

Learning Guide for Disability Support Workers 2022



PEPA Program of
Experience in the
Palliative Approach

PEPA Indigenous Program
of Experience in the
Palliative Approach



Online resources

Scan the QR code below for easy access to all the links, videos and other resources listed in this learning guide.



https://padlet.com/pepa_workshops/DisabilitySupportWorkers

This code or link will take you to the PEPA/IPEPA Padlet Resource for the Learning Guide for Disability Support Workers. As you go through the learning guide, you will find it helpful to have this resource page open on your smartphone, tablet or computer so that you can easily access the online resources.

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Acknowledgement to Country

PEPA/IPEPA acknowledges and pays our deepest respect to the past, present and future Traditional Custodians and Elders of the many lands on which we work and live, and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.

We recognise the contributions and partnerships of Aboriginal and/or Torres Strait Islander and non-Indigenous Australians in the development, promotion and delivery of the program to ensure Aboriginal and/or Torres Strait Islander peoples have equal and genuine access to quality, holistic and culturally responsive palliative care.

CULTURAL SENSITIVITY WARNING

Aboriginal and/or Torres Strait Islander people are respectfully advised that this resource contains material of a sensitive nature. This resource and others in links and videos may contain images of people who have passed away.

Recognition

This learning guide for the Program of Experience in the Palliative Approach (PEPA) and Indigenous PEPA (IPEPA) has been developed with funding from the Australian Government Department of Health.

The PEPA/IPEPA Team acknowledges the contribution of the following individuals and groups in the development of this learning guide:

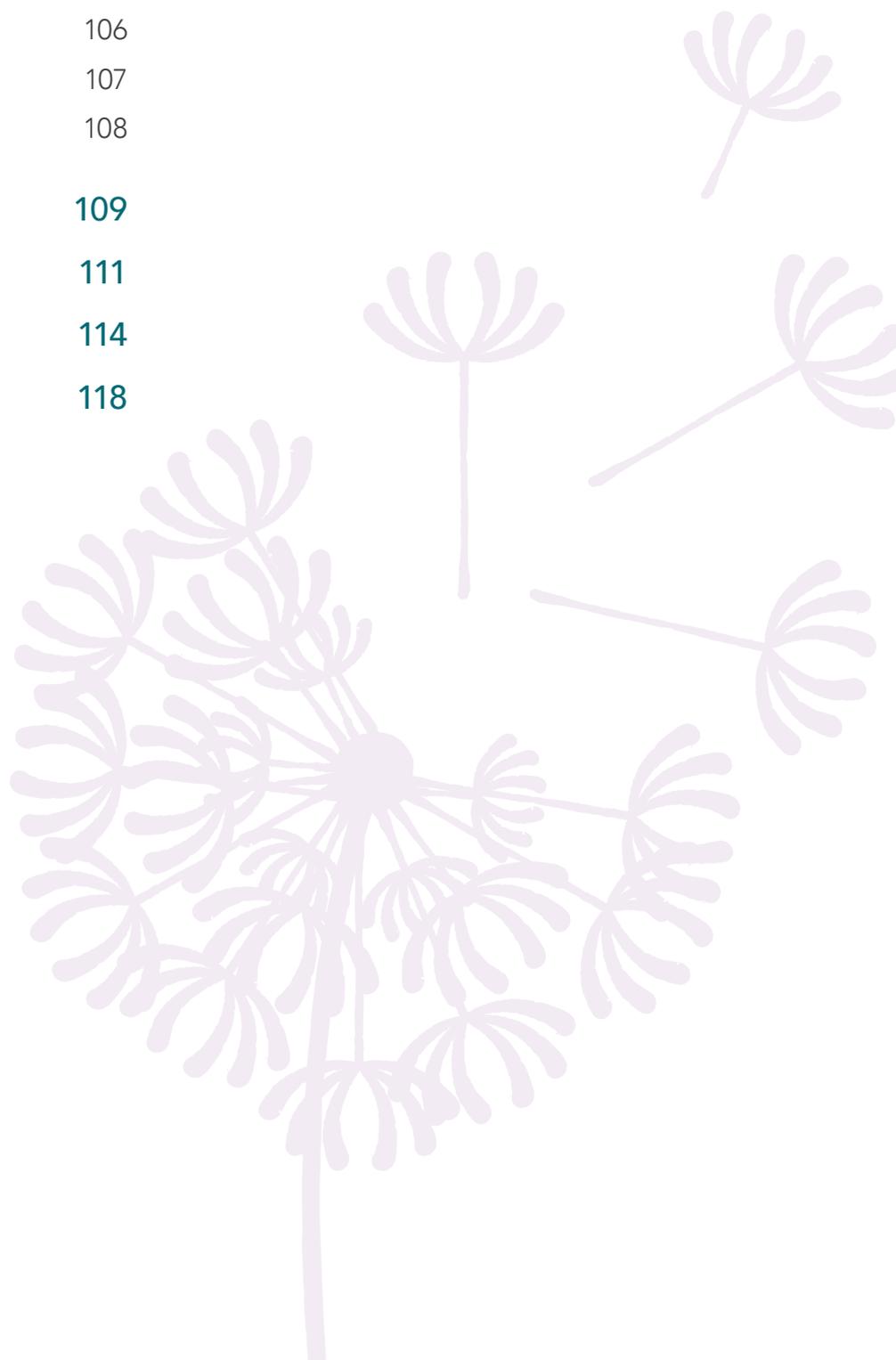
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Section 1: Overview



About palliative care

“Palliative care” is the term used to talk about the comfort and support given to a person and their family when they have been diagnosed with an illness that will shorten their life.

Some people are diagnosed with this kind of illness many years before the end of their lives. They can benefit from palliative care at any time as it provides comfort and support at all stages of their illness.

About PEPA/IPEPA

PEPA stands for the	IPEPA stands for the
Program of Experience in the Palliative Approach	Indigenous Program of Experience in the Palliative Approach

They both form part of the *Palliative Care Education and Training Collaborative*, which is a government-funded palliative care project.

PEPA aims to provide education and support to healthcare providers through work placements, educational workshops and learning guides.

Learning pathway

As a Disability Support Worker, you have an important role in supporting people living with disability and especially those who also have a serious or life-limiting illness.

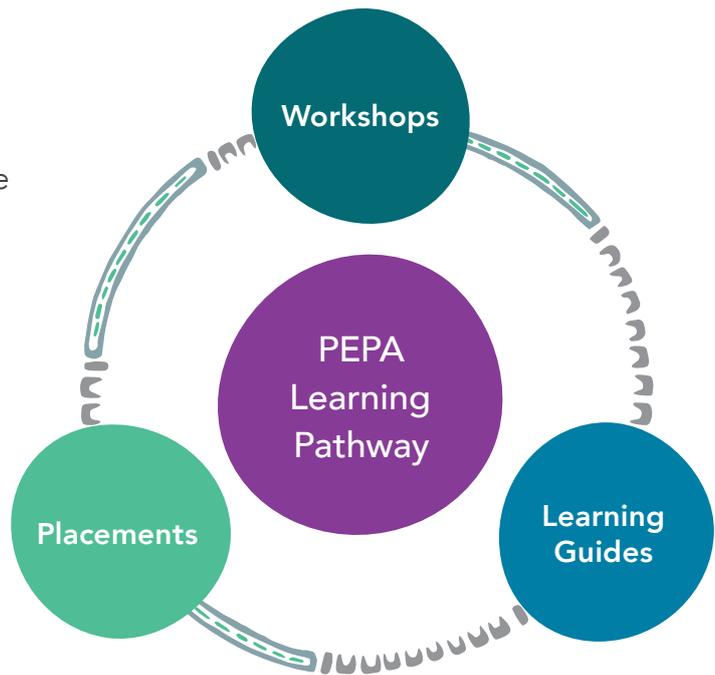
Whether your role is in the community, hospital or residential care setting, you will no doubt be involved in providing comfort and support to people living with disability who have serious illness and are nearing the end stages of life.

PEPA/IPEPA aims to help you develop your skills, knowledge and confidence in the palliative approach to care and educates you on how to:

- Provide support and comfort
- Manage symptoms
- Reduce stress and anxiety
- Give support to family and friends.

The PEPA learning pathway includes learning through:

1. Workshops
2. Learning Guides
3. Placements



Workshops	Placements
<p>PEPA offers a range of workshops in palliative care, which are aimed at healthcare providers working in:</p> <ul style="list-style-type: none"> • Hospitals • Disability Services • Aged Care Contexts • Rural and Remote communities • Aboriginal and Torres Strait Islander Health Settings. 	<p>The PEPA/IPEPA placements which are 2–5 days are guided by a Learning Coach – a specialist in palliative care who will come to your workplace and teach you about palliative care.</p> <p>This training is available in:</p> <ul style="list-style-type: none"> • Aboriginal and Torres Strait Islander Health Settings • Rural and Remote areas • Residential and Aged Care Facilities.

Ongoing support

You can stay up-to-date and connect with others in the **PEPA/IPEPA Network**, by:

- Following us on Facebook – [PEPA](#) and [IPEPA](#)
- Visiting our [website](#).

Notes

Introduction to the learning guide

This learning guide is used to support learning in PEPA/IPEPA workshops and placements and can also be used as an individual resource.

Learning objectives

When you have completed this learning guide, you will be able to:

1. *Describe the palliative approach to care and outline important points*
2. *Communicate well with people and their families about palliative care*
3. *Plan ahead and ensure the necessary care and support is provided*
4. *Understand the common care needs for people with life-limiting illnesses and how you can help to meet their needs*
5. *Know what is important to be able to care for someone living with a disability at the end stages of their life*
6. *Understand ways to support people who are experiencing grief and loss*
7. *Outline important points of self-care.*

Parts of the learning guide

The learning guide has different parts, and you can recognise the different parts by these icons/images and colours:



Information Summary:

A brief summary of the information.



Links:

Further information or other types of resources (articles, videos, websites) available to you. Use the QR code link on the first page to access all the links and resources in the guide.



Dictionary of Terms:

A list of common palliative care terms that are used throughout the learning guide. These terms are written in **green** text the first time they are used.



Learning Activity:

Activities to practice the information from the learning guide.



Thinking Back:

Being able to learn from past experiences on how to care for people with serious illnesses.



Case Study:

The learning guide will follow a case study to help understand palliative care in action.

References:

Information in the guide that comes from a particular source will have a small number (like this ¹) next to it. The reference list at the end of the guide has all the sources of information listed in number order so can look anything up if you want to find out more.



Reminder: look after yourself

This learning guide discusses lots of different issues about serious illness, dying, end-of-life care and death, and thinks about the impact on families, carers and community.

Thinking and learning about these issues can be upsetting. It is very important to look after yourself and talk to a friend or co-worker if you need support.

Please ensure you read: [Section 9: Caring for yourself](#) for more information.

Section 2: Disabilities



What is a disability?

According to the *Disability Discrimination Act 1992*,¹ a disability can be described as:

- Complete or some loss of the person's bodily or mental functions
- Possible loss of body parts (such as arms, legs etc.)
- The presence in the body of bacteria causing disease or illness
- An abnormality to a part of the person's body
- A disorder or defect (fault) that results in the person learning differently from a person without the disorder or defect
- A disorder, illness or disease that affects a person's thinking and understanding of reality, emotions or reactions which causes bad behaviour.

There are many kinds of disability. A disability can be present at birth or occur after an illness or accident.

A 'disability' includes a condition that:

- Presently exists, or
- Previously existed but no longer exists, or
- May exist in the future because of a family history (genetic) of the condition.

The types of conditions covered by the *Disability Discrimination Act 1992* include:

- **Physical** – affects a person's ability to walk or move
- **Intellectual** – affects abilities to learn
- **Mental Illness** – affects thinking and/or behaviour
- **Sensory** – affects a person's ability to hear or see
- **Neurological** – affects the brain and nervous system such as a brain injury from an accident
- **Physical disfigurement** (causing them to look different to other people)
- **Immunological** (functioning of the immune system) – a bacteria/virus etc causing disease in the body such as meningitis affecting the brain.¹

The Australian Bureau of Statistics reports that in 2018:²



4.4 million Australians

(almost 18% of the population)
had a disability



1.4 million Australians

(5.7% of the population) had
a severe disability (need help with
one or more of the three core
activity areas of self-care, mobility
and communication)



One-quarter

of people with a disability
reported a mental or behavioural
disorder as their main condition.
The most common disorders
were mood disorders; thought,
understanding and development
disorders; and stress-related
disorders.



