's self-report will inform the care team how they can help the person even before the pain increases. However, be mindful of the barriers that get in the way of accurate and truthful reporting. You can revisit these in Subchapter 1.3.

Asking questions is the most straightforward way to get information. You can ask your clients questions about the pain they are experiencing. If the client has a condition that makes communication difficult, ask the family, carers or relevant others.

In pain assessment, you must ask about the following aspects of the pain:



- **Location**
 - Where is the pain felt?
 - Is the pain felt on one part of the body (i.e. localised)? Is it widespread?
 - Does the pain move elsewhere?
- **Intensity**
 - How would you rate the pain on a scale of one to 10 (one being *no pain* and 10 being the *worst pain possible*)?

▪ **Duration**

- Does the pain persist, or does it come and go?
- How long does the pain last?

▪ **Type**

- Can you describe the pain (e.g. pinpricks, tingling, sharp pain)?

▪ **Onset**

- Since when was the pain felt?
- Is it a new pain, or has it been felt before?

▪ **Contributing and relieving factors**

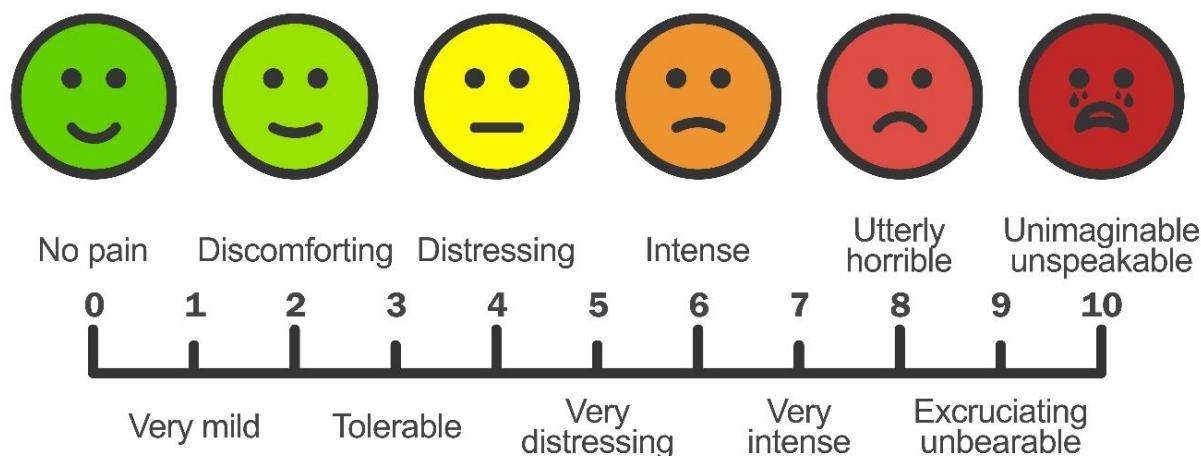
- What was happening when the pain occurred?
- What makes the pain worse?
- What makes the pain go away?

▪ **Other symptoms**

- Are there other symptoms of the pain (e.g. nausea, vomiting)?

Aside from answering questions and self-reporting, the client can be shown a pain intensity scale. This helps them visualise pain levels. This can be helpful for clients who have communication difficulties or limited vocabulary to describe their pain.

Below is an example of a pain intensity scale:



You can supplement self-reports with observations from you or other relevant people around the client. Other indications of pain can be observed in the following traits and activities of the client:

Facial expressions

- Grimacing
- Frowning
- Wincing

Body language

- Tense posture
- Restricted movements

Vocalisations

- Grunting
- Groaning
- Screaming

Activities

- Decrease in appetite
- Fatigue

Social interactions

- Aggressive behaviour
- Withdrawal

Other signs

- Sweating
- Paling of complexion
- Rapid breathing

Aside from pain, there are other symptoms that the client may be experiencing. These could be symptoms of their illness or side effects of current medications. No matter the cause, these other symptoms can also affect their QoL.

Remember to observe these other symptoms as well. Some of the common symptoms a client might feel include the following:

Nausea

Constipation

Fatigue

Difficulty sleeping

Shortness of breath

Loss of appetite

Documenting Pain and Other Symptoms

Documentation refers to written material or report that serves as an official record of something. Documentation is important in pain management because this:

- Serves as a means to communicate between care team members, making it easier for them to check and be updated on the client's pain condition
- Improves the consistency of care provided by the care team to the client
- Ensures there is a point of reference when comparing the effectiveness of pain management interventions
- Allows care team members to identify and track the client's needs and issues related to pain management
- Helps monitor the quality of pain management within the service

When documenting pain and other symptoms, you must note down all the information from the observation stage in your report. The information will include the following:

- Pain and other symptom reports from the client and relevant others
- Observations about the client's pain and other symptoms

According to organisational policies and procedures, you must complete any documentation promptly, accurately and objectively. Timely completion ensures the report is submitted promptly. Thus, information can be disseminated faster to concerned care team members, and support provisions can be updated.

Accurate and objective documentation go hand-in-hand. To be objective is to use language that describes what was seen, observed or heard. To be subjective is to use language that reflects your emotions or opinion. Objectivity is important because it ensures your reports are not affected by judgments, stereotypes, assumptions or opinions. In short, objectivity makes your report factual and accurate.

Organisations may have different approaches to documenting the client's pain and other symptoms. Some may use electronic means to upload documentation to an online portal. Others may require you to fill out printed forms as well. Remember to check your organisation's protocols and procedures for this process.

Consider the case study below on completing documentation in a timely, accurate and objective manner according to organisational policies and procedures:

Vita's Pain

Vita is a 70-year-old woman diagnosed with Stage 4 breast cancer. The cancer cells have begun to metastasise or spread to her bones in this late stage. She experiences extreme joint pain, particularly in the pelvis and thigh areas.

Vita has been receiving pain medications to help manage her pain. She has currently been prescribed morphine. However, despite taking prescription medication, she felt pain in the last week. Gina, Vita's support worker, wrote a report on the incident using the template that the organisation provided. The documentation is as follows:

Date of report	5 January 2023
Observation	<p>On 3 January 2023, Vita said that her medications 'seem not to be doing their job well'. She had difficulties sitting down, standing up and walking and required help moving around. She shared that problems moving around started last 31 December 2022, but the pain then was not as intense as it is now. She rated her pain on 31 December as a four on a 10-point scale. As of 3 January, Vita said she feels her pain at nine.</p> <p>When Vita moves from one place to another, she expresses her discomfort in many ways. For example, she grunts and winces. These expressions are accompanied by verbalisations such as, 'Ohhh, this really hurts,' and, 'Oh boy, my hip feels like it's about to fall off.'</p>

Upon completing the documentation, Gina submitted the report to her supervisor on the same day.

As you can see, Gina followed her organisation's policies and procedures by using the required template for documentation. She used objective and easy-to-understand language in her report. She also included important details, like when Vita's pain started and how painful it was for her. Lastly, she submitted her report promptly.

Reporting Pain and Other Symptoms



Information gathered from your observations must regularly be reported to the appropriate care team member. The relevant people may include your supervisor and the medical staff (e.g. nurse). Reporting keeps the relevant care team members updated on the client's pain and comfort levels. This is especially important when there are changes in the client's condition. Continuous monitoring will help relevant care team members decide what pain management strategies to use.

The process of reporting is straightforward. The information you will report includes the following:

- Pain and other symptom reports from the client and relevant others
- Your observations about the client's pain and other symptoms

Organisations may have different approaches to reporting the client's pain and other symptoms. Some may use informal means, like reporting verbally. Others may require filling out forms as part of the documentation process. Check your organisation's protocols and procedures to proceed with this process.

Checkpoint! Let's Review



1. Pain and other symptoms must be monitored appropriately so that these can be managed. Managing the client's pain and symptoms will improve their QoL.
2. Pain management is integrated into the client's individualised plan. Pain management outlines the strategies the care team must follow to lessen the pain and other symptoms of the client.
3. In pain assessment, you must ask about the following aspects of the pain:
 - Location
 - Intensity
 - Duration
 - Type
 - Onset
 - Contributing and relieving factors
 - Other symptoms



4.2 Implement Pain Management and Comfort Strategies



Pain management requires good communication between the care team and the client. The client's report of what they are feeling can assist you and the care team in helping reduce pain symptoms. It can also help you plan and anticipate the client's comfort needs.

The strategies to promote comfort include the following:

- Regular observation, reporting and documentation
- Provision of pain-relieving measures
- Other measures to promote comfort and relieve pain

4.2.1 Regular Observation, Reporting and Documentation

In the previous subchapter, you learnt the importance of observing and documenting pain and other symptoms. Your observations will inform the care team of the client's most appropriate pain management strategy. Pain management is a continuing process of observation, assessment and implementation. This process is very important because pain experience varies over time.

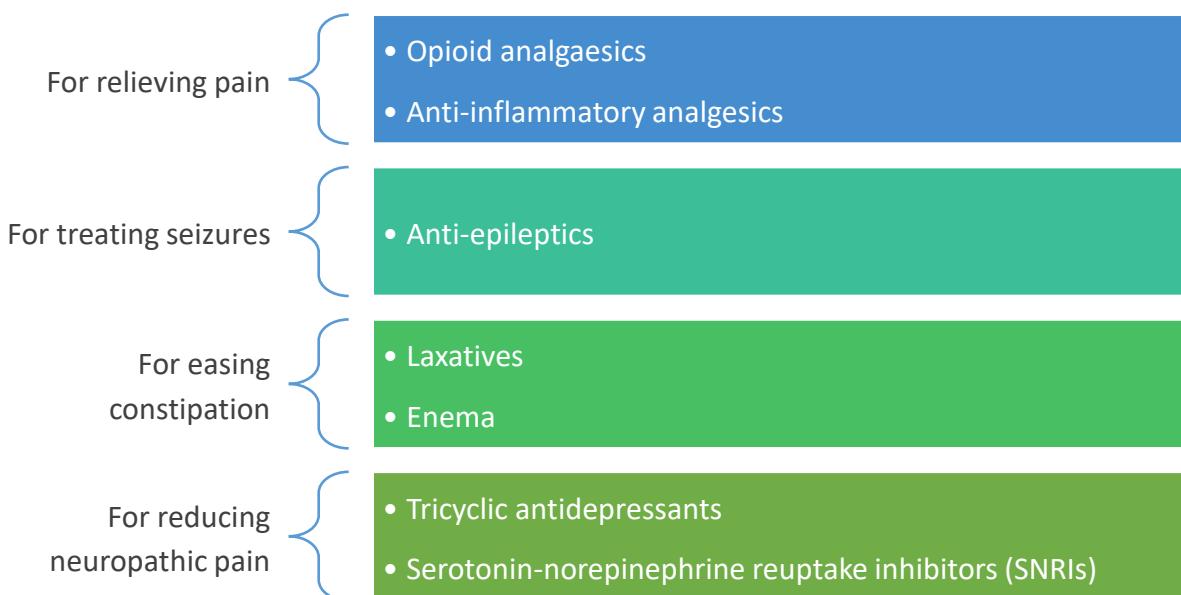
For example, the client may have breakthrough pain despite having scheduled medication. *Breakthrough pain* is episodic pain felt (or ‘breaks through’) even with scheduled medication. It would be best if you relayed this to the care team to prescribe additional medicine to address the breakthrough pain.

You must do a continuous assessment and pain monitoring to know if the pain management strategy works. You may refer to the previous subchapter for the tools you can use for pain assessment. Check with your supervisor if there are organisational procedures you must follow. Document the information carefully and report to the appropriate care team member.

4.2.2 Provision of Pain-Relieving Measures

Pharmaceutical medicines are an important part of pain management. They provide the client relief from pain and other symptoms. Prescribing medication is outside the scope of your job. Still, it would be best if you familiarise yourself with the common palliative care medicines. Doing this will help you during documentation and assessments.

Below are some of the prescribed medicines in palliative care:



Medications often provide pain relief. The following are examples of how to relieve pain:

- Administration of analgesics to prevent pain from returning
- Administration of drugs, such as antidepressants, to counter neuropathic pain

When supporting the client with pain management and relief, always be aware of the scope of your responsibilities. Administering pain medication and facilitating therapy will require the assistance of other health specialists.