Over three- quarters

of people with a disability
reported a physical disorder as
their main condition. The most
common disorders were arthritis
and back problems



Half of all older Australians

(those over 65) had a disability

Important point: most of the research and reviews that have been done on health outcomes for people with disabilities focus on people with **intellectual disabilities**. This section of the learning guide provides information that is about people with intellectual disabilities.

There is not a lot of information available about the health outcomes for people with **physical disabilities** as a whole group. You can find information about those with physical disability by searching health outcomes information on particular disease or disability types. A good place to start is the [Health Direct website](#).



What is intellectual disability?

An intellectual disability needs the following three points for a diagnosis:³

<p>1. Lower level of intelligence</p>	<p>This includes difficulties such as:</p> <ul style="list-style-type: none">• Planning• Being able to work things out• Thinking quickly and clearly and learning from past experiences.
<p>2. A reduced ability to cope by themselves</p>	<p>This includes difficulties with:</p> <ul style="list-style-type: none">• Reading• Writing• Using numbers• Understanding language. <p>It may also include difficulties with:</p> <ul style="list-style-type: none">• Social skills (knowing how to relate to other people)• Making decisions• Self-confidence• Problem solving• Knowing how to behave in public.
<p>3. Difficulties with practical skills</p>	<p>Difficulties completing daily activities such as:</p> <ul style="list-style-type: none">• Maintaining safety• Taking care of their health• Being able to travel alone• General daily organisation.



Health outcomes for people living with disability

Many people with intellectual disability have:

- Difficulty getting the healthcare they need
- More than double the number of health conditions than people without this disability
- Many other health conditions that are not identified – it is likely that half of the health conditions of people with this disability are not identified

People with intellectual disability also:

- Experience mental health issues
- Visit the emergency department and are admitted to hospital very often
- Stay in hospital much longer than people without this disability
- Die at younger ages (on average 20 years earlier) than people without this disability. Many of these deaths are from possibly avoidable causes.⁴

The higher rates of death from possibly avoidable causes are directly related to the poor quality of healthcare that people living with intellectual disability receive.

Provision of care, planning treatments, coordination across services, and record keeping have been found to be of a **much lower standard** for people with intellectual disability than the general population.⁵

There are a number of **health risk factors** that are seen more often in people with disabilities than in the general population, these include:

- Low rates of vaccination
- Obesity
- Smoking
- Lack of physical activity
- Lack of regular health check-ups
- Poorly managed mental health concerns
- Poorly managed epilepsy
- Poor dental health, swallowing problems and lack of mealtime support – contributing to poor nutrition.⁵





What causes death in people with disabilities?

Across Australia, the majority of deaths in people with disabilities are found to be 'unexpected'. This means that the person's death was not the result of the natural progression of their illness. Many of these deaths were the result of accidental choking on food or other objects.⁵

The main causes of death in people with disability are serious breathing problems, serious heart problems and serious brain and nervous system problems. Deaths from cancer are generally lower than in other Australians (apart from gastrointestinal / digestive system cancers).⁶

There are higher numbers of deaths from:

- Obesity (being very overweight which affects general health)
- Long-term illness or disability
- Epilepsy (fits and seizures)
- Mental health issues
- Breathing problems.



Dementia and disability

People living with intellectual disabilities are up to four-times more likely to develop **dementia** than the general population.⁷

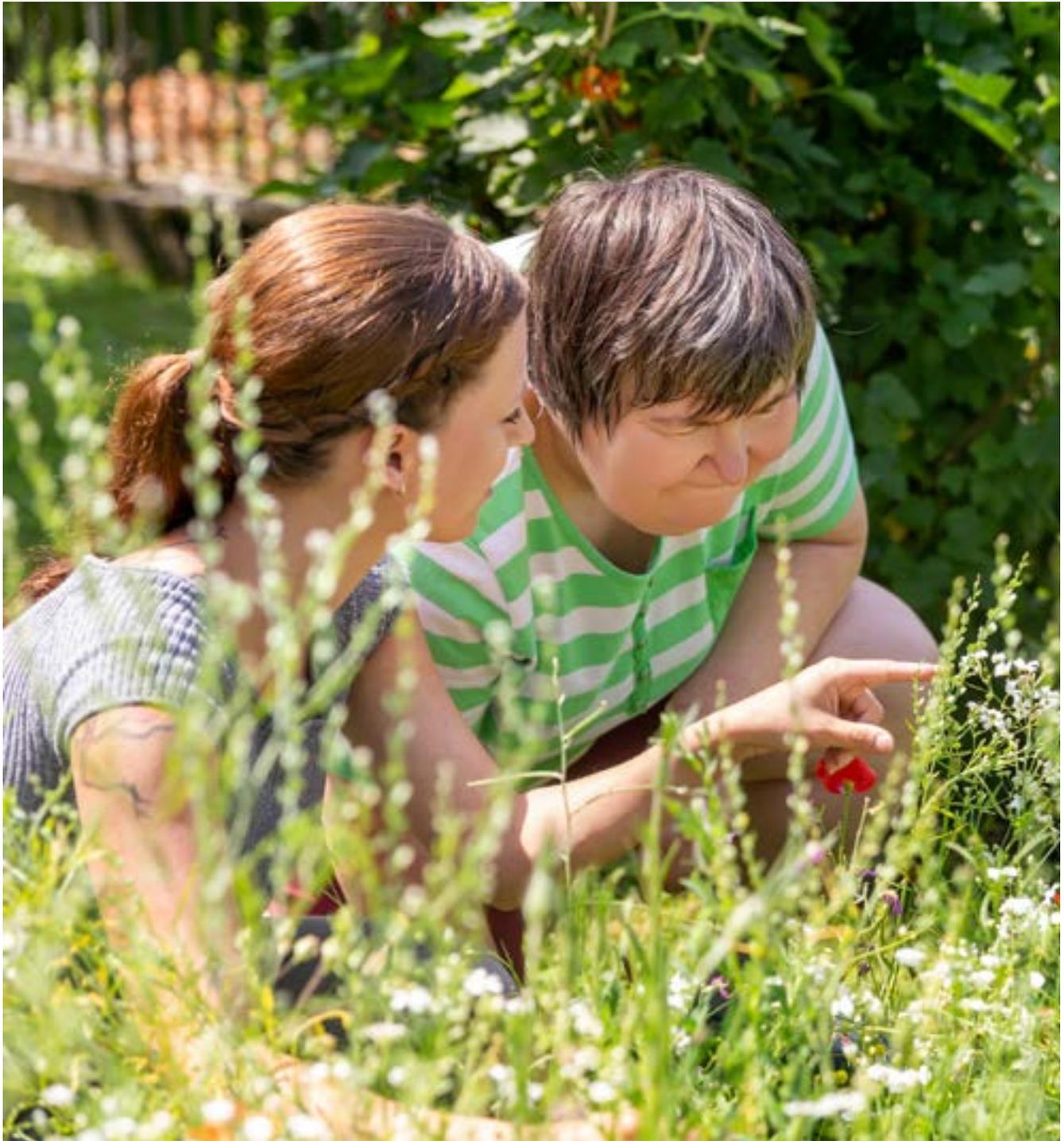
Dementia is an illness that affects the way the person's brain works. The brain controls everything that we do and so dementia can cause changes in the way the person thinks, their memory, the way they see things and the way they talk.

For example, people with **Down Syndrome** are now living longer, however, because they are living longer, there is an increased chance of developing dementia. 55% of people with Down Syndrome over the age of 60 are now being diagnosed with dementia.



Link:

If you would like to learn more about Dementia, The University of Tasmania have [free dementia training](#) that you can access.





Equity (fairness) and equality (being treated equally)

The Australian Government acknowledges that people with disabilities have long-term physical, mental, intellectual or sensory (smell, taste, touch and sight) problems which prevent them from taking part in society on an equal level with others.⁸

The experiences that a person with disability has can be influenced by the people around them in their community and the attitudes that people show towards the disability.

The picture on the next page helps to explain the differences between the concepts of **Equality** (being treated the same) and **Equity** (fairness).

Notes



EQUALITY (Being treated the same): everyone has the same rights and access.

EQUITY (Fairness): everyone has the level of help they need to have the same rights and access.

In this example, everyone is treated the same. They have all been given a box to stand on to help them see the game.

The results are:

- The person in the wheelchair is unable to use the box so they are not able to see the game
- The child stands on the box, but it is not high enough for her to see the game properly
- The able-bodied adult can see the game, even without the box. He is not excluded.

In this example, each person's needs have been thought about individually and different things done to help them see the game.

The results are:

- The person in the wheelchair has a ramp, so they can now see the game and remain independent
- The child has been given two boxes, so she can see the game and be included
- The able-bodied adult can see the game without needing any assistance.

The principle of **equality** (everyone being treated the same), seems fair, but in reality, some people need more assistance to be able to have the same opportunities.

The principle of **equity**, ensures the correct assistance is given to people as needed, to achieve the same results.

Each person is an individual, with **specific needs**, and these needs should be assessed for **EACH** person.

People living with disabilities may require help so they can access what they need and be included (rather than left out). Inclusion of **ALL** people, especially those with disabilities, is important for their physical, social, mental, emotional and spiritual wellbeing. It is also important for a strong, healthy communities.



LGBTIQ+ and disability

LGBTIQ+ stands for Lesbian, gay, bisexual, transgender, intersex or queer and other sexuality, gender and bodily diverse people and communities. People who identify as LGBTIQ+ face lots of challenges, such as being judged and excluded from groups or events in the community or society in general.

LGBTIQ+ people living with a disability suffer from **anxiety and distress** at higher rates than LGBTIQ+ people without disabilities.

This is partly due to a lack of health education on sexual and gender diversity in schools for people with disabilities. It is also due to a lack of education on disabilities in mainstream schools. This leads to people being treated differently and being left out, which creates anxiety, stress and poor self-esteem.⁹⁻¹¹

How can you support the LGBTIQ+ disabled community?

- By learning that each person is different and comes from a different background and by encouraging others to do the same.
- By learning to accept and support everyone, no matter what their sexual or gender identity, or disabilities are.



Link:

For more information view the [LGBTIQ+ Health Australia – Disability Inclusion](#) page.



Role of the Disability Support Worker

As a Disability Support Worker, it is important that you make sure the person with the disability, and their family, are the central focus of their care. All health and care plans should be made with their best interests and quality of life in mind.

In your role, it is important that you are aware of the usual behaviours of the person you are working with. You should be able to notice even the slightest change in their behaviour and must **ALWAYS** inform your supervisor or the person's healthcare team, as these changes can be connected to other health problems that the person might be unable to communicate with you about.

Decision-making

Decisions about a person's care should be made with them, their family and other important people, all involved in the conversations.

Including the person and their family in all decisions about their care helps to build a trusting relationship. It also means that:

- Vulnerable groups such as intellectually disabled, people with dementia and older people feel protected with people who they know and trust
- Routine can be developed and maintained
- Slight changes in the person's behaviour can be picked up early on and treatment started if needed.

If the person does not have family around to help make decisions, then decision-making for the person becomes the responsibility of the **Public Guardian**.

Family can mean different things to different people. Some people have a 'chosen family' (important people in their life) who they may feel closer to than the family they were born into. It is good to have a broad view of family in this role.



Links:

For more information, download and read the fact sheet explaining the [National Standards of Public Guardianship](#). This 'easy read' information helps to explain the process of decision-making through a Public Guardian to people who are living with an intellectual disability.

For more information about your role in communicating about end-of-life decisions, review the module from *Talking End of Life... with people with learning and understanding disability* – [Your role as a Disability Support Professional](#)



Case Study:



Introduction: Meet Mary

Throughout this Learning Guide, we will follow the journey of Mary, a 60-year-old lady with cerebral palsy.

Cerebral palsy is a group of disorders affecting movement and balance related to a brain injury during development in the womb, or around the time of birth.

Mary has had poor eyesight since birth and needs reading glasses for close work. Mary has used a wheelchair to get around since the age of 32 due to stiffness and tightness in her leg muscles.

She can move onto a chair or bed from the wheelchair with the help of one person.

Mary has been diagnosed with dementia and is frequently confused and forgetful.



Learning Activity:

Click the link here to learn more about [Cerebral Palsy](#)

Make some notes about what you learn here:

Notes

Section 3: Palliative approach to care



What is palliative care?

When someone has a sickness that can't be cured and it affects their everyday life, it is called a serious or **life-limiting illness**.

Palliative care is the term that describes the support given to people with serious illness.

This includes the care that is provided at any stage of the person's illness and when they are near the end of their lives.



Learning Activity:

What do you think of when you hear the words, 'palliative care'? How do you feel?

Write a list of all the words, or phrases that you can think of that could describe palliative care.

Notes



Learning Activity:

*Watch the following video from
Palliative Care Australia*

Palliative Care: It's more than you think
(30 sec)

As you watch this video, write down
the kinds of words that are used to
describe palliative care.

Notes

Palliative care is holistic (whole of life), person-centred and focused on quality of life

The palliative approach looks at all the areas of a person's life that are needed to make them feel happy and respected. This is called **holistic care**.

Palliative care is **person (and family) centred care**. This means that the person living with disability and their family, should be included in all discussions about care and what is likely to happen in the future.¹²

The person and their family know the most about the things that bring meaning to that person's life, such as:

- Their likes and dislikes
- What makes them happy
- What helps them feel safe.

The palliative approach helps manage symptoms and make people comfortable, so that they have a good **quality of life**, and they are able to do the things that make them happy for as long as possible.

'Person and family-centred care' looks to find what is special for that person to make them happy and meet their needs.



Thinking Back:

What does 'person and family-centred care' mean for you and your needs?

Notes



Case Study:



Mary loves her family, especially spending time with her brother, John.

John plays a big role in Mary's life. He sees Mary at least four times a week and Mary loves it when he takes her out to the gardens, and when he sings to her. She is also close to John's daughter, Jane but unfortunately as Jane doesn't live close by, they don't get to see each other much.

Quality of life for Mary includes seeing her family regularly, being able to watch her favourite television programs and feeling safe. When Mary feels unsafe, she gets very upset, often making a strange groaning sound. She hides away from people and won't look at them. She also becomes confused more easily. It can be difficult to calm her down.

How does finding out what 'quality of life' is to Mary, help you in caring for her?

Notes

It is important to understand these points before continuing with your learning:

Person and family-centred care

Care that focuses on the needs of the person and the family as a supportive group.

This means that they are listened to, respected, and included in their care.

Making sure the person and their family understands what is happening, helps them to feel respected and understood. You can help the healthcare team to learn as much as possible about the person and what they like and dislike.¹³

Life-limiting illness

A life-limiting illness is a serious illness that:

- The person will not recover from (there is no cure)
- Will continue to get worse
- Will eventually result in the person's death.

Life-limiting illnesses can include:

- Cancer
- Heart problems
- Lung problems
- Dementia
- Brain and nerve issues
- Kidney problems

Palliative care is available to everyone with a serious or life-limiting illness, at any stage of their illness experience.¹⁴

Quality of life

Quality of life is different for every person and is made up of different areas. To understand what quality of life means for a person, we need to think about their needs and wishes.

It is helpful to think about these questions:

- Physical – How does the person feel? How independent and active are they?
- Emotional – How happy they are? Do they feel valued and respected?
- Social – Are they seeing the important people in their lives regularly? Do they feel valued by these people?
- Spiritual (not religious) – Do they feel connected to or a part of something bigger that adds value to their life?

Curative vs palliative care

Curative care aims to treat the illness and make the person fully recover to good health.

Palliative care aims to comfort and provide a good quality of life when someone has a life-limiting illness rather than healing them or 'making them better'.

Although curative care and palliative care can be provided together, the main aim of palliative care is to:

- Make sure that people have the best quality of life while they are alive and that they can live as actively as possible until they die
- To support family, friends and carers to understand the illness and dying process
- It helps support people with grief and sadness and dealing with loss.¹⁴

*Our ultimate goal after all, is not a good death but a good life to the very end.*¹⁵



Learning Activity:

Think about the following questions:

1. How would you describe the palliative approach to a person and their family in your work? Write out the wording / explanations you would use.
2. What is your role in providing palliative care? Think about the kinds of care you provide in your current role.
3. What things might be stopping people from being able to access palliative care?
4. What care or support would you like to see added to your workplace to improve the way palliative care is provided?
5. Access this link to find information for those people who are [Living with life-limiting illness](#) from CareSearch.

Notes



Who needs palliative care?

Every person living with a life-limiting or serious illness will have different experiences of the illness. But there are some general patterns that different types of illnesses have that can help people and their families understand their illness and plan for the future.¹⁶

Understanding this also helps the healthcare team to give them the right support at the right time.

The main illnesses that require palliative care are caused by:

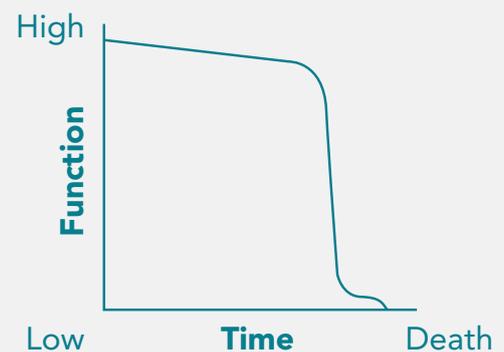
- End-stage/ **terminal** cancer
- **Chronic disease**/organ system failure – heart, lungs, liver, kidneys etc
- General decline such as getting older, **frail** and weaker, as well as dementia.

Patterns of life-limiting illness

These examples and images show the pattern of a person's experience and how their function (ability to manage everyday tasks) changes over time.

Example 1 – people who have a cancer that can't be cured:

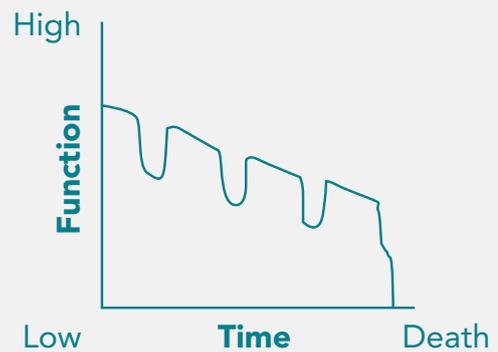
- Usually feel OK and can continue with their everyday life for a while
- Once they start feeling really sick, they go downhill quite quickly and being the end-of-life journey.



Example: Joan is a 45-year-old woman living with paraplegia after a road accident. She has breast cancer, which has spread to the bone and liver. Joan continues to receive a range of anti-cancer treatments. She is suffering from weight loss, reduced appetite and pain, and is increasingly weak and tired.

Example 2 – people who have a chronic disease with organ system failure:

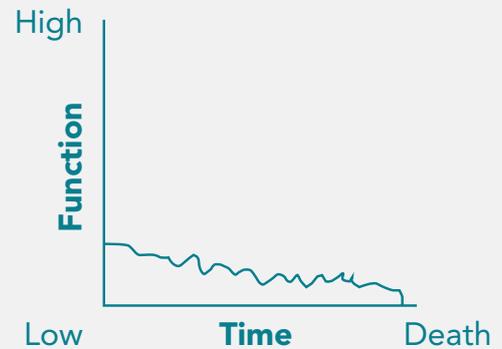
- May have more than one or many health problems
- Often become very sick and need to be admitted to hospital for treatment
- Recover a little in between hospital admissions but don't fully recover
- Have a slow downward path, and death sometimes seems sudden or unexpected.



Example: Bob is a 59-year-old man living with Autism. He has end-stage heart failure and is experiencing tiredness and increasing breathlessness. Bob has had three emergency hospital admissions in the past 12 months. He is worried about what his future holds and when he will die.

Example 3 – people who are elderly, frail (weak) or have dementia:

- Have a long, slow decline in function – it can be hard to predict when they might die
- Often need a lot of personal care and support toward the end of their lives
- Death maybe caused by infections (eg, chest infections), falls or fractures (broken bones).



Example: Hans is an 85-year-old man with arthritis and early-stage dementia. Hans is very forgetful, and he finds it hard to get around by himself. He lives alone but his family are becoming increasingly concerned for his safety. They can see that he is getting a little bit worse each week.



When does a person need palliative care?

Palliative care should be offered to a person when they are diagnosed with a life-limiting illness, so that they can be supported to have the best possible quality of life.

If you are unsure whether or not a person needs palliative care, there are some ways you can find out.

Example 1: The **Surprise Question**

Ask yourself, 'Would I be surprised if this person died in the next 6–12 months?'

If your answer is 'No, I would not be surprised', then it would be helpful to talk with your supervisor or the person's healthcare team about whether the person would benefit from palliative care.¹⁷

Example 2: The Supportive and Palliative Care Indicators Tool (SPICT)

This tool aims to make it easier for everyone to recognise and talk about signs that a person's overall health is getting worse. It can help families and carers get better support for the person.

The **SP ICT-4ALL** tool has three key questions with detailed information and options for each:¹⁸

1. Does this person have signs of poor or worsening health?
2. Does this person have any of these health problems (cancer, dementia, nervous system problems, heart/circulation problems, lung problems, kidney problems, liver problems)?
3. What can we do to help this person and their family?

Notes

Notes

People living with disabilities who have difficulty communicating are at risk of not getting the care they need.

If a person can't tell someone when they have pain (or other symptoms), their illness might not be diagnosed. This can mean that they experience suffering and are not able to enjoy life. It can also mean that they don't have much time to think about their end-of-life wishes and plan for the future.

People with communication difficulties might show that they have pain and other distressing symptoms in different ways including:

- Shouting
- Crying
- Withdrawing (pulling away or hiding)
- Anger and frustration.

As a disability support worker, **you may be the first person to notice changes in a person's usual habits and behaviours**, that might show they are in pain or suffering. When you notice changes, it is important to talk with your supervisor or the person's healthcare team about what can be done to help.¹⁹



Link:

[ELDAC Toolkit: Recognise End of Life](#)



Case Study:

Mary and the palliative approach to care

To help understand when the palliative approach to care is helpful, let's look at Mary's health history. This includes:

- Cerebral palsy (since birth)
- Poor eyesight
- Mary uses a wheelchair to get around
- Mary has a new diagnosis of dementia causing her to be increasingly forgetful and confused.



We know from the different 'Illness Patterns', that a person with dementia will slowly get worse and eventually die. This is why it is called a life-limiting illness.

Knowing this, it makes sense to have the healthcare team involved in Mary's care to talk about how Palliative Care can help Mary to have the best possible quality of life. Mary will be able to live well with her symptoms for a certain amount of time if she has the right support.

- Treatments such as Diversional Therapy (lifestyle-based activities) can help Mary to know where she is (orientation) and help with her confusion.
- Medication might help with hallucinations (seeing things that aren't there) and confusion, as well as other physical problems.

Eventually, the confusion, forgetfulness and other physical symptoms will no longer respond to treatment. When this happens, the healthcare team will talk with Mary and her family about providing comfort and **reducing** the symptoms rather than trying to remove the symptoms completely.

The healthcare team might talk to a **Specialist Palliative Care Team** to help make decisions about the best care for Mary. You will find out more about this in the next section.



What type of care do people need?

Notes

Not everyone with a life-limiting illness will need to go to hospital or to get help from a **Palliative Care Specialist** Team.

Some people might need help but only from time-to-time. Others might need to go to a special Palliative Care hospital ward or a hospice to receive care.

The type of care provided is based on what the person needs.

Palliative care can be provided in many different places and by many different healthcare providers.



Primary healthcare

Palliative care can be provided in the person's home or at a local clinic.

Care can be provided by a GP (general practice doctor), community health nurse, community allied health professionals, personal carers, disability support workers etc).



Specialist palliative care

Palliative care can be provided in a specialised hospital ward or hospice (care facility for people at the end of life).

Palliative care can be provided by a specialist palliative care team in the person's own home.

Care can be provided by doctors, nurses, care workers and allied health professionals who are trained to provide palliative care.



Primary healthcare and specialist palliative care

Care is provided by a person's primary healthcare team with support and advice from the Specialist Palliative Care Team.

Many people move between these different types of care depending on what they need.²⁰



Who provides palliative care?