Further Reading

The provision of pain-relieving medications is closely regulated to prevent drug abuse and misuse. The *National Medicines Policy* is a framework that advocates for access to high-quality and affordable medicines. It also promotes their safe and wise use. Read more about the policy below:

[National Medicines Policy](#)

4.2.3 Other Measures to Promote Comfort and Relieve Pain

Aside from medicines, other measures can supplement pain medications. You can consult the client's individualised plans if they indicate a preference for these measures.

Complementary and Alternative Therapies

Complementary therapies are measures that can be used alongside mainstream medical treatment. Some clients may use these to supplement their medication. *Alternative therapies* are measures that are used instead of mainstream medicine. Some may prefer complementary therapies over pain-relieving medicines. Depending on the purpose, one measure can both be a form of complementary or alternative therapy. Below are common options to promote comfort:

Physical therapy

Aromatherapy

Music therapy

Acupuncture

Meditation

- **Physical therapy** – This is the use of special exercises and equipment to improve a person's mobility and physical functioning.
- **Aromatherapy** – This is the use of essential oils and other aromatic extracts to improve a person's health and wellbeing.

- **Music therapy** – This is a therapeutic approach that uses music-based interventions to address mental health concerns (e.g. anxiety, depression) and improve mental health and general wellbeing.
- **Acupuncture** – This is an ancient Chinese medical approach that aims to relieve pain by using thin needles to pierce the skin at strategic points of the body.
- **Meditation** – This is a practice that aims to focus and calm the mind using specific techniques (e.g. breathing exercises, reflection).

Other Measures

Experience of pain can also be affected by psychosocial and existential factors. For instance, depression and anxiety strongly influence the pain experience. These factors must also be assessed and treated. With these, it may be helpful to refer the client to a counsellor, support group leader or psychologist. Professional help can relieve pain by countering depression, anxiety and other psychosocial and existential factors that intensify physical pain.

Consult with the client first before implementing any of the pain management strategies. The client's right is to accept or refuse the medication or other measures. It would be best if you respected their decision.

4.2.4 Seek Clarification and Guidance From Health Professionals

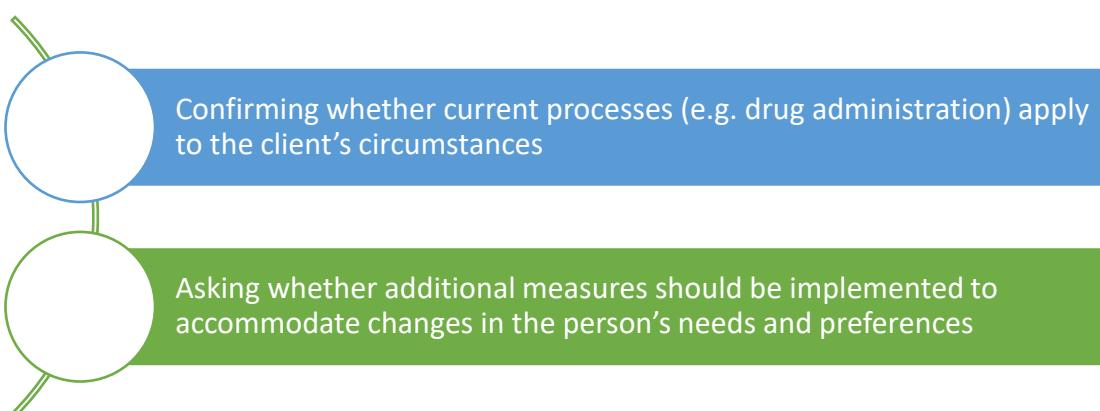
A big part of pain management involves providing pain medications that offer pain relief and comfort. A health professional is the best person to seek clarification and guidance from for any questions or concerns regarding pain relief and comfort provision. Points of clarification and guidance may include, but are not limited to, the following:



- Medication provision
- Possible side effects of medications and how these can be addressed
- Necessary accommodations following any changes to the client's needs and preferences.

To seek clarification and guidance about pain relief and comfort provision, you must follow these steps:

1. Prepare and prioritise matters of concern regarding pain relief and comfort provision for the client. You can do this by listing all the whats, whys and hows you need to discuss with the health professional.
2. Coordinate with your supervisor and set an appointment with the appropriate health professional.
3. Meet with the appropriate health professional to discuss any clarifications concerning pain relief and comfort provision. This may include:



4. Note the health professional's inputs in the form prescribed by your organisation.
5. Have your organisation's prescribed form signed by the health professional.

Multimedia



Learn more about pain management for older people by watching the video below:

[Management of pain and behaviour difficulties, delirium in aged care](#)

Checkpoint! Let's Review



1. Pain management requires good communication between the care team and the client. The client's report of what they are feeling can assist you and the care team in helping reduce pain symptoms. It can also help you plan and anticipate the client's comfort needs.
2. The strategies to promote comfort include:
 - Regular observation
 - Documentation and reporting
 - Provision of pain-relieving measures
 - Implementation of other measures to promote comfort and relieve pain
3. Pain management is a continuing process of observation, assessment and implementation. This process is very important because pain experience varies over time.



4.3 Document Effectiveness of Pain Management Strategies

As mentioned in the previous subchapter, pain management is a continuing observation, assessment and implementation process. Each person has a different pain threshold. Pain may also vary depending on the stage of the client's illness. Thus, you must update pain management strategies to minimise the client's pain.

You must review the client's current pain management plan and check how they have responded to treatment. Doing this will inform you and the care team how well the current treatment plan addresses pain. You may use any of the pain assessment tools mentioned in Subchapter 4.1. Document any changes carefully and report to the appropriate care team member. Documentation may include information on the following:

Pain locations

Pain behaviours

Functional impairments

Other associated symptoms

Reasons for discontinuation of therapy

Previously attempted pain therapies

You can also do the following and add the answers to your documentation:

- Ask the client about their pain level before and after taking pain medication.
- Ask the client what interventions were taken if the client's pain level is not acceptable



Checkpoint! Let's Review

1. Reviewing the client's current pain management plan helps you know the effectiveness of current pain management strategies.
2. Document any changes carefully and report to the appropriate care team member.

4.4 Identify and Report Concerns About the Use of Pain-Relieving Medication



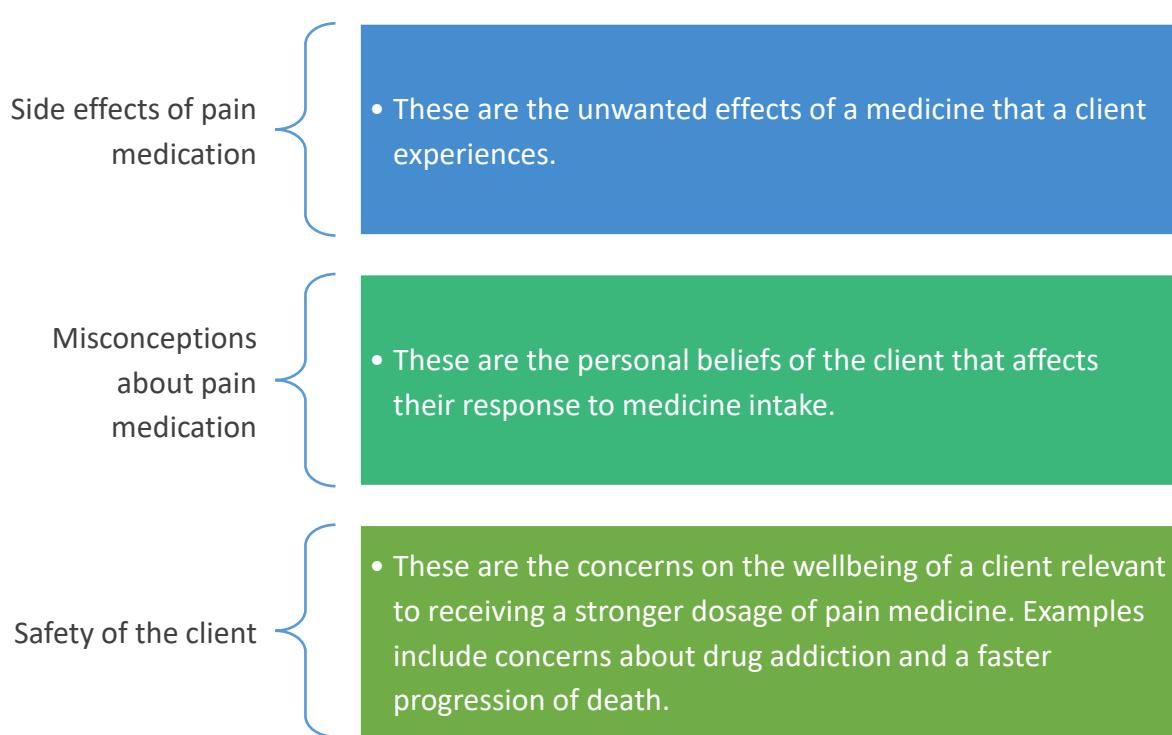
The previous subchapters have discussed the methods of managing pain among palliative care clients. You learnt about the pharmaceutical medicines used for pain relief. You also discovered the various measures and therapies that are used to provide comfort for your client.

Pain-relieving medications are substances that clients take to ease the suffering brought on by their health illnesses. The provision of pain relief is part of what palliative care offers. The type of medication, as well as their frequency and amount, varies on the client's condition. Common pain relievers include analgesics, laxatives, and antidepressants, as mentioned in Section 4.2.2.

This subchapter will cover the common concerns that clients and their family members bring up about pain medication. These concerns can be due to the medicine's negative impacts on the client's body. The beliefs and misconceptions of people towards certain drugs can also influence them. As a support worker, you must be able to determine and act on these concerns, as they might worsen the client's current condition. You must also follow your organisation's policies and procedures when relaying information to your supervisor.

4.4.1 Identifying Concerns About the Use of Pain-Relieving Medication

The common concerns about using pain-relieving medication include the following:



Side Effects of Pain Medication

The common side effects associated with pain medication include the following:

- Nausea
- Constipation
- Breathlessness
- Fatigue
- Delirium
- Drowsiness
- Dry mouth
- Itchy skin

When your client experiences any of the side effects above, you must perform ways to provide them relief following the policies and procedures. Contact your supervisor if the client's condition does not improve or worsens as time passes.

Misconceptions About Pain Medication

Clients might have beliefs that can negatively affect their perception of pain medicine. These beliefs lead to misconceptions that greatly impact comfort provision by doing the following:

- Affecting the client's adherence to taking prescribed medicines
- Contributing to the client's reluctance to receive pain medications
- Making the client feel apprehensive about taking pain relievers
- Causing the client to report their pain levels inaccurately

Below are the common misconceptions about pain medication:

Pain relief should only be given for pain that is currently present.

Doctors and nurses are the best judges of a client's pain.

Clients should not receive pain relief until the cause is determined.

Strong analgesics may shorten life.

Pain management alone is not palliative care.

The client may become too drowsy to communicate with family.

The client (or even their relevant others) must be given pain education to clear these misconceptions. *Pain education* refers to providing information to clients and their relevant others on managing pain and improving health. Pain-relieving medication is an essential topic in pain education. However, note that clearing up misconceptions about pain medications is outside of your job role. What you can do is refer these concerns to your supervisor.

To refer, you must follow the following steps:

1. Note any misconceptions the client and the relevant others have about pain medications.
2. Inform your supervisor about the misconceptions that the client and the relevant others may have about pain medications.
3. Schedule a consultation between the client, the relevant others and your supervisor so they can talk about these misconceptions about pain medications.

Clearing any misconceptions about pain medication will ensure the following:

- The client takes their prescribed medications.
- The client reports their pain levels accurately.
- The client's pain levels are managed.
- The client's QoL can be improved through proper pain management.

Safety of the Client



Concerns about the safety of the client arise when they are prescribed stronger medicine to relieve extreme pain. For example, opioids like morphine are given by doctors when drugs like ibuprofen are not effective anymore on the client. The client's family members might worry that taking opioids can lead to the client's addiction. There could also be concerns that opioid medication hastens the client's death.