The phrase **Palliative Care Is Everyone's Business** is a way of saying that all members of a person's healthcare team have a part in providing palliative care. The people who know the most about how to support a good quality of life though, is the person themselves and their family.²¹

Explore the table below to understand the roles of those in the healthcare team in providing palliative care:

Doctor	<ul style="list-style-type: none">• Formal physical assessment of patient• Prescription of care• Prescription of medications.
Psychologist	<ul style="list-style-type: none">• Assessment of the mind and emotions related to behaviours• Assessment and diagnosis of needs and goals.
Social Worker	<ul style="list-style-type: none">• Assist with practical difficulties including – social, financial and legal matters.
Registered Nurse	<ul style="list-style-type: none">• Administration of prescribed medications and oxygen therapy• Care planning based on doctors prescribed care• Care provision• Provision of care with any additional competencies that may have been completed.
Enrolled Nurse	<ul style="list-style-type: none">• Under supervision of Registered Nurse• Administration of medications and oxygen therapy• Assist the Registered Nurse with care planning• Basic care provision• Provision of care with any additional competencies that may have been completed.
Care Worker	<ul style="list-style-type: none">• Basic cares• Assistance with activities of daily living• Comfort and emotional support role.

Physiotherapist	<ul style="list-style-type: none"> • Treatment of musculoskeletal issues through exercise and massage.
Occupational Therapist	<ul style="list-style-type: none"> • Assessment of activities of daily living and assessing and implementing care to maximise independence.
Dietician	<ul style="list-style-type: none"> • Nutritional support and education.
Diversional Therapist	<ul style="list-style-type: none"> • Implement activities to support wellbeing of people through activities that support holistic wellbeing.
Pastoral Care	<ul style="list-style-type: none"> • Caring responsibilities relating to spiritual care and wellbeing.
Cultural Liaison	<ul style="list-style-type: none"> • Inclusion of culturally appropriate knowledge and care and involvement of the community for support and wellbeing.

Image Source: PCC4U Care Worker Toolkit²²



Quality of life

Notes

The main goals of palliative care are to provide comfort and to support the best possible quality of life for the person and their family.

Quality of life means different things to different people. It can include:

- Being comfortable and pain-free
- Being able to socialise or spend time with loved ones
- Having as much independence as possible
- Not feeling that they are a nuisance to anyone
- Feeling emotionally well.



Learning Activity:

View the Palliative Care Australia video resource '[What matters most?](#)' (2:00 min) and think about what quality of life means to you.

Write down three things that you believe bring quality to your life.

What would it mean to you if you were no longer able to achieve these things?

For many people, quality of life is about helping them to be part of their community. Being part of a community can help them to feel **included** and helps them to build a **support system**.

As a Disability Support Worker, you can help people to feel included in their local communities through:

- Helping them to build friendships in the community
- Supporting them to get involved in a community group (eg, gardening club, craft group, choir)
- Supporting them to learn a new skill or follow a new interest
- Going on day trips and outings with them
- Supporting them to build confidence using public transportation (if applicable).





Case Study:



We have learned that Mary's quality of life is connected to seeing her family and spending time with them in the gardens, listening to her brother sing, and watching her favourite television shows.

Based on this, what activities would you suggest that would help Mary feel included in her local community?

Notes



Principles of palliative care

There are a number of key principles or values that are part of the palliative approach to care. These are summarised in the table below, along with some practical things you can do to show these principles in action:²¹

Principles	What does it mean?	What can you do?
Dignity	Dignity is feeling worthy, respected, and valued. Every person is different, and their care needs will be different and can change over time.	Respect the person's privacy and personal choices. Listen (to really hear) their opinions and concerns.
Independence and choice	Empowering a person gives them the power to make their own choices.	Allow the person to do as much as they can themselves and assist them when needed. Support them to make their own choices about their healthcare.
Compassion	Compassion is being able to feel for another person's suffering and wanting to help.	Let the person talk about how they feel without judging. Show them that you are listening by paying attention.
Equity (Fairness)	Equity in healthcare means everyone having access to the same levels of care. Healthcare options should be available to everyone with a life-limiting illness. Some people require more help to reach the same level of care as others.	Make sure you really understand the person living with disability so that you can support them by reporting pain and other symptoms. This will help them receive the care and services they need.

Principles	What does it mean?	What can you do?
Respect	Respect makes sure that the person is thought of highly and cared for.	Show respect for the person and their family. Provide a safe environment where all people affected by life-limiting illness can live and die with respect and dignity.
Advocacy	Advocacy is the act of supporting a person's actions or beliefs.	Practise good communication. Sometimes you will develop a deep relationship with the person living with disability. Make sure you use the time you have with them to understand their wishes. Then you will be able to support them if they are not able to speak for themselves.
High Standards of Care	Aim to always provide the best possible standards of care and support for both the person and their family / carers.	Keep up to date with required training, current evidence and new practices. Remember to always be compassionate.



Links:

[What is Palliative Care?²³](#)

[Culturally Safe and Responsible Care²⁴](#)



Thinking Back:

Have you been involved in the care of a person with a life-limiting illness before?

- If you have – what do you think was most important to them about the way they were supported and cared for?
- If you haven't – talk to one of your co-workers about their experiences.

Notes



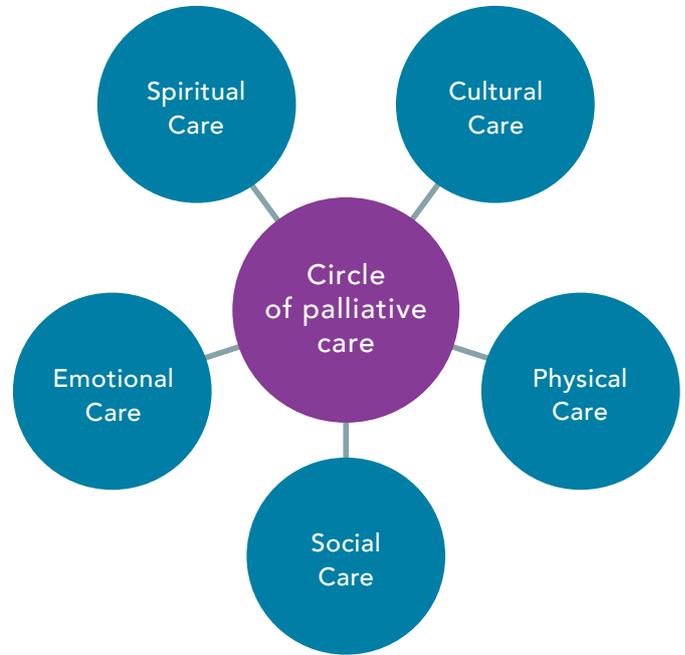
Holistic care

Palliative care uses a holistic or whole-of-life approach to caring for a person and their family.

This means that care and support is not just about managing physical symptoms, but about all the needs of the person:

- Spiritual
- Cultural
- Physical
- Social
- Emotional.

Palliative care focuses on comfort, quality of life and living well.



Spiritual needs

Spirituality is not the same as religion, although for some people religion is an important part of their spirituality.

To find out about a person's spiritual needs, you might ask about their:

- Values – what's important to them?
- Relationships – who is important to them?
- How do they describe their beliefs – faith, religion, rituals, stories, Dreaming/Songlines?
- What do they think or believe about dying and death?
- What gives their life meaning and purpose?
- What helps them feel hopeful about the future?

Cultural needs

Understanding a person's unique cultural experiences and background is an important part of holistic care.

When we help people to follow their beliefs and culture, this can give them strength to face difficult or challenging situations. It also helps to provide community connections for people.

Physical needs	<p>A person's physical needs can include:</p> <ul style="list-style-type: none"> • Symptom understanding and management • Providing information about treatment • Body image • Sexuality questions or concerns.
Social needs	<p>The social aspect of holistic care can include a person's:</p> <ul style="list-style-type: none"> • Family • Friends • Housemates • Community • Neighbours • Pets • Financial/legal issues • Support groups • Travel and accommodation plans and preferences.
Emotional needs	<p>A person will have a range of emotional needs. It is important to think about:</p> <ul style="list-style-type: none"> • Depression • Anxiety • Denial • Language differences or communication difficulties • Fear of hospitals and treatment.



Learning Activity:

1. Watch the video "Introduction to Spiritual Care" from Meaningful Ageing Australia to understand the impact that recognising spirituality can have on people at the end of life (1:51 min).
2. Watch the video "See me, know me" from Meaningful Ageing Australia to see how understanding the person and their needs/likes/wishes/wants can improve their quality of life (3:25 min).
3. Watch the video "Final Footprints" from Palliative Care Australia to learn about holistic care for Aboriginal and/or Torres Strait Islander peoples (11:38).

Note: this video link will start at the 1:35 min mark, which covers the importance of returning to Country to finish up, if this is the person and family's wishes.

WARNING: Aboriginal and/or Torres Strait Islander peoples may find this content distressing.

Make some notes about what you learn from watching these videos:

Notes



Case Study:



Mary's needs

You were helping Mary with a shower this morning and she started crying.

You asked her what was wrong, and she said that she felt lonely and scared. She knows that she is becoming more dependent on people, and that she is becoming very forgetful.

How can you provide a holistic (whole-of-life), person-centred approach to her care?

Think about these questions:

- What does 'quality of life' mean to Mary?
- What is her story and life goals?
- What are her beliefs and values?
- Who are the important people in her life?
- What are their important roles in her life?
- What is important for Mary now and in the future?

Notes

Section 4: Communication



Effective communication

Communicating well is at the heart of palliative care. It is an important skill needed to be able to help the person and their family deal with the effects of their life-limiting illness. The topics discussed in palliative care can often be difficult and are usually talked about over many conversations with the person and their family, rather than in just one conversation.

There are many problems that affect communication in healthcare, including:

- Healthcare providers who do not communicate properly with each other or listen to people and their needs
- People living with disability not understanding what healthcare providers are saying due to problems with:
 - Sight or hearing
 - Language differences and lack of interpreters
 - Difficulties speaking and understanding
 - Healthcare providers speaking too fast or not explaining in a way that is easy to understand
- Misunderstanding health issues
- People living with disability not trusting healthcare providers due to previous bad experiences
- Disability support workers wanting to protect the people they support from getting upset by “bad news” conversations
- Disability support workers’ own values, beliefs and personal experiences.



Case Study:

Thinking about Mary's situation, the problems that she might experience with communication could be:

- Poor vision
- Times of confusion due to her dementia
- Not fully understanding her illness and the choices she has for her care.



Learning Activity:

Think about the communication barriers or problems that might be affecting communication with the people you support. Make a list of what you come up with?

There are many resources available to help people with intellectual disabilities understand the meaning of dying and death as well as, grief and loss.

For example,

- Simply written books explaining complex subjects with minimal words (eg, "When someone dies" from VALiD, the Victorian Advocacy League for Individuals with Disability)
- Flash cards with pictures
- Sign language games
- Videos
- Online case studies and learning packages.

Notes



Trusting relationship

In order to build a trusting relationship, you need open and honest communication.

The person living with disability needs to feel that they can ask any questions, that their voice is being heard, and that they are not being judged. They need to feel that they can express their opinions about their care in a safe environment where they are respected and supported.

Remember, your role is not to give advice or make decisions for people. It is to listen and allow them to talk about their experience, feelings, hopes and worries.

There are two important parts to a trusting relationship – **empowerment** and **empathy**:

Empowerment (feeling in control)

Empowerment is the ability to make a person feel in control and have confidence in their life and the things they want to achieve.²⁵

Empowered people are given the confidence and ability to make their own decisions, based on the support of the healthcare team.

You can help people to feel in control by listening to them and passing on important information to the healthcare team.

Empathy (understanding others)

Empathy is putting yourself into someone else's position and trying to understand how they are feeling and what their worries might be.²⁶

Empathy in palliative care involves really listening and trying to understand the person's journey by asking questions related to their illness and experience.

Allowing people to talk about their feelings, and really listening to them, helps them to feel understood and cared for.



Learning Activity:

Watch the following video, "[Brené Brown on Empathy](#)" to help you understand empathy and the importance of making true empathic connections (2:53 min)

How would you describe empathy?

How is empathy different to sympathy?

Notes



Learning Activity:

Watch the following video from Breaking Bad News, "How to break bad news to people with intellectual disabilities" (6:30 min)

What were the main points that Amanda stated were problems in communicating with the doctor when she was in hospital?

In the video, Amanda stated that she wanted to be allowed to speak with the doctor herself and not someone else speak for her.

Is this something you have experienced in your role?

What could you say to help support a person living with disability to speak for themselves?

Notes

To help you work out how much information the person living with disability has understood during a healthcare conversation, you can ask them questions, such as:

- *"How do you feel about what you have just heard?"*
- *"Would you like to hear the information again, or have it explained in a different way?"*
- *"Can you tell me in your own words, what the doctor said about...?"*



Difficult conversations

Communicating with people living with disability, especially intellectual disability can sometimes be difficult. Some support workers feel the need to protect people from bad news. It is also common to think that because we might not know how much someone understands, we shouldn't explain anything confusing or upsetting.

It should be assumed that any person with a learning and understanding disability has the ability to understand dying and death, unless determined otherwise.²⁷



Thinking Back:

Try to remember a time when you felt very upset, perhaps after the death of a family member or close friend.

Imagine how you might have felt if no one had told you that the person was sick or had died.

When we don't share important information with someone, it can cause them to lose trust.

They might become confused, frustrated or afraid, knowing something is not right and that they are not being told something important.

Speaking about dying and death and any 'difficult' conversations should never be avoided. Providing simple explanations and being honest will help to prevent misunderstandings.

Notes



Talking about going to hospital

For many people living with disability, going to a hospital or a care facility and needing to stay there for a time, can be very frightening and stressful. They might prefer to be cared for at home throughout their whole experience with life-limiting illness.

There may be times when a visit to the hospital or a hospice (specialist palliative care facility) is necessary. There are ways that you can reduce the stress and anxiety about these visits, including:

- Explaining by using simple books or pictures and showing what will happen, what their bed will look like and also explaining who they are likely to meet such as nurses, doctors and other members of the healthcare team
- Going on a visit to see what the hospital or hospice looks like, to become familiar with the smells and sounds, and to see the equipment (eg, x-ray machines, monitoring equipment)
- Watch the person's body language and behaviour for signs of distress
- Talk with them about this and listen to what their fears are.

Making a **Health Passport** – a booklet containing information all about a person's health and care needs – can help start discussions about hospital visits and what is important to the person. It explains the usual behaviours of the person so that information can be passed to the healthcare team so they can also pick up on behaviours which might show that the person is upset.



Learning Activity:

Download the [Health Passport](#) (Queensland Health). Read through and try and complete some of the information for yourself.

This will help you to find out the information needed by the healthcare team to really understand the person and provide good care.

Hospital Identifier:

This is my Health Passport

Capturing important information about me and my health care needs.

If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me. It needs to be available to staff and a copy should be put in my notes.

My name is:

Nursing and medical staff please look at my passport before you do any interventions with me.

- 1 Things you must know about me
- 2 Things that are useful to know about me
- 3 My likes and dislikes

I am NDIS registered:

Date completed: Completed by:

This document belongs to me. Please return it to me or my carer.

Write down your thoughts about the Health Passport and how you think it could be helpful?

Is this something that you already use in your work? Talk with your supervisor or co-workers about it.

Notes



Nonverbal communication

It is important to remember that a lot of information is communicated nonverbally (or without words). Nonverbal communication includes things like facial expressions, body language, tone of voice etc.

Sometimes, when speaking with a person, we say more with our nonverbal communication than with the words we say. For example, compare the image below with the statement:



"I'm having the best time at this party!"

Silence

Silence is an important part of communication. It provides an opportunity for people to think about and process information.

- Some people need silence in a conversation to process information, especially sad or upsetting information
- Others wait for a silence to feel that it is their turn to talk. If there are no silences, they may not speak at all
- It is helpful to learn to be comfortable with silences.

Eye contact

Some people avoid eye contact when communicating as a way of showing respect. Many also do this when they feel afraid or uncomfortable.

- How much eye contact you use when speaking with someone should be guided by the person and family
- If they seem uncomfortable then this may be a sign that you need to change your approach.

Cultural influences

It is important to be sensitive to the ways that culture (or how someone has been raised) influences how people hear and understand information. For example, in many Aboriginal and Torres Strait Islander communities, speaking openly about dying and death does not usually happen.

Other words that might be used include:

- Not going to get better
- Bad or sad news
- Finishing up
- Passed on or gone
- Sorry business.

Check with the person and their family to find out which are the preferred words to use in conversations and how these conversations should be managed.²⁸



Learning Activity:

In the next few conversations you have, whether with co-workers, friends or family members, pay attention to the nonverbal communication you both use.

From what you notice, think about how the other person might be feeling.

Check with them to see if what you thought was correct.

You might say something like:

- *"I noticed while you were talking that you seemed... Is that right?"*
- *"It sounds like you're feeling sad (for example)... Have I got that right?"*

If you are not able to tell how they might be feeling, then it can be helpful to say:

- *"I imagine you might be feeling sad/scared/relieved... about this. Is that right?"*

Continue to practice this during conversations to improve your communication skills.

Notes



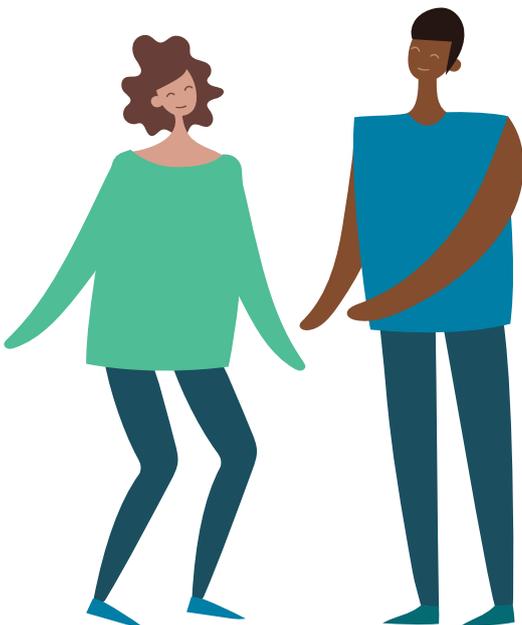
Following up communication

It can be very helpful to pass on important information from healthcare conversations to your supervisor when it is needed.

Making some notes about what has been discussed can be a good idea. Check with the person and their family that this is OK first.

When you have had conversations with people that have been difficult or sad, it is important to talk with your supervisor about this. You might find you need some support and a chance to express your own feelings about it.

Remember, it is not your role to give advice or tell people what to do when making difficult decisions. Listening and being open to talk can sometimes be all that is needed for a person to answer their own questions.



The role of hope

It is normal to want to give people hope or to stop them from feeling sad or upset. We all need hope, but it needs to be real – based on truth.

Saying hopeful comments about things that you know won't happen is not helpful. For example, telling someone who has a life-limiting illness they will "be better soon" or "have nothing to worry about" is not helpful.

Talking about real hopes allows people to understand the situation, make their own decisions about what they want to do and understand how bad the situation is.

Ways to give hope might be to say:

- *"I know this is hard, but I want you to know that I will do everything I can to give you the support you need to be comfortable."*
- *"What are you most worried about at the moment?"*
- *"I want to make sure you have all the important information you want to have about your illness and what might happen. What do you want to know more about?"*
- *"What do you feel hopeful or positive about?"*



Learning Activity:

Watch the [“Don’t talk too much”](#) video from [Vital Talk](#) to learn more about building rapport and allowing discussion of difficult topics (0:47 sec)

Notes



Case Study:



Mary has just returned from an appointment with her doctor. The doctor told Mary about her dementia and that she would eventually die because of it. He suggested a referral to the palliative care team.

Mary is upset and confused because she didn’t understand what the doctor meant, and she is now feeling very sad.

Things to think about:

- What is your role in this situation?
- How would you start a conversation with Mary about this? Write down some things you would say to help her talk about her feelings.
- What could you say to help Mary know that she is supported and cared for?
- How would you explain to Mary what the ‘palliative care team’ is?

Notes

Important points:

Remember, it is not your role to provide advice to Mary. You need to listen to her worries and pass on any information that may be helpful to your supervisor and the healthcare team so that they can arrange for the right support for Mary.

Listening is the main point of this conversation – let Mary talk about what is worrying her. You might be able to help her write a list of questions to ask the doctor next time she sees him.

Let Mary talk about how she feels about dying and try to find out how much she understands. Make sure you talk with your supervisor about these conversations.

You can help Mary by explaining that the 'palliative care team' help people who have a serious illness to get the support they need to live as comfortably as possible during the time they have left.



Learning Activity:

The set of Learning Modules from *Talking End of Life... with people with learning and understanding disability* have resources to support communication on a range of topics.

Have a look at the [TEL website](#) and review the modules that are available. Make a note of the ones that you are interested in for further learning.



Notes

Section 5: Advance care planning



What is advance care planning?

Advance care planning is a process of “thinking ahead” to talk about what people would like to happen when they are very sick and at the end of their life.

It can include:

- Treatment they want and treatment they do not want to have
- Where they would like to be cared for when they are dying (eg, at home, in hospital, in a care facility)
- What is important to them and what helps them feel safe.

Advance care planning conversations help people to talk about their own hopes, goals and choices.

Advance care planning can be just a conversation with family and carers, but it is very helpful if the plan is written down. A **written advance care plan** helps everyone to know what the person wants if they are not able to speak for themselves.

These conversations are usually led by a specialist nurse or doctor and the advance care plan written down in a specific form.



Link:

Different states and territories call these documents different names, view the [Advance Care Planning Australia](#) website for more information.

An advance care plan should be made as soon as possible after a person finds out that they have a life-limiting illness. This means that when the person is at the end of life, the family and carers know exactly what to do.

Notes



Learning Activity:

1. Watch the "Be open, Be ready, Be heard" video from Advance Care Planning Australia (1:55 min)
2. Watch the "Advance Care Planning" video from Talking End of Life (4:11 min)

What have you learned about advance care planning through watching these videos?

What experiences do you have of advance care planning? How is it viewed in your family or community?

Have you ever thought about what your wishes would be if you were facing a serious illness?



Conversations about advance care planning

Knowing how to start a conversation with someone about their wishes can be the hardest part of advance care planning. There are many resources available to help with this.



Learning Activity:

Have a look at the “[Discussion Starter Online Card Game](#)” on Palliative Care Australia’s Dying to Talk website.

Choose a set of cards and have a look through some of the points that are helpful to think about in a conversation about a person’s wishes.



Link:

Many organisations supporting people living with disabilities have an approach for talking about and writing down a person’s wishes for end of life.

The document [My information and advance care plan](#) is one example.²⁹

This example shows one way a person’s end of life choices can be discussed and noted for people living with intellectual disabilities as a starting point. This kind of document can be a starting point for a formal advance care plan.

Your organisation might use a different document however, the following is an example of a possible way to document a person’s wishes.

Notes



Case Study:

Mary and her brother John have had a conversation with Mary's doctor about advance care planning.

Although it was difficult for Mary to talk about this, she was able to tell John and her doctor what she wanted:

- That it is important for her to be cared for at home as much as possible – she does not like being in hospital as she does not feel safe there
- She would like John to be the person to make decisions about her care and treatment if she is not able to communicate these for herself
- She would like to be able to go outside every day if possible, as being outdoors and close to nature is where she feels most peaceful.

Things to think about:

How would you support Mary's choices?

In your work situation, where would a record of Mary's advance care plan be kept and how would her choices be communicated with carers and her healthcare team?

Notes

Section 6: Recognising and responding to needs



In working closely with people affected by life-limiting illness, you will be able to see the small changes that others might not see. You will also be aware of the day-to-day problems and worries that people have.

It is important that you talk to your supervisor and the healthcare team about any changes you notice so that the person can get the care and support that they need.



Talking about symptoms

Symptoms are feelings in the body or mind that cause anxiety, pain or suffering.

To support quality of life, the healthcare team needs to know about the distress (concern or worry) caused by a person's symptoms. If the healthcare team can understand this, then they can manage these symptoms better.

Some helpful questions to use when talking to people about their symptoms are:

- *Of the things that have been bothering you, what bothers you the most?*
- *How do the symptoms affect you? How much do they affect your life (eg, sleep, daily activities, mood or emotions)?*
- *What ideas do you have about how to manage these symptoms?*
- *Do these symptoms make you worry about your health/illness?*
- *What are you most worried about?*
- *How are your symptoms affecting your family and friends?*

Talking about the symptoms that people are experiencing can help the person to understand their illness. When they understand their illness better, it will help them understand the care or treatment that they need.

Remember, these conversations can happen over time. Just give a little bit of information at a time and check that the person understands before giving more.



Thinking Back:

Try to remember a time when you were experiencing pain or were sick. How did you feel? What were you most worried about?

Many people living with disabilities will feel less anxious if they are given the time and space to talk about how they feel about their symptoms, and how they are affecting their day-to-day life.

It is important that you feel supported to have conversations with people about their symptoms.

What could you (or the team you work with) do to help you prepare for these conversations?