When you hear these concerns, explain that health professionals follow guidelines on using opioid medicines in palliative care. Assure the client and their family members that an objective assessment will be conducted to prevent the risk of dependency, overdose, and other issues associated with opioids.

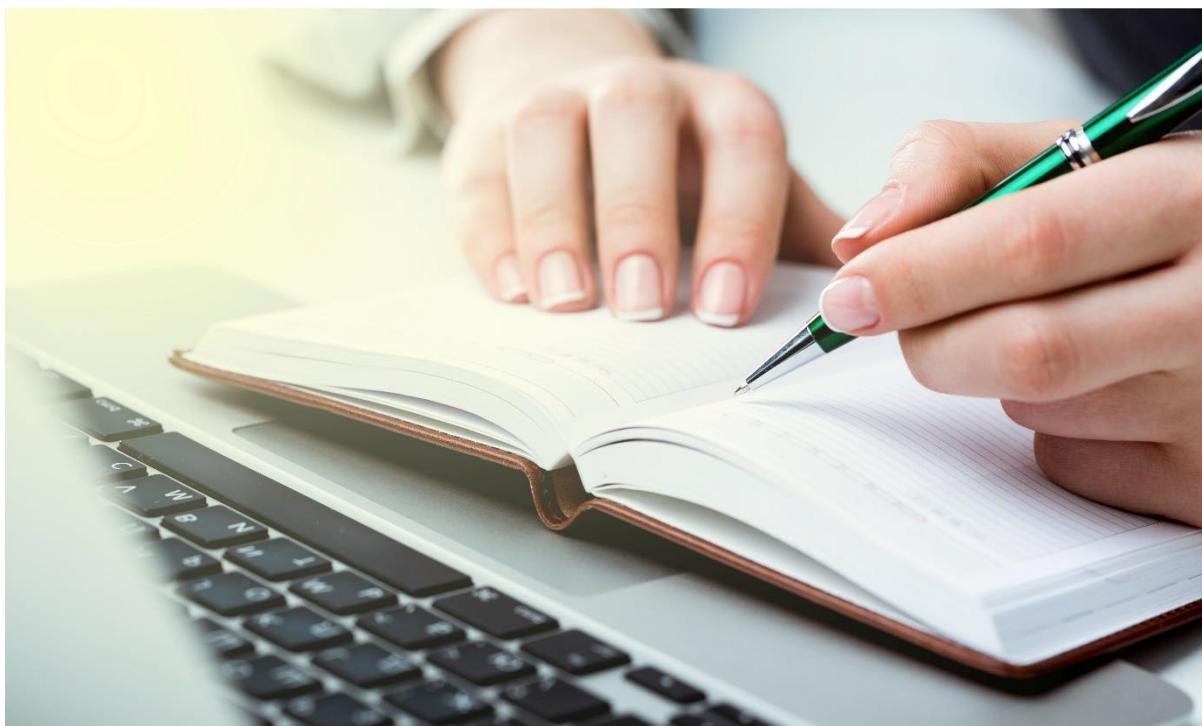
Further Reading



There are many misconceptions about pain medicines, especially morphine. But what is real and what is not? You can check through the link below:

[Learn more about pain and pain management](#)

4.4.2. Reporting Concerns About the Use of Pain-Relieving Medication



Any concerns about the intake of pain relievers, like side effects, misconceptions, or worries about the safety of the client, must be reported appropriately to your supervisor. This is important since concerns about medication must be addressed immediately to prevent the client's condition from worsening.

You can consider the following steps when filing a report to your supervisor regarding a client's concern about using pain relievers:

1. Conduct a check-up on the client's condition.

Your duty as a support worker is to conduct a regular check-up on your client. In addition to the standard tests, you can also check on how they respond to their current pain-relieving medication. Ask if they are experiencing any discomfort like nausea or diarrhea. You can also ask if they have any concerns regarding their medication.

2. Document your observations and received concerns from the client.

Record all your observations in a single document to help you organise the report you will submit to your supervisor. For example, you have noticed that your client's appetite has greatly decreased after taking a particular pain-relieving medication. These observations must be noted as they might harm the client if left unattended.

In addition, ensure that the record of your client's concerns is complete. This can help your supervisor in decision-making and sharing information with other staff.

You can use the details below as a guide when you make your report:

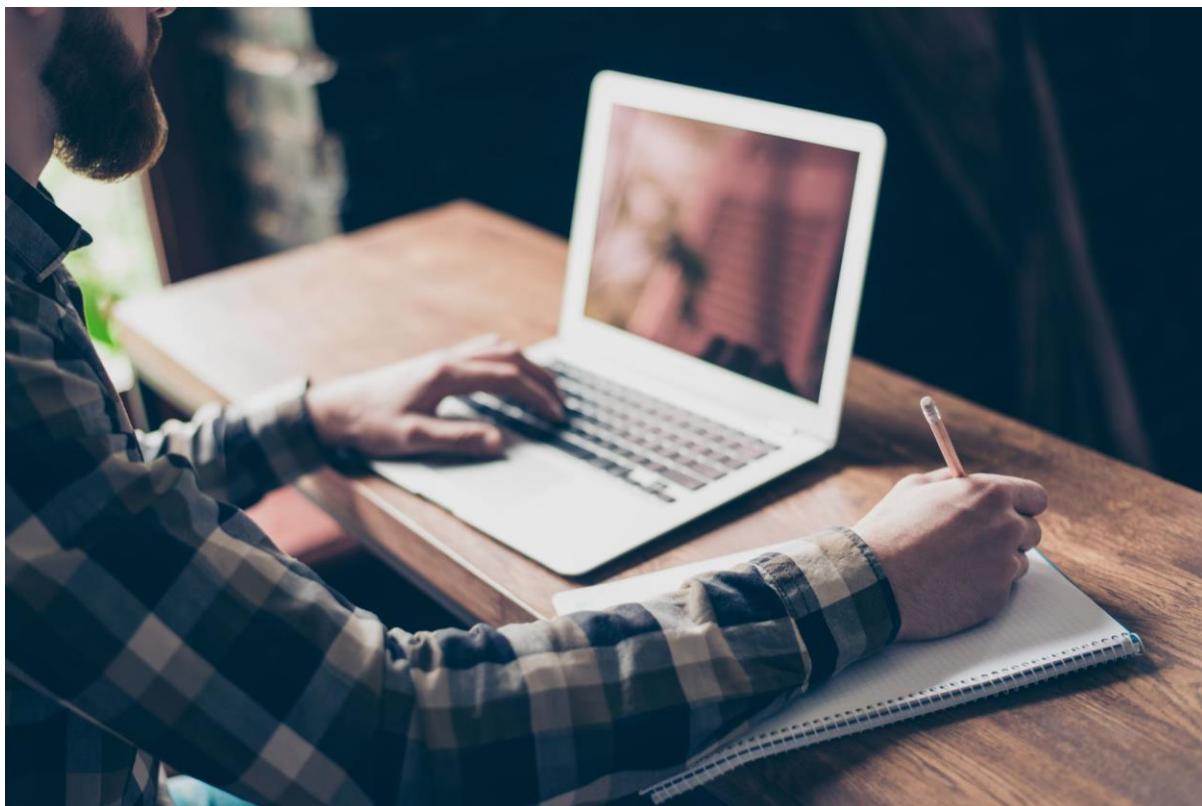
- Date and time that the concern was raised
- Complete details on the concern/s of the client or family
- Personal assessment of the client on the pain medicine they are taking
- Personal requests about pain medication of the client or family
- Your own observations on the client's response to the pain medicine

3. Submit your report to your supervisor and answer their questions.

Follow your organisation's policies and procedures when filing the report to your supervisor. You can also provide a verbal description of the client's concerns together with the documented report.

Make sure to answer your supervisor's follow-up questions and follow their instructions on responding to the client's concerns.

Keep in mind that you must prioritise timeliness when submitting reports. Tell your supervisor immediately if the client has concerns or complaints about their pain-relieving medication. This will ensure a quick response from the staff responsible for administering the pain medication.



Checkpoint! Let's Review



1. Misconceptions about the use of pain-relieving medications can affect comfort provision and pain management negatively.
2. Pain education refers to providing information to clients and their relevant others on managing pain and improving health.
3. Follow organisational policies and procedures when reporting concerns about the client's pain-relieving medication.



Learning Activity for Chapter 4

Well done completing this chapter. You may now proceed to your **Learning Activity Booklet** (provided along with this Learner Guide) and complete the learning activities associated with this chapter.

Please coordinate with your trainer/training organisation for additional instructions and guidance in completing these practical activities.

V. Follow End-of-Life Care Strategies



The previous chapters showed you how to identify and address your client's needs, their family and relevant others. You also learnt many strategies that can help you in your work. Discussions are more general and, thus, applicable at any stage of palliative care. In this chapter, the focus is specific: end-of-life care. The strategies and procedures you will learn here will be applied in this care context.

The *end of life* refers to the client's remaining days, weeks or months. Individuals who are also assessed as likely to die within 12 months are also considered at the end of life. *End-of-life care* is given to a person approaching the end of life. When a person is said to be in the end-of-life stage, death is expected shortly. Because of this, the goals of medical treatments and procedures change. End-of-life care is not focused on curing the illness. Instead, its primary goal is to focus on comfort and improving the QoL in their remaining days.

End-of-life care strategies refer to action plans that promote the client's comfort and improve their QoL during their last days. End-of-life care strategies also aim to provide comfort and support to the family, carer and relevant others during end-of-life and the period after death.



This chapter will cover end-of-life care strategies. You will learn how to do the following:

- Regularly check for changes in the individualised plan
- Provide a supportive environment to the person and their relevant others during end-of-life care
- Respect and support the person's preferences and culture when providing end-of-life care
- Maintain dignity of the person throughout end-of-life care
- Recognise and report any signs of imminent death, dying or deterioration
- Provide emotional support to bereaved when death has occurred

5.1 Regularly Check for Changes in the Individualised Plan



The client's needs will change throughout the care. These changes can often occur during end-of-life care when a decline in health is expected. Once the client's health deteriorates, they may need additional services. You must check the individualised plans regularly to accommodate any changes or additions to the person's needs and keep everyone in the care team updated. You must also review these changes frequently to aid the care team in addressing the person's current needs to ensure it is based on the most recent information.

Refer to your organisation's policies and procedures for tracking and reviewing these changes. Policies and procedures may include the frequency or schedule of review and tools to be used. Remember the importance of completing and keeping documentation, discussed in Subchapter 3.3.



Checkpoint! Let's Review

- Once the client's health deteriorates, they may need additional services.
- Regularly checking and reviewing the care plan ensures that everyone on the care team is updated on any changes.

5.2 Provide a Supportive Environment to the Person and Their Relevant Others During End-of-Life Care



End-of-life care has a great psychological and emotional impact on the person, family, carer and others. During end-of-life, the client suffers from impaired functioning and increased symptoms. They become weaker, and their body slowly deteriorates. They will require higher levels of care but may still experience pain that cannot be alleviated by medication or treatment. At this stage, the client and their family are being prepared for inevitable death.

Psychological impact refers to the effects of a situation on a person's mind or thoughts. On the other hand, *emotional impact* refers to the effects of a situation on a person's emotions. There may be similarities and differences in the psychological and emotional impacts felt by the client and their relevant others.

Refer to the table on the next page for the possible psychological and emotional impact of end-of-life care on the person, family, carer and others.