Notes

To prepare for conversations regarding symptoms, illness and care/treatment options, you and your team could:

- Agree, that when conversations about a person's healthcare occur, the person is part of the conversation. Try to make sure that healthcare providers **talk** with the person, instead of **about** them
- Make time for the person to understand the information and ask if information needs to be explained again, or in a different way
- Use resources that support communication including pictures or diagrams. You can even show rooms or places to the person to help them understand
- Don't hold back information from people because you think they won't understand it, or it might upset them
- Practice having conversations like these with your co-workers to help you learn the skills.

Notes



Tools to find out about symptoms

There are a number of tools that can be used to find out about a person’s symptoms and care needs during their experience with life-limiting illness. You might come across some of these in the person’s healthcare record or see the healthcare team using them.

Tool	Description	Further information
Symptom Assessment Scale	<p>The <i>Symptom Assessment Scale</i> is a tool that helps a person talk about how they are feeling about their symptoms.</p> <p>The person can score the symptoms themselves, or a family member or carer can help. These scores help the healthcare team to plan and provide the support the person needs to help with their pain or distress.</p>	<p>Palliative Care Outcomes Collaboration (PCOC) Resources:³⁰</p> <ul style="list-style-type: none"> • Talking about symptoms • Symptom assessment tool for care workers
Abbey Pain Scale	<p>The <i>Abbey Pain Scale</i> is used to assess pain in people who are not able to speak.</p>	<p>This example of the Abbey Pain Scale can help you to know the things you should be looking for to tell if someone is in pain.³¹</p>
Disability Distress and Discomfort Assessment Tool (DisDAT)	<p>The DisDAT identifies distress (rather than pain) in people with intellectual disability.</p> <p>The DisDAT is like the Abbey Pain Scale, but also includes observation of the person’s usual ways – what they are like on a normal day and their normal behaviours.</p> <p>When we understand what someone’s normal behaviour is it becomes easier to understand when they are in pain or distress.</p>	<p>The DisDAT can help you know how to tell if a person with intellectual disability is distressed or in pain.³²</p>



Learning Activity:

1. Watch this section of the video “Ben’s Story” from the PCC4U Care Worker Toolkit to see an example of someone using the Symptom Assessment Scale (4:28 min).
2. Watch a section of the video “Understanding the Language of Distress” (21:02 min). Watch the video from 0:46 – 7:00 min to understand the main concepts of the DisDAT Tool and how to use it.

Notes

The organisation you work for may use different assessment tools to these. However, it is important that you understand **how a person living with disability (who is not able to communicate) can show changes in their behaviour due to distress and pain**. Once you notice changes, you can help the person by talking with your supervisor or the person’s healthcare team about it.



Common symptoms and care needs

There are many symptoms that a person affected by life-limiting illness can experience.

This table shows some of the common symptoms and provides a description and some links to more information.

Pain	
Description	How to help
<p>Pain is something bad that a person feels. It can be due to:</p> <ul style="list-style-type: none">• Physical issues – aches, bruises, swelling, burns, sprain, tension etc.• Emotional distress – feeling lonely, frustrated, missing someone or something• Spiritual distress – lack of meaning or purpose.³³	<p>To treat pain means looking at all areas of the person's life (not just physical) and talking to them about their pain.</p> <p>You can use tools (like those covered in the previous section) to help find out about pain for people who have problems with communication.</p> <p>Remember: not all pain can be treated with a tablet, we need to look for other reasons for pain too.</p>
Problems with breathing	
Description	How to help
<p>Breathlessness is "having a shortness of breath or feeling like you can't breathe. It is an extremely common symptom but can be both distressing and frightening for patients and carers".³⁴</p> <p>Breathlessness is often caused by many issues – it can be due to the illness or as a result of anxiety, stress, fear, anger, or pain.</p>	<p>Treating breathlessness requires looking for the possible causes and might require:</p> <ul style="list-style-type: none">• Making changes to the person's environment or position (eg, sitting the person upright, removing or covering any object that may be causing anxiety such as medical equipment)• Using a fan to help the person feel like they are able to get more air• Helping the person to relax by talking calmly with them, playing soothing music or use of warm blankets or light hand massage. <p>Severe breathlessness should be reported to your supervisor or the person's healthcare team immediately.</p>

Fatigue

Description	How to help
<p>Fatigue is an ongoing and upsetting feeling of tiredness, not caused by activity levels and not helped by sleep or rest.</p> <p>Many people affected by life-limiting illness feel more and more fatigued as their illness progresses. Fatigue is often described as a feeling of “no energy”, “tiring easily” or “weakness”.</p> <p>Fatigue can:</p> <ul style="list-style-type: none"> • make everyday activities very difficult or impossible to complete • cause difficulties thinking clearly, poor memory and lack of motivation. • have a major impact on quality of life, relationships and the person’s ability to manage their everyday needs.³⁵ 	<p>A big part of managing fatigue is about finding out and treating the cause. This could be related to medication, anxiety, pain or other physical symptoms.</p> <p>For those towards the end of life, it can help to space out activities and try to rest when possible – saving energy for the things that are really important to them.</p> <p>Some people also find meditation and relaxation therapies to be helpful.</p>

Nutrition

Description	How to help
<p>A range of problems to do with nutrition (eating and drinking) can occur:</p> <ul style="list-style-type: none"> • Problems with swallowing are common for people living with disability. They are also a common symptom for people with life-limiting illnesses. • Weight loss can be a sign of a person’s illness getting worse. • Poor appetite (not feeling like eating) happens more often as the person’s illness progresses. The idea that encouraging a person with life-limiting illness to eat well or trying to help them put on weight will make them live longer is not correct. • Nausea (feeling sick in the stomach) and vomiting can be caused by the illness or can be a side-effect of treatment.³⁶ 	<p>There are medications and special diets that can help manage these problems.</p> <p>Talking to your supervisor or the person’s healthcare team is important if you notice any of these problems.</p> <p>If you notice that a person has new or different swallowing problems, this should be reported to your supervisor or the person’s healthcare team urgently.</p> <p>They should not be given more food or drinks until their swallowing problem has been checked by a healthcare provider.</p>

Confusion and Delirium

Description

Confusion is a state of mind where a person's reactions to what is happening around them are unusual because they are unable to relate to where they are or understand times of the day.

Delirium is when confusion develops very quickly or when it comes and goes (eg, times of confusion at night, usual behaviour at one time and then confused).

You might recognise these problems when a person has:

- Changes in behaviour or mood
- Problems understanding where they are, or knowing what time of day it is
- Emotional changes, such as fear and anxiety
- Problems focusing or concentrating
- Restlessness
- Experiences of seeing or hearing things that aren't real (hallucinations).

There are lots of different causes of confusion and delirium (eg, medications, dehydration (lack of fluids), constipation, infection etc).³⁷

How to help

To manage confusion and delirium, it is important to try to find out the cause and treat that.

When someone develops new confusion or delirium, it is important that they are assessed by a member of the healthcare team.

Things you can do to help include:

- Making sure their room is quiet and calming
- Trying to keep to normal routines to help the person understand times of the day
- Speak clearly and in short sentences, and allow time for understanding of what has been said
- Encourage use of reading glasses and hearing aids if they have these to help with communication.

Suffering

Description

Suffering is living with pain, distress or difficulty. It is a complicated experience and often has many causes.

Suffering is very often about physical symptoms but is also affected by emotional and social problems. (eg, "I suffer from arthritis" or "I suffer with depression").

Many people with life-limiting illness also experience spiritual distress which can be about:

- Fear of dying and death
- Questions of meaning and purpose
- Questions about what will happen when they die.

They may have other concerns such as loss of connections, loss of hope, and loss of identity.

Suffering can impact a person's quality of life and affect their daily activities.³⁸

How to help

Focusing on spirituality and consideration of spiritual and cultural needs can bring comfort for many people who are suffering.

The importance of religious practices for some people needs to be recognised, as this can bring a lot of comfort in stressful times.

People may find it comforting to:

- Talk about how they're feeling
- Attend a church service or speak with a religious leader
- Walk in nature or on their traditional Country
- Enjoying patting or watching animals
- Listening to music
- Seeing family and friends.



Learning Activity:

Many organisations have education resources on common symptoms and their management, that are written for people affected by life-limiting illness and their carers.

Choose 2–3 of the symptoms we have looked at and take some time to look at these resources:

- **Pain:** Cancer Council Resource – [Pain](#)
- **Breathing problems:** Cancer Council Resource – [Breathlessness](#)
- **Fatigue:** Cancer Council Resource – [Fatigue](#)
- **Nutrition problems:** Cancer Council Resource – [Loss of Appetite](#)
- **Confusion and Delirium:** Marie Curie Resource – [Delirium](#)

Notes



Case Study:

Mary has been unwell for a couple of weeks now.

She does not speak very much, and her confusion is worse. She has problems finding the right words and cannot speak in full sentences. She often forgets what she is trying to say.

Mary's movement has also become more difficult. Her legs are very stiff, and she is no longer able to get herself out of bed into her wheelchair without help. She doesn't want to get out of bed most days.

You've noticed that Mary doesn't make eye contact with you anymore and she makes groaning sounds (like she does when upset) more often.

- *Think about the assessment tools and the symptoms that you have read about.*
- *What could be causing Mary to not make eye contact? Why do you think she is making groaning sounds?*
- *What can you do to help and support Mary?*

Important points:

Remember – noticing these changes and talking to your supervisor or Mary's healthcare team about them, is a really important part of helping Mary.

Here's some examples of what might be done for Mary at this time:

- The stiffness in Mary's legs might be causing pain, which could explain the groaning. You could try using a tool like the DisDAT to help understand the changes in Mary's behaviour
- Mary might need some medication to help manage the pain and some physiotherapy to reduce the leg stiffness.
- She could also be assessed by an Occupational Therapist who can suggest machines to help Mary get in and out of bed more easily (eg, a lifting hoist).

Notes



Recognising needs

It is important not to assume that because someone is groaning, shouting, or hitting out that it is because of physical pain or bad behaviour. They might be cold, tired, hungry, lonely, sad or frightened.

Try to find what comforts them. It might be a warm blanket, a sleep in a calm room, something to eat and drink, or a visit from family or friends.

Notes



Case Study:



Mary has improved a lot after having some new pain medication and seeing the physiotherapist. She is able to move about more freely now. You notice though that Mary is still groaning more than she used to and that she still doesn't make eye contact with anyone.

You are worried that there is something other than physical pain that is a problem for Mary. It could be an emotional or spiritual need that you can help with.

Thinking back to what you know about Mary, what do you think she might need to help comfort her?



Case Study

Being able to spend time with her family is very important to Mary's quality of life.

You notice a photo in Mary's room of her with her niece Jane and a dog, who Mary is cuddling. When you ask Mary, she says that the dog is called "Benji" and she groans again.

You decide to talk to your supervisor about trying to organise a visit for Mary with Jane and Benji.



The visit from Jane and Benji was very emotional. Mary became tearful, yet very happy to see Jane and Benji.

After the visit, Mary was not as upset, her groaning has stopped, and she has started making eye contact with you again.

This visit made the team realise how important Mary's spiritual, social and emotional needs were to her quality of life.

Regular visits with Jane and Benji were organised. You were also able to arrange for Mary to have some visits with a therapy dog, which she enjoyed.

Important points:

Remember, everyone is unique and has their own ideas about what makes them happy and gives them comfort.

When supporting people who have problems communicating, it can be very helpful to think about what you know about them and ask yourself, “**What would they want?**”

To support a person’s spiritual, social and emotional connections think about:

- **Maintaining connections** – key workers, family, friend visits, house mates, pastors, faith leaders, ministers of religion and maintaining cultural connection.
- **Maintaining normality** – try and maintain people’s usual routines like allowing pets to visit, going to the park, introducing familiar smells, having a slice of cake on a Sunday!



Recognising when someone is getting worse

If possible, palliative care should be provided early in a person’s experience with life-limiting illness. Sadly, this does not always happen. Sometimes a person can be nearing the end of their life before their healthcare team recognises that they need palliative care support.

You can help to recognise when someone might be coming to the end of their life by watching for these signs:

- Not being able to care for themselves as well as they have done before
- Becoming very weak
- Needing to go to hospital or have the healthcare team visit more often
- Having trouble swallowing food, fluids and tablets and having choking episodes
- More tired than usual, with the same amount of activity
- Sleeping more
- Not feeling hungry as often
- Not going to the toilet as often or not being able to control when they do
- Losing weight
- Getting worse each day even with good care and support.¹⁹

If you notice these signs, or any other changes to a person’s usual behaviour that worry you, it is important that you talk to your supervisor or the person’s healthcare team about it.