The possible psychological and emotional impact may include the following:

Person	Possible Psychological Impact	Possible Emotional Impact
Client	<ul style="list-style-type: none"> ▪ Lack of interest in doing things usually enjoyed ▪ Depression ▪ Anxiety ▪ Fear 	<ul style="list-style-type: none"> ▪ Despair ▪ Helplessness ▪ Anger ▪ Grief
Family	<ul style="list-style-type: none"> ▪ Restlessness due to thinking about the things that need to be done ▪ Depression ▪ Anxiety 	<ul style="list-style-type: none"> ▪ Guilt ▪ Helplessness ▪ Anticipatory grief
Carer	<ul style="list-style-type: none"> ▪ Depression ▪ Anxiety ▪ Fatigue ▪ Burnout ▪ Sleep problems 	<ul style="list-style-type: none"> ▪ Guilt ▪ Helplessness ▪ Anticipatory grief
Client's Friends	<ul style="list-style-type: none"> ▪ Panic disorder ▪ Depression ▪ Anxiety 	<ul style="list-style-type: none"> ▪ Guilt ▪ Helplessness ▪ Anticipatory grief
Colleagues	<ul style="list-style-type: none"> ▪ Reduced focus in some stretches during work hours ▪ Depression ▪ Anxiety 	<ul style="list-style-type: none"> ▪ Guilt ▪ Helplessness ▪ Anticipatory grief

The grieving process may start as early as the end of life for the people close to the client. *Anticipatory grief* is when a loved one is still living, but death is inevitable. For some time, the family and others witness the client's struggles with their illness. It can be difficult to see their loved one become a shadow of their former self. This grief can feel as painful as when a loved one dies. They may feel the following:



In this challenging time, the client and their relevant others need a safe space to grieve or express their feelings. Those struggling with anticipatory grief may need to be reminded that feeling a sense of loss does not mean they are giving up. Although difficult, this period may also help them make the most of the remaining time. You may revisit Subchapters 1.2 and 2.1 for helpful tips on how you can support them.

You can also encourage family and others to do the following:

- Talk about their feelings
- Reach out to other people or groups for help and support
- Reach out to a higher being as a source of strength
- Create memories with the client while they still can
- Be prepared for any situation and find ways to take control
- Take care of themselves physically and emotionally

You can provide emotional support during end-of-life care in different ways. See how a support worker below provided emotional support to the person, carer and family:

Amin's Prognosis

Amin has terminal-stage kidney disease. He responded positively to treatment, but his health suddenly deteriorated upon contracting pneumonia. His attending physician, Hanna, informed Amin, his family and his carer that his body was not responding to treatment anymore. Amin is likely to die within the month. Thus, the physician advised everyone to prepare themselves.

The news deeply shocked Amin and his loved ones. The family cannot accept the prognosis, and Amin has withdrawn from the others. Amin's carer avoids bringing up the topic of death for fear of upsetting Amin and his family. Hanna noticed the tension between these people and encouraged them to talk about their feelings. Hanna approached each person and asked them how they were doing. Although these people were initially reluctant to speak about Amin's condition, they eventually opened up about their concerns.

Remember to approach the concerned individual with empathy and sensitivity when providing emotional support. Doing this will make them more likely to open up to you. If you feel that further support is necessary, confirm the next steps you need to take with the appropriate person.

In addition, you can also give support by ensuring there is proper coordination between the services needed by the client. Since a client's health condition may change rapidly, it is necessary to coordinate with other relevant services (e.g. hospitals, emergency services or the person's physician).

Below are some things you can do to ensure that relevant services are well-coordinated:

- Communicate as soon as practicable any updates regarding the person's condition, including their wants, needs and care preferences, to the relevant services to ensure everyone involved is on the same page.
- Ensure the palliative care team has quick access to emergency service helplines or contact methods.
- Develop and establish a coordination system with the relevant services to ensure the smooth delivery of services for the person.



Checkpoint! Let's Review



1. End-of-life care has a great psychological and emotional impact on the person, family, carer and others.
2. During the end of life, they will require higher levels of care but may still experience pain that cannot be alleviated by medication or treatment.
3. At the end of life, the client and their family are being prepared for inevitable death.
4. Anticipatory grief is when a loved one is still living, but death is inevitable. For some time, the family and others witness the client's struggles with their illness.
5. In this challenging time, the client and their relevant others need a safe space to grieve or express their feelings.
6. Remember to approach the concerned individual with empathy and sensitivity when providing emotional support.



5.3 Respect and Support the Person's Preferences and Culture When Providing End-of-Life Care



Part of providing end-of-life care is to deliver appropriate care to the client's needs and condition. You must also align care with their expressed wishes. A client's wishes often reflect their values and beliefs. These impact the healthcare decisions they make as well. You must understand and respect your client's beliefs. Their cultural, religious or spiritual beliefs can often help them cope with their illness and suffering.

Furthermore, a client's values and beliefs should not interfere with their rights to receive end-of-life care. The client's individuality, values and beliefs must always be respected and supported, as discussed in Subchapter 2.2.

5.3.1 Cultural Differences in Relation to Death and Dying

Culture significantly influences a person's view of sickness, death and dying. There are many practices and beliefs surrounding death. Differences will also exist within the same culture. However, these practices have this in common: they help the sick transition to the afterlife peacefully. The table on the next page lists some beliefs and practices of cultural groups. It is not exhaustive, and you may find that every family has a unique tradition. You can broach the topic sensitively with the family if there is one and coordinate with a cultural liaison, too.

Refer to the table below for some examples of cultural beliefs and practices:

Cultural Group	Beliefs About Death	Beliefs About Dying
Aboriginals and Torres Strait Islanders	The family members mourn the passing of their loved one through 'sorry business'. The community mourns the deceased. Some do not conduct business and activities during this time.	Immediate and extended family and friends gather to spend time with the person to show respect and prepare them for their 'greater journey'.
Latin Americans	Death does not stop the connection between the living and the deceased. The dead are honoured during <i>Día de los Muertos</i> (Day of the Dead). They believe that the departed can rise from the dead and celebrate them.	Rituals, such as last rites, baptism or bedside prayers, are conducted
East Asians	Death is viewed as a part of life. Grief and mourning are also relational and filial. Family members are expected to be present at the time of death. They believe that the deceased will look after the ones left behind.	Family members are expected to care for the person, which is considered an obligation.
Central Americans	Death is an occasion for family and friends to get together. Some groups celebrate the departed's life. They share memories of them over drinks and food.	Instead of sending the ill person to a residential facility, family members care for them at home until they pass away. The female relatives usually provide care.
Mexicans	Death is seen as a new beginning. The Day of the Dead is an occasion for celebration. The deceased are remembered and celebrated through joyful songs and dances.	Religious items like miniature statues and rosary beads are often placed near the dying person's bed. This is to give reassurance and comfort to them that God is present.
Africans	Death rituals are very important in their culture. They believe that the departed's spirit can be at peace if they are given proper rituals.	In some tribes, the person is given water to drink just before dying. This is to prepare them for the long journey ahead.



Further Reading

You can read more on the different death and funeral rites around the world through the link below:

[Death around the world](#)

5.3.2 Religious Differences in Relation to Death and Dying

Religion refers to a specific and established set of organised beliefs and practices shared by a community or group. Each religion has its higher being. People follow the higher being's teachings in their own lives. Be mindful that each person or family may practise their faith differently. It is best to consult with them regarding their religious needs.

Below are the common religions practised around the world:

Religion	Beliefs About Death	Beliefs About Dying
Christianity	Upon death, their spirit separates from the physical body. They believe that death is just a passage or transition towards eternal life.	A pastor visits the dying person to read the Scriptures and pray over the dying person. This is done to help the person repent for their sins and prepare them for the afterlife.
Catholicism	Catholics believe they will come face to face with God upon death. However, those who did not repent upon committing a grave sin cannot enter heaven.	When the person is nearing death, they should receive the sacrament of Anointing of the Sick. This will absolve them of their sins and give them the strength, courage and peace of mind to face death.
Islam	Death is not the end but a transition to the next stage of existence. While on earth, they must endeavour to prepare for the next life that is to come.	A person's death is predetermined. Only Allah knows the exact time of a person's death. Therefore, methods such as suicide, euthanasia and murder are prohibited.

Religion	Beliefs About Death	Beliefs About Dying
Judaism	Death is a natural process that must be allowed but not hastened. They forbid euthanasia, suicide and assisted suicide.	They believe a person should not be alone towards death. For this reason, the dying person must have a companion with them during the last hours of their life.
Hinduism	They believe in reincarnation. To escape the cycle of death and rebirth, they must achieve nirvana.	Hindus believe that a dying person should die at home. Their family and friends will sing sacred hymns and recite prayers.
Buddhism	Buddhists believe rebirth follows after death. Death and suffering are part of life. They can achieve nirvana or enlightenment through good actions and earned wisdom. Achieving enlightenment stops the cycle of death and rebirth.	Buddhists believe that how they live affects their future, including how they will die. Thus, they need to do good deeds for themselves and others to achieve calmness when they die.



5.3.3 Spiritual Differences in Relation to Death and Dying

Spirituality is distinct from religion. While religion is a shared practice in a group or community, spirituality is an individual practice. It is one's journey towards discovering their inner self. A person may be influenced by their religion when practising spirituality. Those who do not follow a specific religion may practice spirituality alone. They make their own sets of beliefs that guide them daily.

Below are some examples of spiritual beliefs related to death and dying:

Death

- Death is a constant reminder that one should live their purpose each day.
- There is no such thing as an afterlife.

Dying

- Mercy killing may be appropriate in some instances as this does not prolong the dying person's suffering.
- Necessary rituals might be provided for the dying person to ensure they will have a peaceful death.

Spiritual beliefs vary for each person, so it is better to ask the client about their practices and beliefs.



Further Reading

Know more about the different cultural, religious and spiritual practices through the links below:

Resources

Spirituality and Faith

Multicultural resources for healthcare professionals

Care at the end of life for all communities

Checkpoint! Let's Review



1. You must understand and respect your client's beliefs. Their cultural, religious or spiritual beliefs often help them cope with their illness and suffering.
2. A client's values and beliefs should not interfere with their rights to receive end-of-life care.
3. The client's individuality, values and beliefs must always be respected and supported.
4. Culture significantly influences a person's view of sickness, death and dying. There are many practices and beliefs surrounding death. Differences will also exist within the same culture.
5. Spirituality is distinct from religion. While religion is a shared practice in a group or community, spirituality is an individual practice.



5.4 Maintain Dignity of the Person Throughout End-of-Life Care



Maintaining a person's dignity is essential before and after death. You must follow their wishes as indicated in their advance care directive. Refer to the My Health Record website, discussed in Chapter 3, for further information regarding their advance care directive. Such wishes may involve refusal or agreement to certain medical treatments during end-of-life care. It can also include specific medical decisions in the event of critical deterioration. For instance, resuscitation plans can be refused if they will not improve their QoL.

Other directives may take place when death has occurred. Such wishes may include honouring any cultural or religious requirements. Familiarise yourself with these and coordinate with the appropriate care team member as needed.

5.4.1 Death at Home

When the client has chosen to spend their remaining days at home, the family needs to know what will happen. You or someone from the care team can discuss what is to be expected when death occurs so the family can be prepared. Because care is provided at home, a health professional may not be present when the client dies. In such situations, it is better to plan with the family.

Part of planning is educating the family on the death process. They should be familiar with the signs and symptoms of death or deterioration. This prepares them for the next steps they have to take. In particular, the family must be given a heads-up that the body may release fluids or waste after death. They need safety measures to avoid getting in direct contact with these. You can refer to Subchapter 5.5 for more information on the death process.

It would be best if you also informed the family of the processes and procedures following death. Depending on the client's wishes, the family may have to contact certain individuals or religious persons when death has occurred. Before death, the family should also coordinate with the medical practitioner who will issue the cause of death certificate. Ideally, this is a doctor who knows the client's medical history. The doctor needs to complete the medical certificate and give notice of the death within 48 hours of passing. You must remember some families may need more time to process the passing away of a loved one. You can reassure them that it is all right to take their time. It is okay not to do something straight away. When they are ready, then they can proceed to the next steps.

It may be difficult for the family and others to remember what steps to take when they are dealing with the death of a loved one. It would help to have all the relevant information written down. Written information can include the physical processes that a dying person may experience. It can also include a list of who to call. If a death happens in the middle of the night, it is also good to have a 24-hour palliative care service that they can contact.



5.4.2 Death at a Residential Aged Care Facility

Residential aged care facilities have their policies and procedures when dealing with the death of a client. Depending on previous discussions with the family, you may have to notify them when the client is nearing death. Be mindful of the client's and their family's cultural or religious requirements. There might be a need to make a confessional prayer or receive the last rites for some. You must contact the family and a religious person or leader regarding this. Refer to the advance care directive for guidance about this matter.

In most instances, the staff helps the family with practical matters, so loved ones can say their last farewells to the deceased. Some practical matters include the following:

Preparing the body

Organising the death certificate

Contacting a funeral director

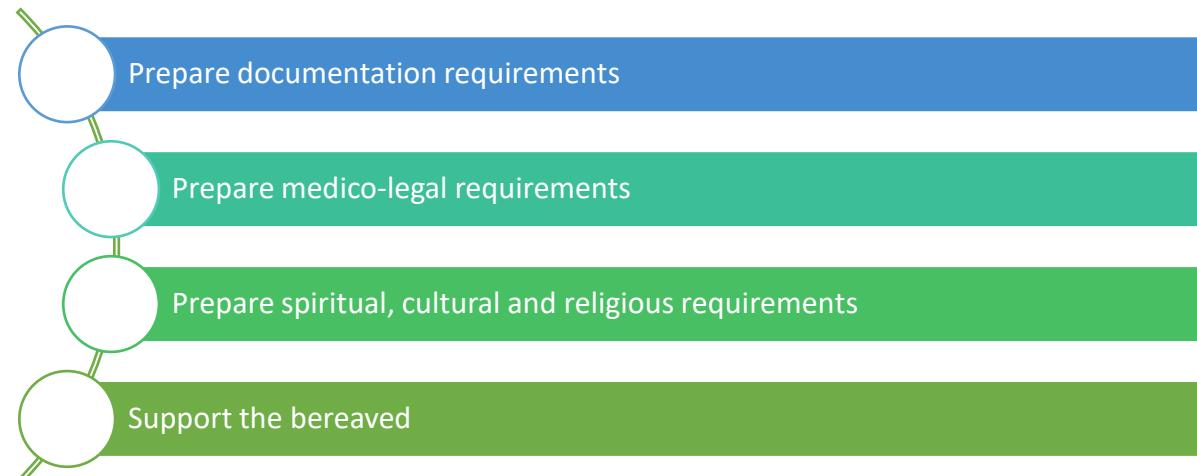
Still, what must be done follows the wishes of the deceased. In some religions and cultures, the body's preparation is a family affair. They may also need a funeral home that caters to their cultural or religious needs. In such instances, the facility must prepare to accommodate these wishes. Many facilities honour the passing of their residents by holding a ritual or ceremony. This may range from lighting a symbolic lamp or forming an honour guard detail as the body leaves.

Check with your organisation on how you can further support the family during this time.

5.4.3 Processes for Care Following Death

Many matters need to be taken care of after death has occurred. You will find that forms need to be submitted, individuals have to be contacted, and things have to be arranged.

Here are the following matters that may need your attention:



Documentation Requirements

Death requires proper documentation. After death has occurred, you must notify a general practitioner or doctor. They will sign a *Medical Certificate Cause of Death (MCCD)* that confirms the death of the person and the cause of their death. The doctor's certificate is required for the issuance of a death certificate.

Births, Deaths and Marriages Registration Act

The *Births, Deaths and Marriages Registration Act* outlines registering a death. For one, the doctor has to notify the registrar-general of the death within 48 hours. The death certificate can only be issued after the initial step is taken.

Each state/territory has its website detailing procedures for applying for a death certificate. You may find them below:

State or Territory	Links
Australian Capital Territory	Apply for a birth, death or marriage certificate
New South Wales	NSW Registry of Births Deaths & Marriages
Northern Territory	Apply for birth, death or marriage certificate
Queensland	Applying for a death certificate
South Australia	Apply for a death certificate
Tasmania	Apply for a death certificate
Victoria	Get a death certificate
Western Australia	Apply for a death certificate

Advance Health Care Directive

As mentioned, advance care directives are typically uploaded on My Health Record. You will often refer to this website for information and updates about the client's care. The advance care directive will outline the client's care preferences at the end of life. It would also contain their wishes and preferences following death, including funeral preparations or ceremonies. Instructions regarding the care of personal effects and belongings may also be there. Ensure to check the website for any of the client's last wishes.

Services Australia

Services Australia is a government agency that delivers a range of services for Australian citizens. They provide welfare, health and social services, among others. In the case of death, they have to be notified as well. The advice of death form (SA116) should be duly accomplished and submitted.

The image below shows a portion of a form for adult death:

<p>Filling in this form</p> <p>You can fill this form digitally in some browsers, or you can open it in Adobe Acrobat Reader. If you do not have Adobe Acrobat Reader, you can print this form and sign it.</p> <p>If you have a printed form:</p> <ul style="list-style-type: none"> • Use black or blue pen. • Print in BLOCK LETTERS. • Where you see a box like this Go to 1 skip to the question number shown. 	<p>8 Their relationship status</p> <p>Single <input type="checkbox"/> Married <input type="checkbox"/> Registered <input type="checkbox"/> Partnered <input type="checkbox"/> Widowed <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Not sure <input type="checkbox"/></p> <p>Partner's name (if applicable)</p> <p><input type="text"/></p>
<p>Deceased person's details</p> <p>1 Mr <input type="checkbox"/> Mrs <input type="checkbox"/> Miss <input type="checkbox"/> Ms <input type="checkbox"/> Mx <input type="checkbox"/> Other <input type="text"/></p> <p>Their family name <input type="text"/></p> <p>Their first given name <input type="text"/></p> <p>Their second given name <input type="text"/></p> <p>2 Their date of birth (DD MM YYYY) <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p>	<p>9 Read this before answering the following question.</p> <p>This question is voluntary. If you do answer, the information will help us to continue to improve services to Aboriginal and Torres Strait Islander Australians.</p> <p>Were they of Aboriginal or Torres Strait Islander Australian descent?</p> <p>If they were both Aboriginal and Torres Strait Islander Australian descent, tick both 'Yes' boxes.</p> <p>No <input type="checkbox"/> Yes – Aboriginal Australian <input type="checkbox"/> Yes – Torres Strait Islander Australian <input type="checkbox"/></p> <p>10 Read this before answering the following question.</p> <p>This question is voluntary. If you do answer, the information will help us to continue to improve services to people of Australian South Sea Islander descent.</p> <p>Australian South Sea Islanders are the descendants of Pacific Islander labourers brought from the Western Pacific in the 19th Century.</p>

Sourced from *Advice of death form (SA116)*, used under CC BY 3.0 AU. © Commonwealth of Australia

Informing Other Organisations

You may also inform the family about services that can send a notice of death to multiple organisations online. The Australian Death Notification Service is one example. This will greatly help the family manage or close the departed's memberships in various organisations.



Further Reading

Access the Australian Death Notification Service through the link below:

[Let organisations know that someone has died](#)

Medico-Legal Requirements

An expected death refers to a foreseeable death. In the community context, this means death is known to and expected by the staff member who discovers it.

Expected death refers to death that:

- Results from a terminal illness
- Involves palliative care services
- Has a formal agreement between the care team and the family that active intervention will not be used to prolong the life

On the other hand, unexpected deaths must be investigated before a death certificate can be issued. The *Coroners Act* states that unforeseen deaths must be reported to the coroner and the police. Each state/territory has its version of the Act. Each also outlines different circumstances in which death may be considered unexpected.

Below are some examples of cases:

The death is unexpected, unnatural or violent

The death resulted, directly or indirectly, from an accident or injury

The death is attributed to a medical operation or procedure

The deceased was not attended to by a doctor within the last six months

Deaths in palliative care are usually expected. However, a coroner's report may still be submitted if the death happened due to an unrelated or unexpected event.

Unrelated or unexpected events may include the following:

Fall accidents

Overdose on medications

Delayed medical treatment

What constitutes a reportable death may vary according to the Coroners Act of your State/Territory. Check the links below for more details:

State or Territory	Links
Australian Capital Territory	Coroners Act 1997
New South Wales	Coroners Act 2009 No 41
Northern Territory	Coroners Act 1993
Queensland	Coroners Act 2003
South Australia	Coroners Act 2003
Tasmania	Coroners Act 1995
Victoria	Coroners Act 2008
Western Australia	Coroners Act 1996

Follow your organisation's policies and procedures when reporting instances of reportable deaths. You may access your state/territory's coroners court below for more information regarding the process and the list of documents that must be submitted:

State or Territory	Links
Australian Capital Territory	Coroner's Court
New South Wales	Coroners Court New South Wales
Northern Territory	Coroner and Inquests
Queensland	Coroners Court
South Australia	Coroners Court
Tasmania	Magistrates Court of Tasmania
Victoria	Coroners Court of Victoria
Western Australia	Coroner's Court of Western Australia

In addition to reportable deaths, you can check the legislation applicable to your state or territory regarding the processes relevant to the disposal of the deceased body. These processes include the following:

- Dealing with organ donation
- Donation of the body for scientific purposes
- Preparation, transportation and disposal of dead bodies
- Investigation of sudden, unexpected and unnatural deaths
- Official certification of death
- Burial of dead bodies

Respecting Spiritual, Cultural and Religious Requirements

The spiritual, cultural, and religious needs of the clients must be respected before and after death. Certain rituals and practices in some cultures and religions are observed to ease the person's journey to the afterlife. Some clients and families may want to perform sacraments or special blessings before death occurs.

It would be best if you informed the family when death is bound to happen soon. They may have to make the necessary arrangements for clergy or a religious person. The care team may also arrange for pastoral care if the family does not have their own. For the Aboriginal and Torres Strait Islanders, a gathering of immediate and extended family and friends happens. You must make the necessary arrangements to accommodate them.



Usually, the first thing to do after death is to prepare the body. Someone who has undergone training performs the task of caring for the deceased's body. If it is within your job role, ensure to follow your organisation's policies or procedures. When providing care, you must observe appropriate precautions and infection control standards. These include proper handwashing, personal protective equipment (e.g. gloves and apron) and proper waste disposal. Some families may wish to perform or assist in preparing the deceased's body. This may be part of their religion or culture to fulfil the client's last wishes. The care team must accommodate these needs and tell the family about the precautions for infection control.

Personal belongings of the deceased must be handled carefully and with respect. Ornaments (e.g. jewellery and watches) are typically removed when preparing the body. Some families may wish for certain religious ornaments to remain with the deceased. As for soiled clothes, you can ask the family if they would like them to be bagged up, returned or disposed of. If the client stayed in a residential care facility, their room might have to be cleared as soon as possible. There may be an occupant lined up to take the room.

In some cases, the family may not yet be ready to pack the departed's belongings. However, you may sensitively explain to them the need to do so. If unsure, you can refer to your supervisor for further instructions.

Supporting the Bereaved

The time immediately following a death can be a busy and confusing one for the family. They have to attend to many practical matters. Some tasks are accomplishing forms and documents and arranging funeral services. In the middle of all this, it can be difficult for them to grieve. They must be given support during the dying and after the death of their loved one. Support can be assistance in practical matters concerning death and funeral.



Organisations usually brief the family on the documents they have to fill out and the next steps they need to take. Most also aid in contacting the relevant people (e.g. general practitioner, funeral director) to ease the burden on the family and others' shoulders.