Section 7: End-of-life care



End-of-life care is a part of palliative care that focuses on the care people need during the last days or weeks of life. The principles of the palliative approach to care (covered in Section 3) are just as important at this stage.

Quality care at the end of a person's life is about:

- The rights and wishes of people and their families
- Supporting people to make their own choices
- Providing support for the person's physical, social, emotional and spiritual wellbeing and not just their illness – a holistic or whole of life approach
- Supporting carers and family
- Focusing on quality of life
- Providing comfort.



Recognising when someone is dying

Being able to tell when a person's death might be near gives everyone a chance to prepare.

Many people fear the process of dying and do not know what to expect, so it helps to explain it in simple terms. With good care it is possible for most people to die comfortably.³⁹

You can support the healthcare team by recognising that a person is getting worse and explaining carefully to the person, their family and carers and even their housemates. This helps to comfort the person and their family.

At this time, you might notice that the person:

- Spends more and more time in bed
- Is not able to do much to help themselves with things like eating and drinking, moving in bed, personal hygiene and toileting etc.
- Is sleepy or asleep most of the time and they could even be confused, or unconscious (not responding at all)
- Is unable to swallow or do not feel hungry or thirsty
- Passes very little or no urine
- Has noisy or uneven breathing
- Shows signs of blood not flowing around their body like before (eg. pale skin, cold hands and feet).



Learning Activity:

Watch the following video, '[What is death like?](#)' from *The Art of Dying Well* by Dr Kathryn Mannix (8:35 min).

Make a note of three things you learn through watching this video.

Notes

When the healthcare team recognise that a person is in the end-of-life stage, they can:

- Check what the person and their family need and provide the support needed to manage their symptoms (eg, medications, equipment and access to other care services if needed).
- Consider stopping some treatments (eg, medications and activities) that no longer have any benefit to the person
- Start using the person's advance care plan to help with decisions if the person is not able to speak for themselves
- Make sure that there are written instructions, based on the advance care plan, to avoid unnecessary tests, procedures, transfers or resuscitation (bringing back to life) attempts
- Provide information and support to prepare family and carers for the person's death.

Where can end-of-life care happen?

The place where a person is cared for at the end of life should be a calm, peaceful setting where people feel respected and cared for. For some people, a comfortable environment can help them to cope with the physical and emotional problems they have at the end of life.

In advance care planning discussions, it may already have been discussed where the person would like to be cared for when they are dying. The person's wishes should be followed as best as possible.

Many people want to stay in their familiar settings with the people, things, animals, smells, noises etc around them that are familiar and comforting.

If a visit to hospital or another care facility is needed, you can use the Health Passport (covered previously in Section 4) to help support good communication and care.





What's your role in end-of-life care?

You have a very important role at this stage in **continuing to support the person and their family**. Working with the healthcare team, you can be a source of great comfort and support for them.

At this time, it is **important to the person and their family and friends** that they are able to:

- Keep control of what happens, especially care options, place of care and who is present at the end
- Tell important stories while the opportunity remains
- Have access to information and skills of whatever kind that may be needed (eg, healthcare, legal)
- Have access to spiritual, cultural or emotional support as needed
- Have time to say goodbye.
- Not have life prolonged needlessly.⁴⁰

Some families may like to be **involved in caring for the person at end of life**. You can support them in doing this in a number of ways, including:

- Helping them understand what to expect – share what you know about the dying process (as covered in the “What is death like?” video activity)
- Helping them to provide physical care for the person (eg, mouth care, moving in bed, hygiene care)
- Encouraging them to continue talking with the person, playing their favourite music or reading their favourite book, even if the person does not respond
- Encouraging them to care for the person in ways that maintain their dignity and privacy, including practical things like clothing choices and having familiar things around them.



Learning Activity:

View the “[Carer Help](#)” website:

1. Watch the videos “When the person is dying” from Doctor Mark Boughey and Nurse Regina Kendall (specialists in palliative care).
2. Download the fact sheet on “[Caring for the dying person](#)”

Talk through this information with your supervisor or a co-worker.

Notes



Dying at home

Many people want to be able to die at home. The healthcare team will do everything they can to carry out these wishes. Sometimes though, there are problems that make this impossible.

These problems include:

- Lack of staff to support care in the home
- Lack of access to the right equipment
- Family members may find that they are not physically strong enough to care for the person, or that it is too emotionally exhausting
- Access to healthcare support after hours is expensive or not able to be arranged
- Difficulty accessing and storing pain medications safely.

Many of these problems can be solved by planning ahead and communicating the person's wishes with the healthcare team. Thinking about what the person's family and other carers **need to know when caring for them at home is very important**, including:

- How to manage symptoms in the last days of a person's life
- How to get the equipment and supplies that are needed
- How to contact healthcare support at any time if they have questions they need to ask.

Knowing what to do when the person dies is also very important, including:

- What is likely to happen in the time leading up to death and at the time of death
- How to recognise that the person has died
- How to wash and position the person's body after death (if they wish to)
- Knowing that it is okay to spend some quiet time with the person before calling anyone
- That it is not necessary to call the police or ambulance when an expected death occurs at home
- The people who should be called. It can be helpful to make a list beforehand of who they want to call.⁴¹



Link:

More information on this can be found in the "[Planning for a home death](#)" page from CareSearch.



Dying in a care facility

Some care facilities use a **care plan** or **care pathway** to help guide the care for people who are dying. These documents or charts are used by the healthcare team to monitor the functions and care needs of the person during the end-of-life stage.

If a person living with disability is being cared for in a hospital, hospice or residential care facility when they are dying, it can be hard for disability support workers to know what their role is.

It can be helpful to remember that,

- The role of the disability support worker is to provide **comfort and support** for the person and their family
- The role of the healthcare team is to provide the **clinical or medical care** that they need.

Sharing what you know about the person's needs and wishes, what they like and don't like, and what their behaviours might mean with the healthcare team can be very helpful.



After death

When a person has died in a care facility or in community care, there are several things that need to be done:

- A doctor needs to certify and document the death
- The person's family will need to be told that they have died (if they are not present)
- The healthcare staff who are present need to tell the other members of the healthcare team
- The healthcare team need to provide family support as needed
- The healthcare team need to prepare the person's body and arrange for the body to be sent to the funeral director or mortuary.

You can still play an important role in supporting the healthcare team at this time. Under the direction from your supervisor and according to specific workplace policies, you can be involved in:

- Assisting with preparation and transfer of the body
- Packing belongings
- Supporting the person's family and/or housemates, and other carers.⁴²

Personal care after death should be performed within a few hours of the person dying to preserve their appearance and dignity. It is important to allow the person's family and others close to them, to have time alone with them if they choose to. They can also be involved in bathing and dressing the body if desired.

Everyone's choices are different at this time and can change from their original plans. It is best to ask them how they would like to be supported or involved at the time.

Notes

Key areas of personal care after death ⁴³

What you can do to help	
Maintaining privacy	<ul style="list-style-type: none"> • Close doors or curtains.
Cultural and Religious considerations	<ul style="list-style-type: none"> • Be mindful of the cultural or religious beliefs and practices of the person and their family and carers.
Communication	<ul style="list-style-type: none"> • Show empathy and communicate respectfully and sensitively with family, carers and housemates.
Family	<ul style="list-style-type: none"> • If family wish to assist with washing the body, check with your supervisor or the healthcare team that they can provide support during the process. • Talk through what is happening with the family to ensure their wellbeing during, and after the process.
Respect	<ul style="list-style-type: none"> • Maintain dignity and respect for the person by covering their body with towels or sheets as you would if they were alive.
Position the body	<ul style="list-style-type: none"> • Lie the body flat and support the head with a pillow. Close the eyes and mouth.
Wash and prepare the body	<ul style="list-style-type: none"> • Using warm water, wash the body, maintaining respect and dignity. • The family may provide specific clothing to be worn, if not, a body covering can be worn. • Pay attention to making sure the face and hands are clean. • Ensure the hair is neatly combed as the person would usually style their hair. • Put false teeth in place if possible as they help to shape the face. • Change the sheets and pillowcase if needed.

What you can do to help

Present the body respectfully

- Cover them with a clean sheet ensuring the arms are out over the top of the sheet. It is important that family and others close to them can hold their hands if they want to.
- The body should look like they are peacefully sleeping.
- Check with your supervisor about removing any jewellery to give to the family. Ensure that the person's belongings are packed neatly to give to their family and that this is documented in line with your workplace policies. **Do not use plastic rubbish bags to pack their belongings as this is highly disrespectful and undignified at the end of a person's life.**

Prepare the room

- Ensure seating, tissues and drinks are available.
- Ensure the room is clean and tidy with any excess equipment (hoists etc) removed.
- Freshen the room air by opening a window if possible.

Talk with the other patients, residents or housemates

- Ensure that there is someone available to talk through what has happened with the other patients, residents or housemates.
- In shared housing and in residential care, other patients, residents or housemates are generally aware that someone has died. This needs to be acknowledged openly by staff and support provided as required.

Notes



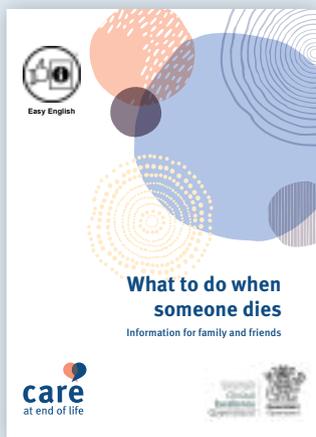
Link:

More information on this can be found in the "Care of the body" page from CareSearch.



Learning Activity:

Clinical Excellence Queensland have produced a helpful booklet to support families and friends with the practical elements of what to do when someone dies.



There is an 'Easy English' version which could be useful in helping people living with intellectual disabilities to understand.

Have a look at this booklet and the list of things that need to be done when someone dies.

Are there things on this list that you haven't thought about before?



Supporting family, carer and housemates

After the person has died, the family, carers and housemates might need support in relation to:

Cultural practices	<ul style="list-style-type: none">• The healthcare team should keep in mind the cultural or religious beliefs of the person and their family and carers after the person has died (eg, in some cultures, burial is expected to take place before sunset on the day of the death).• Specific wishes might be included in the person's advance care plan or you can ask the family (eg, <i>Are there any particular things that you would like us to do now that are important for you culturally or spiritually?</i>).
Saying goodbye	<ul style="list-style-type: none">• People will want to say goodbye in their own way. How this is done is determined by personal choice and cultural practices.• Family members might wish to wash and dress the body with the support of a member of the healthcare team, some prefer to leave it to the funeral director.• If the person was in a residential care facility, other residents, families and staff may wish to say goodbye in their own way (eg, a memories book, a candle, a guard of honour as they leave the facility). It is important to speak with your supervisor to discuss how this is done in your workplace.
Emotional support	<ul style="list-style-type: none">• Be sensitive to the family's needs. They need to be able to cry and mourn the death and spend as much time with the body as needed.• Be aware that people express grief differently. Some may be very quiet while others are very loud and expressive. There is no right or wrong way to express grief.• It is helpful to acknowledge the care that the family and carers gave, and the value it had for the person. Sometimes, providing a calm, quiet presence is the most helpful action.• Members of the healthcare team who cared for the person may also need emotional support at this time.



Learning Activity:

Watch the following video, '[How to talk to someone who is grieving](#)' from Palliative Care Australia (2:30 min)

Make some notes about things **are or aren't helpful** to say to people at this time.

Notes



Thinking Back:

Think about a time when you were involved in caring for someone who died. If you haven't had this experience, talk with your supervisor or a co-worker about their experiences.

What were the things that you did that meant the most – to them, their family, and to you?

How are cultural practices or wishes recorded or communicated in your work setting?

Notes



Case Study:



Over a few weeks you noticed Mary's health getting worse, even with the best care and support. There were many days where she did not want to get out of bed at all. She started sleeping a lot more and she wasn't eating or drinking very much.

Mary's doctor came to see her and went back over her advanced care plan with her brother John. They decided that it was important to be able to keep Mary at home, so the doctor arranged for palliative care nurses to visit regularly.

You were able to help with Mary's personal care needs once the nurses showed you what she needed – mouth rinses, back and hand rubs, talking to her and playing her favourite music. You also moved Mary's bed nearer to the window so that when she was awake, she could see out to the garden.