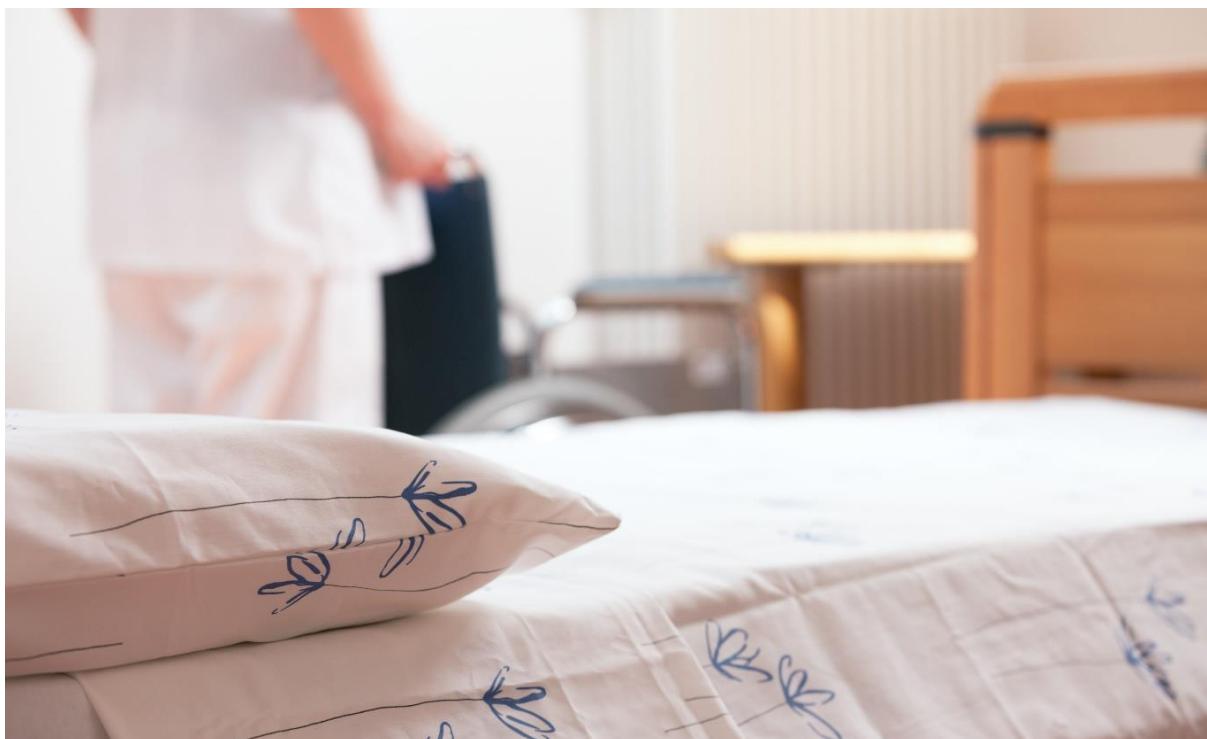
The bereaved will also need emotional support during this time. Understand that each person reacts to death differently. Some may need to be alone, while others may need someone to talk to about their experience. It may also be helpful to have an organisation or support group that they can connect with. We will extensively discuss how to provide emotional support in Subchapter 5.6.

If you are unsure about the process for supporting the grieving, you may check with your supervisor or organisation.

Checkpoint! Let's Review



1. As death approaches, everyone needs to be prepared. Knowing what to expect ensures that they can take the next steps when death happens.
2. Maintaining a person's dignity is essential before and after death. You must follow their wishes as indicated in their advance care directive.
3. Such wishes may involve refusal or agreement to certain medical treatments during end-of-life care. It can also include specific medical decisions in the event of critical deterioration.
4. Other directives may take place when death has occurred. Such wishes may include honouring any cultural or religious requirements.
5. Certain rituals and practices in some cultures and religions are observed to ease the person's journey to the afterlife.



5.5 Recognise and Report Any Signs of Imminent Death, Dying or Deterioration



No one can tell when a person may die, even in palliative care. Some people may pass away while unconscious. Others may stay awake and slowly deteriorate. *Deterioration* is the state where a person's condition becomes progressively worse. Although you cannot predict the exact time, some signs indicate imminent death. It is essential to recognise these signs. This ensures the client can be given the best possible care during the last days of their life. It can also help prepare you, the care team and the family.

Once you recognise signs of deterioration or imminent death, report them to the appropriate care team member. Depending on the advance care directives of the client, there may be some measures that must be taken. For example, life-sustaining measures may be applied or withheld.

A person's last remaining days or hours are called the *terminal phase*. During this period, the person is 'actively dying'. The person experiences deterioration, which is an indication of imminent death.

The signs of a client's deterioration during the terminal phase include the following:

Becoming forgetful

Losing the ability to do a wide range of movements

Becoming more ill than usual

Changing of breathing patterns

Worsening of the person's temperament

Worsening of condition as the day or hour passes by

Becoming less responsive and sleepier

Having noisy chest secretions or 'death rattle'

Even if the client displays the typical signs and symptoms of dying, the actual death may happen after several hours or days. Some signs of imminent death may include the following:

Spending a lot of time in bed and becoming less responsive

Having little interest in food or drink

Being restless

Getting confused about time, place or identity of loved ones

Becoming cooler to the touch

Breathing irregularly, shallowly or noisily

Losing bladder or bowel control

A client who has passed away will:

Lose their breath or pulse

Stop blinking or moving their eyes

Have dilated pupils

Have a relaxed jaw and a mouth that is slightly opened

Release their bowel and bladder contents

Be unresponsive to touch or voice

Follow your organisation's policies and procedures when reporting the observed signs of the client's deterioration and imminent death.

Multimedia



The signs and symptoms of death and dying are different in every person. Everyone must be informed to know what to expect. This video shows the experience of different families as their loved ones approach the end of life:

[What to expect at the end of life](#)

Checkpoint! Let's Review



1. No one can tell when a person may die, even in palliative care. Some people may pass away while unconscious. Others may stay awake and slowly deteriorate.
2. Deterioration is the state where a person's condition becomes progressively worse. Although you cannot predict the exact time, some signs indicate imminent death.
3. It is essential to recognise these signs. This ensures the client can be given the best possible care during the last days of their life. It can also help prepare you, the care team and the family.
4. A person's last remaining days or hours are called the terminal phase. During this period, the person is actively dying. The person experiences deterioration, which is an indication of imminent death.



5.6 Provide Emotional Support to the Bereaved When Death Has Occurred



People experience grief and bereavement when they experience a loss in their lives. Many people find that although they may be prepared for the dying process, they may not be ready for the actual death of their loved ones. *Grief* is the emotional response following a loss. *Bereavement* is the process of adjusting following the loss. Each person is different, and you will find that everyone deals with losses in their way.

Grief is experienced in the following stages:

- **Denial**

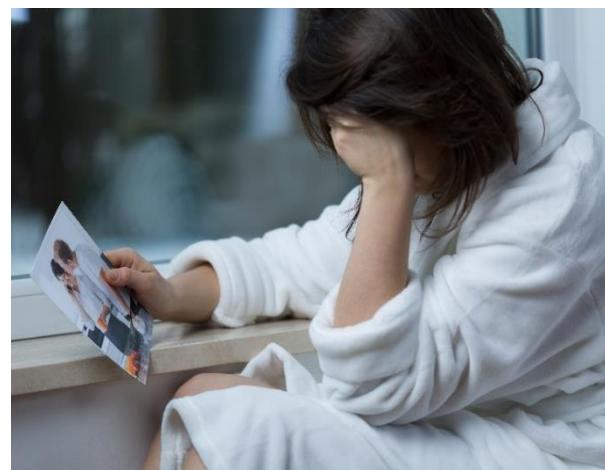
Receiving news that a loved one has passed away can be a surreal experience. For some, it is a reality that can be tough to accept. In this stage, the bereaved often feel lost, numb, and in denial as the reality of death has not fully sunk in. They may feel disconnected from it all. Denial is your body's way of helping you cope with difficult experiences. This allows you to accept the loss at your pace. Without denial acting as a buffer, it is easy to get overwhelmed with feelings of grief. Denial is a temporary response that helps get over the first wave of shock and pain. Once this initial reaction fades, the once-bottled emotions will surface.

- **Anger**

Pain can also be expressed through anger. The loss of a loved one may seem unfair to those left behind. These feelings of unfairness can be amplified when the loved one has suffered much pain during the last days or weeks of their life. Those left behind may ask questions like, 'Why me?' or 'What did we do to deserve this?' Their anger can also be redirected to animate or inanimate objects, themselves or the person who died. Anger is usually seen as a negative emotion, but it is necessary to facilitate healing. It anchors a person back to reality after feeling lost and disconnected.

- **Bargaining**

The feelings of grief may be too much for others that they are willing to do anything to turn back time. Some negotiate with a higher being to spare their loved ones or turn reality into a dream. Feelings of guilt are intensely felt. Often, those left behind drown in thoughts of 'what' and 'if only'. They also explain the possible interventions they could have done to prevent death.



- **Depression**

Depression is the most recognisable form of grief. Emptiness is felt as a consequence of losing a loved one. Feelings of despair and intense sadness are also present. Often, these feelings manifest in other ways. It can be through losing interest in eating, doing work or school, or interacting with others.

- **Acceptance**

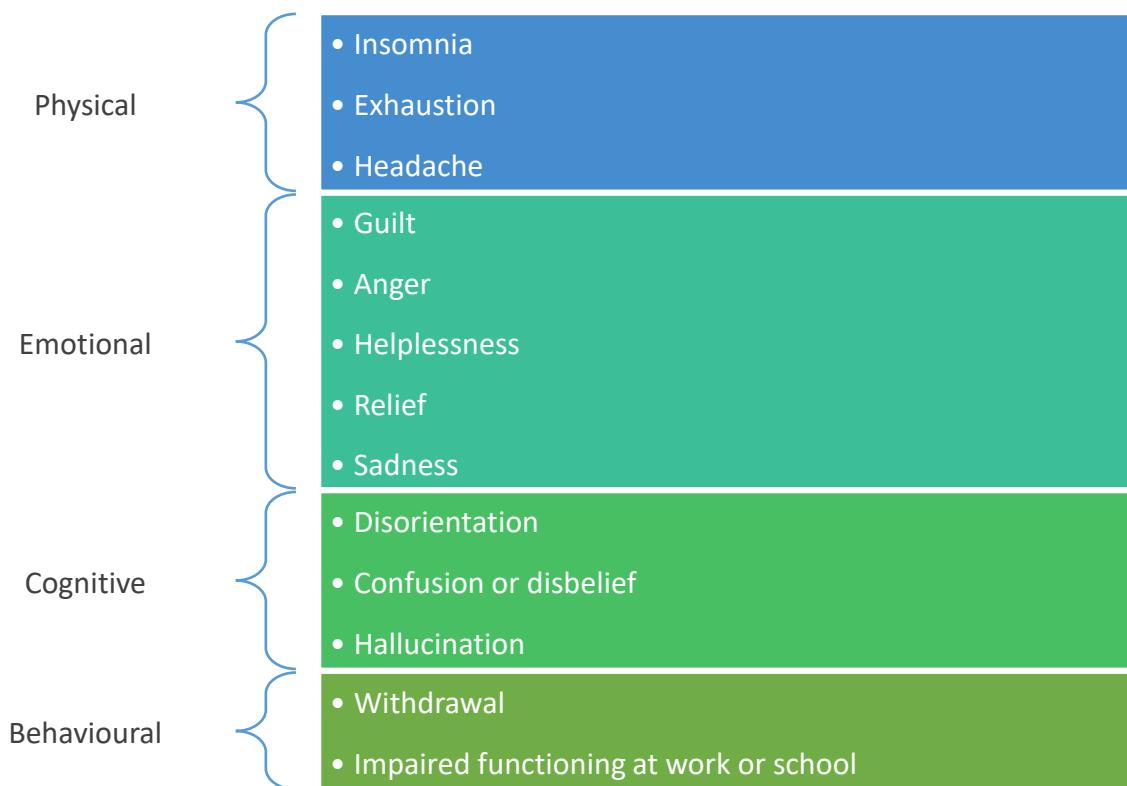
At this stage, a person's emotions start to stabilise. They are beginning to accept the reality that their loved one has passed away. They are adjusting to a life without that person and learning to live again. Although they may not be entirely all right with it, they have accepted the reality of the loss. They may start building their lives again and reach out to friends and acquaintances.

The grieving process varies from person to person. Two people who lost the same loved one may be at different stages of grieving. They may even experience different intensities in their emotional reactions. The process is also not linear. A person may go back and forth between two stages or jump from one to the next. There is no set deadline for grieving.

5.6.1 Addressing Grief and Giving Support

Each person feels the pain of their loss differently. Grief may consist of physical, emotional, cognitive and behavioural reactions. No matter how much people have prepared for or anticipated the loss, the experience of death may still be challenging for them.

They may have the following kinds of reactions:



During this challenging time, you must support the family and relevant others. You can give informal and formal support to help them cope with their loss. As a support worker, you can help by doing the following:

- Understanding the bereaved's grieving process and withholding judgment
- Expressing your concern towards the bereaved (e.g. asking how they are doing)
- Listening with compassion when the bereaved talk about what they are going through
- Offering a comforting presence when the bereaved is not yet ready to talk about what they are going through
- Offering other ways to support them (e.g. connecting them with grief support services according to organisational policies and procedures)

If you are unsure how you can further give emotional support, you can always check your organisation's policies and procedures. You may also refer to your prior discussion with your supervisor regarding the scope of your job role. This will guide you in addressing and supporting the emotional needs of the bereaved within the context of your role.

Multimedia



Grief and loss affect many aspects of a person's life. When it is not properly addressed, it can get in the way of acceptance and healing. Because grief is felt in different parts of one's life, holistic support is needed. Learn more about how the holistic approach can help a grieving person through the video below:

[Loss and Grief](#)



Checkpoint! Let's Review

1. Grief is the emotional response following a loss.
2. Bereavement is the process of adjusting following the loss.



Learning Activity for Chapter 5

Well done completing this chapter. You may now proceed to your **Learning Activity Booklet** (provided along with this Learner Guide) and complete the learning activities associated with this chapter.

Please coordinate with your trainer/training organisation for additional instructions and guidance in completing these practical activities.

VI. Manage Own Emotional Responses and Ethical Issues



In the previous chapter, you learnt about different end-of-life care strategies. You now know how to address your client's needs during the terminal stage of their life. You also know how to provide care after death and support the bereaved. Other people have always been the recipient of your care. This time, the focus is on yourself. This chapter teaches you how to manage your emotions during stressful situations. You will also know how to take care of yourself following the death of a client.

Losing a client can be a difficult experience. If you develop a bond with your client, losing them will be very painful. After their death, many emotions will come to the surface. You may even realise you face ethical dilemmas while giving care. But no matter how challenging things are, you have to learn how to cope with your emotional responses and ethical issues. You need to ensure these do not interfere with your capacity to work. This is a responsibility you have towards yourself and your colleagues.

This chapter will cover the following:

- Manage own emotional responses and ethical issues
- Identify and reflect on own emotional responses to death and dying
- Raise any ethical issues or concerns with supervisor or other appropriate person
- Identify and implement self-care strategies
- Access bereavement care and support of other team members as needed

6.1 Manage Own Emotional Responses and Ethical Issues



Working in the palliative care industry will expose you to stressful situations as you interact with the client. For example, there may be instances when the client is distressed or refuses to take his medication. In such cases, you must be able to keep your emotions in check when you attend to their needs. Even if it is becoming too stressful, you must still prioritise the safety and wellbeing of the client.

However, continuously experiencing this might lead to stress, anxiety or burnout. As such, you must know how to manage your own emotional responses. Remember that taking care of yourself is as important as taking care of your client. You may be unable to carry out your duties if your emotional wellbeing is not alright. Managing your emotions can help you respond to stressful scenarios appropriately. It will also help you protect your mental health when your work is emotionally challenging.

In addition, witnessing your client's death and their family's grief can be difficult for you. It is common to develop a connection with the person you care for. Expect that their death will have an impact on you. You may feel various emotions, including sadness, guilt, anger, relief and shock. This is normal. Their death can also bring up memories of people you have personally lost in your life.

The practices below can help you manage your own emotions while providing palliative care services:

- **Familiarising yourself with the client's condition**

Remember that your client might struggle to deal with their terminal illness. This frustration might lead to emotional outbursts that can hurt you. Do not take it personally when your client gets angry or says hurtful things. Instead, take time to familiarise yourself with their condition. Observe what they like and do not like. Ask for their preferences and listen to them when they share personal stories. Over time a deeper connection with your client can reduce the occurrence of stressful situations.



- **Spending time for self-reflection**

Taking time to be alone and reflect on yourself helps you to manage your emotions. Self-reflection helps you identify your stress level and the factors that cause it. It can also help you recognise how you deal with stress and anxiety.

- **Seeking help from colleagues**

It is not good to keep your emotions to your own all the time. You can talk to your colleagues to share your thoughts when your work gets too difficult. They can be a reliable source of support since they experience the same things as you do. They can also provide comfort and advice to help you overcome negative experiences.

- **Seeking professional help**

When your stress, anxiety, or grief starts to interfere with your work performance, seeking professional help might be the best option. You must consult a health professional if the above methods are insufficient to relieve your stress. Suppose you do not seek professional help immediately. Your condition might lead to health issues such as fatigue, insomnia, or even hypertension.

During care, you may have also faced ethical issues. These are usually related to medical treatment or end-of-life care. You may have felt conflicted when your values do not align with the decisions made by (or you made for) your client. If your feelings impact your work or personal life, reach out for support. You must manage your emotional responses and ethical issues. This is so you can still provide the best care to other clients.

Your relationship with each of your clients will be different. Each loss experience will trigger different emotional responses or raise other ethical issues. You may feel various emotions of different intensities as a response to the process of loss and grief.

You may experience the following:

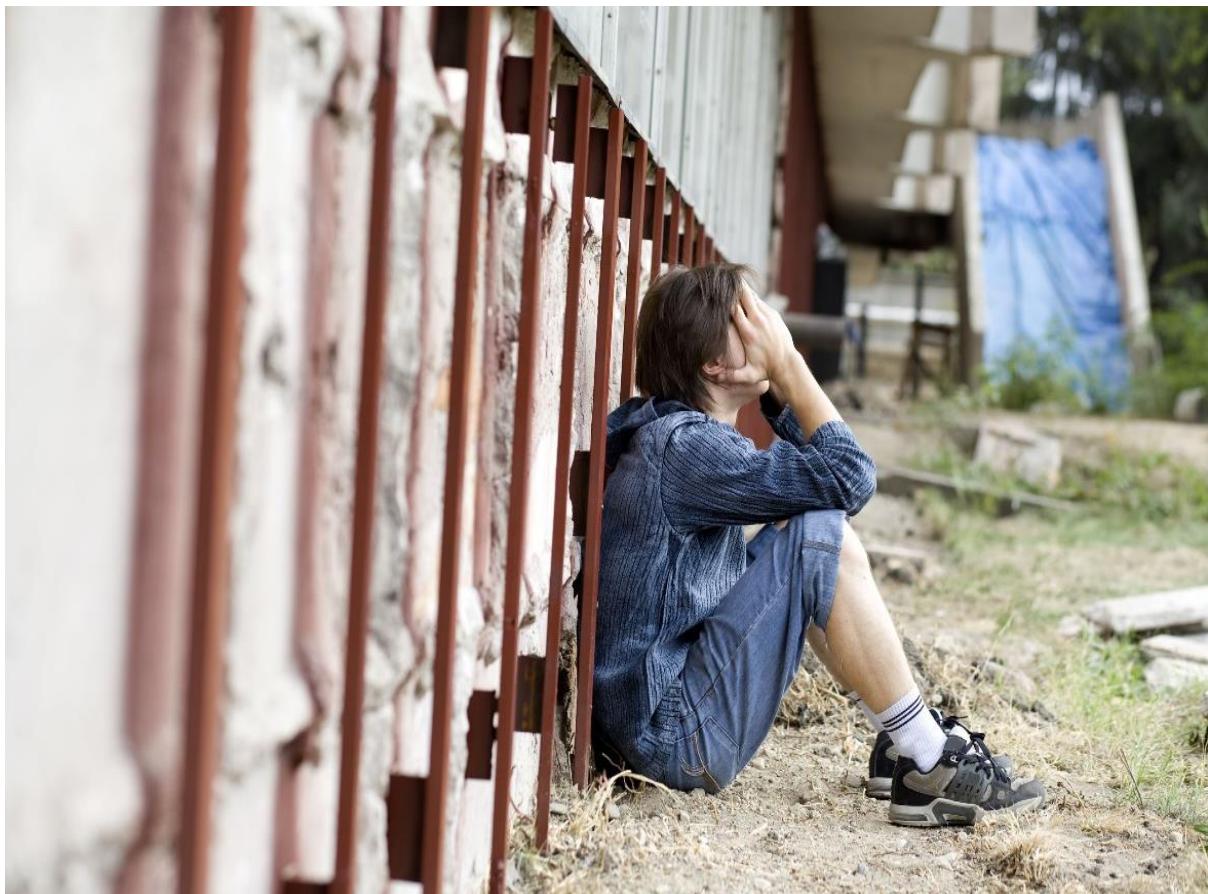
Crying and feelings of sadness

Concentrating poorly

Feelings of fear, anger or silence, which may appear singularly or together

You may go through some or all the stages of grief previously discussed in Subchapter 5.6. You may deal with different emotions during this time. These can be overwhelming and hard to manage. It may be difficult for you to attend to your tasks and responsibilities with so many things going on.

Your organisation's policies and procedures will help guide you during this difficult time. They may connect you with support services, give you time off to rest or have you join a support group. Check with your organisation what steps you may need to take to manage your emotions and ethical issues.



Checkpoint! Let's Review

1. If your feelings impact your work or personal life, reach out for support.
2. You must manage your emotional responses and ethical issues. This is so you can still provide the best care to other clients.
3. Your organisation's policies and procedures will help guide you during this difficult time. They may connect you with support services, give you time off to rest or have you join a support group.

6.2 Identify and Reflect on Own Emotional Responses to Death and Dying



Individual support workers are also vulnerable to feelings of loss and grief when a client dies. You may have known the client for quite some time. You may have also formed a bond with them, making the loss more profound.

Your experience of loss will be different each time. You may feel intense emotions affecting your work or personal life. You may also ignore your feelings to prioritise caring for your other clients. It may also happen that you did not experience much emotional reaction.

There is no right or wrong way to respond to your client's passing. What is important is to identify these responses and reflect on them. This process will help you find the appropriate ways to cope. You can draw upon this experience of loss to build your emotional resilience. Doing this will help prepare you when you face inevitable deaths in the workplace.

Following your client's death, you may ask yourself the following questions:

What emotions am I currently feeling?

Why am I feeling these emotions?

What emotions am I not feeling?

Why am I not feeling these emotions?

What emotions am I blocking out?

Why am I blocking out these emotions?

The way you respond to death is personal. Your client's death may trigger a range of expected and unexpected emotions. You may also recall your experience of death in your personal life. It is you who will best know the emotions you are feeling. Being honest while answering the questions above will help you process your feelings. Once you have identified these emotions, it will be easier for you to address them and look for ways to cope.

After a client dies, it is best to seek help and advice from your supervisor or another appropriate person. They can help you work out your emotions and relieve your concerns. They can also connect you to the proper channels should you need additional support.

Checkpoint! Let's Review



1. There is no right or wrong way to respond to your client's passing. What is important is to identify these responses and reflect on them. This process will help you find the appropriate ways to cope.
2. You can draw upon this experience of loss to build your emotional resilience. Doing this will help prepare you when you face inevitable deaths in the workplace.

6.3 Raise Any Ethical Issues or Concerns With Supervisor or Other Appropriate Person



When you cared for your client, you may have faced some moral dilemmas face-to-face. You may have made some difficult decisions during end-of-life care, some of which may not be aligned with your values and beliefs. For example, you may be against your client's refusal of life-sustaining treatment. However, you have to follow their wishes as described in their advance care directives. It may be difficult for you to deal with situations where your values conflict with the client's decisions. You may experience feelings of guilt or even shame. These feelings may later affect your work or personal life when left unaddressed.

Look for people in your workplace who you can talk to about these issues. It can be your supervisor or any other appropriate person. Talk about your experience and explain how you feel following the event. They may be able to give you advice on this matter.

Checkpoint! Let's Review



1. When you cared for your client, you may have encountered some moral dilemmas face-to-face.
2. You may have made some difficult decisions during end-of-life care, some of which may not be aligned with your values and beliefs.
3. However, you must follow their wishes as described in their advance care directives.
4. It may be difficult to deal with situations where your values conflict with the client's decisions.
5. You may experience feelings of guilt or even shame. These feelings may later affect your work or personal life when left unaddressed.
6. Look for people in your workplace who you can talk to about these issues.



6.4 Identify and Implement Self-Care Strategies



Self-care refers to taking care of yourself to remain physically, emotionally and psychologically healthy. Taking care of yourself is important. When you are healthy, you can attend to your tasks and responsibilities. You can do your job well and do the things you need to do. When you take care of yourself well, you will care for others well.

Losing a client can be a painful and challenging experience. It may be hard for you to go on with your work after the experience of loss. You may go through different stages of grief. If you experience successive losses, your grief can even be prolonged. In the previous subchapter, you learnt why it is important to identify and reflect on your emotional responses to a client's death. Knowing its impact will help you identify which coping strategies can best help you.

Each person's way of coping is not the same. What works for others may or may not work for you. You must find the ones which work for you. Below are samples of personal strategies you can apply to manage your reaction to grief:

- Acknowledging and accepting negative feelings
- Journaling
- Seeking professional help when feelings become too difficult to handle
- Connecting with others in support groups
- Staying physically healthy
- Spend a dedicated time for yourself to reflect on experiences, thoughts and feelings

Practising self-care is also important to help you cope with the potential impacts that working in palliative care can bring to your wellbeing. Since your clients have life-threatening illnesses, you are exposed to stressful events daily. You may witness the suffering of your client due to immense pain. You may also see their episodic emotional outbursts. These recurring events can bring negative effects to your body, such as the following:

- **Work stress**

Your work is not limited to attending to the needs of your client. You must also respond to their family members' questions, requests and complaints. Because of this, work stress can accumulate from frequent concerns or issues with clients and their families.

- **Occupational burnout**

Clients in palliative care require a lot of support, like assistance with mobility and physical and psychosocial needs. Performing these tasks can lead to occupational burnout or exhaustion in your job.

- **Compassion fatigue**

This refers to the feeling of helplessness as you aid a client. Frequent exposure to distressing events can make you feel overwhelmed and full of negative emotions at work.

- **Death anxiety**

Witnessing the death of your clients can develop a fear of death or dying. You may experience body reactions like palpitation and nausea when your anxiety is triggered.

These potential impacts can be lessened with the help of self-care strategies. This can help you develop more self-awareness and build mental health resilience. Self-care also ensures that you can perform your work duties optimally. You can continue to support your client and recover even when you are in difficult situations.

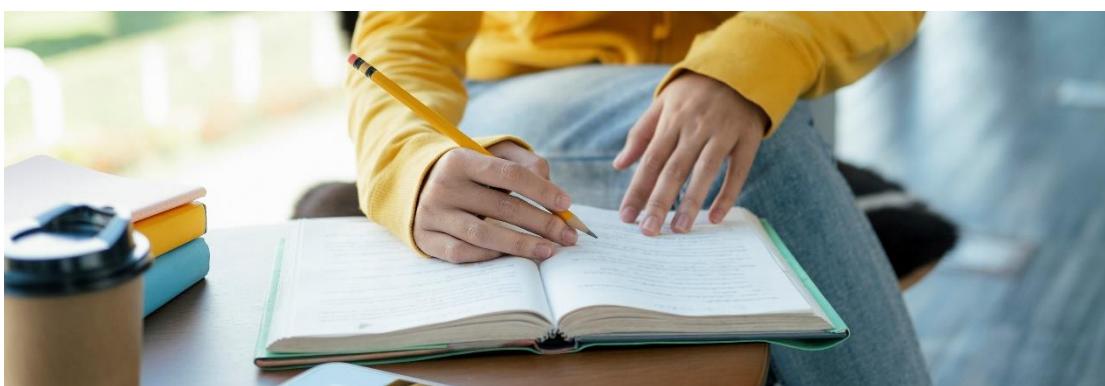


Self-care strategies include the following:

- **Journaling your reflections**

Working in the palliative care industry will expose you to feelings of loss and grief due to your client's death. Emotions brought by loss, like sadness, pain and guilt, are normal. It will help if you do not stop yourself from feeling these emotions. Recognising and accepting them helps manage your own emotional wellbeing.

You can write about what you think and feel in a personalised journal. Doing this practice can help you to face your feelings more. It can help protect your mental health and lower the risk of mental health conditions like depression and anxiety.



- **Debriefing with colleagues**

Debriefing with colleagues in your work involves discussing a client's death and how you are coping with it. This allows you to share your emotions, thoughts, and feelings freely.

Remember that you are not alone. Other staff in your workplace have also experienced dealing with feelings of loss and grief. Talking to them in the debriefing process can help you heal from the loss. They can also give you tips on how they practise self-care. Sharing your feelings can make you stronger in dealing with your emotions. This is because the people around you can provide emotional support during difficult times.

- **Accessing respite care services**

There may come a time when facing your feelings or talking with others is not enough to relieve you of the stress from work. You must seek appropriate support when stress starts interfering with your daily functioning.

Respite care services are provided for palliative care workers to give them enough breaks to recover from physical or emotional exhaustion. There may also be other support services for care workers in your organisation. You can talk to your supervisor or colleagues about your condition so they can help you get the support you need.

- **Taking care of your health**

Aside from managing your emotional response, you must also ensure that you take care of your health. Getting adequate sleep and eating on time is necessary to maintain energy in the workplace. Remember that clients in palliative care require a lot of additional support. You must have the energy to assist them with their daily needs.

Exercises like taking long walks can also help relieve your physical stress. You can also seek massage treatments if you are feeling tired from work. Remember that your physical health is essential to your mental and emotional wellbeing.



- **Exercising compassion-based practices**

Compassion is the feeling of concern for the misfortune or suffering of others. This trait is vital in ensuring that clients' wellbeing is prioritised in all palliative care services. As a support worker, caring for and connecting with your client can help relieve your feelings of guilt and helplessness in critical situations. Recognising your own efforts in helping your client to the best of your ability can ease your stress or anxiety.

Further Reading



How can you take care of yourself? Read more on how to plan for self-care through the links below:

[Self-Care Matters](#)

[Self-Care Matters Aged Care](#)

Using a Self-Care Plan

Aside from the previously mentioned strategies, you can develop a self-care plan to help you organise self-care practices that work for you. A self-care plan is a document that aids in determining the following details which are relevant to your work:

- Current self-care practises
- Personal values and motivation for self-care
- Work-life harmony
- Identified stressors in the workplace
- Self-care strategies to address identified stressors
- Goals for self-care
- Commitment to doing self-care strategies

Since this is a personalised tool, you can change the self-care plan as you wish. You can also review your self-care plan regularly and reflect on the improvements in your work life.



Further Reading

You can access self-care plan templates from the links below:

[Self-Care Matters](#)

[Self-Care Supporting Staff Working in Palliative Care](#)



Whatever strategy you use, it is important to work for you. If you do not take care of yourself, you will experience burnout. *Burnout* is physical, mental and emotional exhaustion caused by too much work stress. In your line of work, you will face more deaths inevitably. It would be best if you were equipped to handle such events in the future. You must be emotionally resilient and mentally prepared.

In order to take care of others, you have to take care of yourself too.

Multimedia



Why is self-care important for caregivers? This video explains why it is important to take care of yourself:

Why Is Self Care Important For Caregivers? #bjmillermd #caring
#palliativecare?

Checkpoint! Let's Review



1. Self-care refers to taking care of yourself to remain physically, emotionally and psychologically healthy.
2. Taking care of yourself is important. When you are healthy, you can attend to your tasks and responsibilities.
3. You can do your job well and do the things you need to do. When you take care of yourself, you will care for others well.
4. Losing a client can be a painful and challenging experience. It may be hard for you to go on with your work after the experience of loss.
5. You may go through different stages of grief. If you experience successive losses, your grief can even be prolonged. Knowing its impact will help you identify which coping strategies can best help you.



6.5 Access Bereavement Care and Support of Other Team Members as Needed



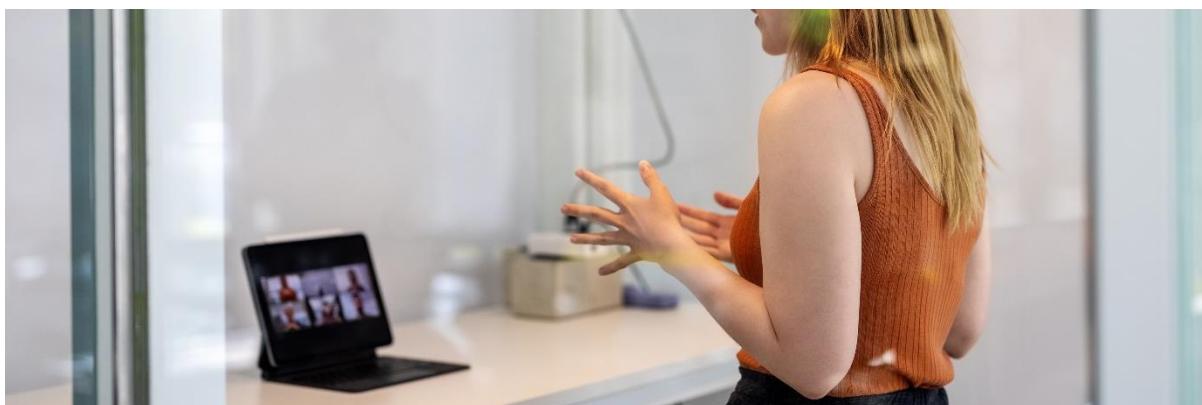
Reaching out for help is another form of self-care. When the emotional response to death is particularly intense, it can be easy to drown in it. You must recognise your limitations and seek support as needed.

For one, you can turn to your colleagues for support. The other care team members may also be going through the same experience as you. You will find that sharing your thoughts and feelings with them will facilitate your healing and theirs. It may also help ease the emotional burden you and the other care team members are experiencing.

When approaching them, you can do the following:

- Talk about how you feel after the death of the client.
- Discuss the ways you can help each other cope.
- Prepare to listen to their stories as well.
- Show empathy and offer support.
- Respect their readiness to talk about their feelings.

Bereavement Support Services



Many organisations across Australia offer support for those who have difficulty dealing with loss. Most of them provide free counselling services, and they can be reached at any time through different channels (e.g. phone, online or video calls).

Refer to the table below for these organisations:

Websites/Organisations	Services Offered
Bereavement Support	This Australian Center for Grief and Bereavement webpage contains links to grief-related websites. They offer free bereavement counselling services for those who need them. They also have telephone support services for practitioners. You can reach them at 1800 642 066.
Talk to a counsellor	The organization Beyond Blue advocates good mental health across the Australian population. You can reach their support services through call, email or chat.
Lifeline	This is a 24/7 hotline that offers counselling support for those who need it. You can reach them at 13 11 14.
MensLine Australia	This organisation offers free counselling for men. They operate 24/7 and can be reached via phone, online or video calls.
GriefLink	Although not a hotline, this website has a wealth of information on death-related grief for professionals. The organisation is based in South Australia, and its grief-related resources (e.g. books and videos) can be helpful for anyone experiencing loss.

Checkpoint! Let's Review



1. Reaching out for help is another form of self-care. When the emotional response to death is particularly intense, it can be easy to drown in it.
2. You must recognise your limitations and seek support as needed.
3. For one, you can turn to your colleagues for support. The other care team members may also be going through the same experience as you.
4. You will find that sharing your thoughts and feelings with them will facilitate your healing and theirs. It may also help ease the emotional burden you and the other care team members are experiencing.
5. When approaching them, you can do the following:
 - Talk about how you feel after the death of the client.
 - Discuss the ways you can help each other cope.
 - Prepare to listen to their stories as well.
 - Show empathy and offer support.
 - Respect their readiness to talk about their feelings.

Learning Activity for Chapter 6



Well done completing this chapter. You may now proceed to your **Learning Activity Booklet** (provided along with this Learner Guide) and complete the learning activities associated with this chapter.

Please coordinate with your trainer/training organisation for additional instructions and guidance in completing these practical activities.

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