Mary's family, her brother John and niece Jane, and even Benji (the dog) were able to visit a few times during those last weeks. John was with her singing some of her favourite songs when she died peacefully one evening.

Section 8: Grief, loss and bereavement



Understanding the words that are used

Grief	<p>This is a way of describing how a person feels after they have experienced the loss of someone or something that is very important to them.</p> <p>Grief is a normal response to loss and can be shown in many different ways and at different times. It is important to allow people (including yourself) to grieve in the way that feels right for them.</p>
Bereavement	<p>Describes the whole reaction to the loss and includes the healing process.</p>
Sorry Business	<p>The term that many Aboriginal and Torres Strait Islander peoples use to talk about grief and bereavement.</p> <p>It can also mean a time of cultural practices associated with death. "Sorry Business" acknowledges that the grief experienced from a loss affects the whole person including their mind, spirit and body as well as the relationships they have with other people.²⁸</p>

When a person is grieving, they can experience a range of emotions, including:

- Shock or numbness (not feeling anything)
- Denial (not believing the loss has happened)
- Ongoing sadness and crying
- Anger at the person who has died or anger at themselves
- Guilt from thinking that perhaps something could have been done to avoid the loss
- Guilt arising from the fact that they are still alive – ‘survivor guilt’
- Relief because the loved one is no longer suffering, or relief that a new beginning can take place.



Why is it important to grieve?

Grief is something that takes time to work through. The emotional and physical pain that we experience with grief should not be ignored. Instead, it can be used as a motivation to process or move the grief energy.

Grief ‘work’ can be hard and use up a lot of energy. It is an active process that takes time and energy away from the usual activities of life.

It is important work though as it can lead to a deeper understanding of what brings life meaning and purpose.

It is helpful to remember that:

- Grief is not an illness – it cannot be cured or hurried along
- Grief is a normal and natural response to loss
- No two people grieve or start healing in the same way
- There are no rules or timetables for grief
- There is no right or wrong way to experience grief.



Supporting people who are grieving

Those who might be grieving after someone dies include:

- The person's family and friends
- Housemates or other residents
- Support workers/ carers and healthcare staff.

It is important to remember that a person with intellectual disability may have had close friends who also have intellectual disabilities. They may be very upset and need support.

In this situation:

- Always be open and honest when talking to them as they know that something has happened
- Information about the death should be explained in a calm manner and questions answered in a simple way
- Guided talks about death and loss using simple picture books can help people understand
- You may need to explain what death is and what happens when someone dies. The person might also need assurance that they are not about to die too
- Explaining once what has happened, to someone who is hurt and upset, is not always enough. You may need to repeat your explanation more than once

- Sometimes hurt and sadness lasts a very long time, so it is important to keep checking in on people to see how they are
- If you find that the person is not able to be comforted, you may need to call on professional help.

Ways to help

Sharing memories and feelings about the person can help everyone to express their grief.

A good way to begin talking with others about the death of a friend is to say, *"Do you remember the times when they used to...?"*

It's okay for people to show their hurt and sadness and cry, including support workers and healthcare staff. Crying shows that the person meant something to you and their lives were important to you. Crying with family, residents or friends is okay, but make sure the family don't end up comforting you!



Other ways to help people manage their grief and express emotions can include:

Memory box	Message tree	Photograph album
 <p>A box of items that help you to remember the person – it might include photos, letters, cards, music, special items etc.</p>	 <p>A way of allowing people to write their own message to the person or the person's loved ones – to say goodbye or record a special memory or thought.</p>	 <p>A collection of photos that help you to remember the person. You can also include cards, memories or quotes.</p>



Thinking Back:

Read the following examples from the resource, “Delivering high quality end of life care for people who have learning disabilities” to get some ideas and understanding of ways to discuss death.⁷

Example 1: *Staff at a local care home were trying to find ways to comfort Sarah, a resident who was grieving for a fellow resident, Tom, who had recently died. Sarah was unable to communicate and so the carers were unsure about how much she understood about where Tom had gone. They got a cushion made up from Tom’s favourite jumper which helped to get rid of Sarah’s anxiety as she often sat hugging it.*

Example 2: *Joseph lived in a group home with three other people with learning disabilities, which was part of a wider community of local homes, where he had many friends with and without learning disabilities. Everyone knew Joseph was dying and many of his friends came to see him. He died peacefully under the care of the local hospice. During the days that followed, we talked a lot about Joseph. The night before the funeral, Joseph’s body was brought back to the house in an open coffin, and everyone who wanted was able to spend some time with him. In the room next door, around 80 people had gathered to share “Joseph stories” together, to laugh and cry and pray together, sing his favourite songs and watch a slide show of his life. Many people, including those with intellectual disabilities were involved in organising the funeral. Symbols, photographs and props are used to remember him year after year including Joseph’s colourful waistcoats!*

- *What are some of the examples you know of that have helped people living with disabilities to understand and express their emotions around death, grief and loss?*
- *Talk about this with a co-worker to find out their experiences.*

Notes

Notes

Links:

There are many resources to help you support people living with disabilities to cope with grief and loss. For example:

- [Supporting people with disabilities coping with grief and loss – an easy-to-read booklet](#)
- Marie Curie: [When someone dies – Feelings you might have](#)
- CHANGE Cancer Series: [How you may feel when someone dies](#)

Funerals

Funerals are a way for people to respect and celebrate the life of the person, show their respect and start the grieving process. If a person wishes to attend the funeral, everyone should try their very best to support these wishes.

The following statement from the GRASSroots group expresses this:

“Going to the funeral is very important. Once a person has taken their final journey, you need to decide if you are going to the funeral or not. It’s a question to think about! That’s if you are even welcome there! Sometimes, your family or carers decide that you shouldn’t go to the funeral. That’s wrong. From the family’s point of view, they want to protect the person. The problem is, if the person wants to go to the funeral, but the parents say no, it’s very difficult. They don’t have the right to make that decision. It’s really, very important. Even if the person has severe and multiple learning disabilities, they still have feelings and emotions inside. They may know [that someone has died]. There is a way that they know. I don’t know how, but they do know it inside.”⁷

Supporting children

When supporting children who are grieving, it is important to:

- Talk honestly and openly about death and dying
- Talk to them so they can understand. Children only start to understand death between 6 and 8 years old
- Find out what the child understands before you give them information (eg, “What do you know about what happened with Grandma?”)
- Help them to feel comfortable to be able to ask questions
- Tell the family to use simple language and to explain honestly to the child what is happening
- Suggest that they take the children to visit the sick person and then to the funeral
- Explain the sadness that they may feel at Christmas time and birthdays, or other special occasions due to the absence of their loved one.

When people need extra support

Be aware that if hurt and sadness carries on for long periods, this may mean that the person needs extra support to manage their grief and they should be referred to a counsellor. In these situations, speak with your supervisor.

If a person has difficulty dealing with grief, it can affect their health and wellbeing.

They might:

- Feel numb, shocked, sad, angry or guilty for a longer time than other family or friends.
 - Feel that other family and friends seem to be 'getting on with life' and they do not feel able to
 - Believe that their loved one is not actually dead and will come back to them
 - Start wanting to be alone, sleeping more and feel like 'no-one really understands them'
- Start picking arguments with family and friends for no reason
 - Blame themselves for the death of their loved one
 - Start using alcohol or other drugs more than usual to help cope with the pain
 - Have bad dreams and find it hard to sleep or keep seeing their loved one's spirit or ghost
 - Feel like they have lost direction and are unable to focus
 - Feel like they do not want to go on living without their loved one – thoughts about suicide.
 - **If this is the case, it is important for them to talk with someone they trust straight away, or use a 24 hour support service such as [Lifeline](#) and [Beyond Blue](#).**





Learning Activity:

The Australian Centre for Grief and Bereavement have a mobile phone app called “My Grief” to help people to manage their grief.

Watch this video about the app for more information (1:42 min)

Other resources that might be helpful include:

- CareSearch – Bereavement, Grief and Loss ⁴⁴
- Good Grief ⁴⁵
- Lifeline Toolkit: Coping with sorrow, loss and grief ⁴⁶
- Supporting a Child through Grief and Loss ⁴⁷

Review at least one of these resources and make a note of the new things you learn as well as the things you think all disability support workers should know about grief and bereavement.

Notes

Section 9: Caring for yourself



When caring for people with life-limiting illnesses, you will be exposed to dying, death, suffering, and grieving.

There can also be stressful situations that happen when someone is dying such as family arguments or requests that you feel uncomfortable about, such as keeping information from a person living with disability.

These can be difficult experiences and they might bring up feelings and thoughts about your own life and death or may make you remember sad personal experiences.

You might find yourself:

- Thinking about your own beliefs about dying and death
- Having trouble dealing with the uncertainty that dying and death can create

- Feeling helpless and questioning whether what you did was helpful to the dying person and their family
- Taking negative feelings home to your family and friends
- Feeling worried about different cultural or religious needs and whether the person and their family's needs were met.

Remember that the effects of many losses experienced over time can build to create extreme stress and anxiety.

Learning what to do to look after yourself is very important.



Effects of stress

Stress can be experienced physically as:

- Extreme tiredness
- Headaches
- Stomach or other physical pain
- Trouble sleeping
- Weight loss or gain
- Increased use of smoking, alcohol or other drugs.

Stress can have **emotional** and **spiritual** effects which can affect your health and wellbeing.

The stress experienced by those caring for people can lead to serious issues, such as **moral distress**, **compassion fatigue** and **burnout**.

These affect the way you perform your role and the support you are able to provide.

Moral Distress	<p>This is caused by acting in ways that go against what you believe in (eg, keeping information from someone when you think they should be told).</p> <p>It can cause physical and emotional suffering and can lead to burnout.</p>
Compassion Fatigue	<p>This is when a person becomes less compassionate and caring over time because they are too tired or exhausted.</p> <p>This can also happen when a person becomes too closely involved in the pain and suffering of others and can lead to burnout.</p>
Burnout	<p>Burnout happens when someone becomes too tired to keep caring. You can notice this in people when they have:</p> <ul style="list-style-type: none">• Negative attitudes about people and their needs• Negative attitudes to work, the workplace, and their co-workers• Ongoing feelings of unhappiness and lack of interest• Poor work performance• Physical and emotional symptoms leading to time taken off work.⁴⁸

Caring for yourself is one of the best ways to help avoid the negative effects of stress.



Health and wellbeing

Research has shown that regularly being involved in certain activities can improve our health and wellbeing.

The **Wheel of Wellbeing** describes six important aspects of wellness:⁴⁹

1. **Body** – be active.
2. **Mind** – keep learning.
3. **Spirit** – give, be kind, be grateful.
4. **People** – connect with others.
5. **Place** – pay attention, take notice.
6. **Planet** – care for the planet.



Image Source: www.wheelofwellbeing.org



Learning Activity:

Follow this link to the [Wheel of Wellbeing](#) website.

Watch the introductory video and explore the website resources to find out more about wellbeing activities for self-care.

Notes



Self-care

Self-care is any activity that is done to take care of mental, emotional and physical health and is a key part of staying healthy.

Some examples of the things you can do to look after yourself include:

- Working on building close relationships such as those with family and friends
 - Maintaining a healthy lifestyle by getting enough sleep, regular exercise, and making time for holidays
 - Not taking work home where possible
 - Establishing and maintaining a good balance between work and social life – and not seeing this as a sign of weakness
 - Scheduling regular breaks – including taking lunch breaks and tea breaks
 - Finding new activities and hobbies
 - Being realistic with time and avoid making promises you cannot keep
 - Being aware of what is happening at the present time – mindfulness
 - Taking part in activities that bring personal joy
 - Trying to think positively about the future
 - Having a healthy routine
 - Keeping connections with community, culture and Country
- Learning relaxation exercises and doing them regularly
 - Having goals – at work and personally
 - Understanding and accepting the feelings you will have when working with dying people
 - Talk with co-workers and supervisors regularly about matters that have been upsetting you
 - Make sure you have a regular GP (doctor) to assist you in managing your own health.



Links:

These links provide further information and guidance on how to develop a self-care plan:

- [Palliative Care Australia – Self-care matters](#)⁵⁰
- [Wellbeing Resources](#)⁵¹

Section 10: Summary

This learning guide has provided a range of information to support you to develop skills, knowledge and confidence in the palliative approach to care for people living with disability who are affected by life-limiting illness.

To support your learning, it is good to think about what you have learnt.



Thinking Back:

You might find it helpful to think about these questions:

- *What important points have you learnt that will help you in providing care for people living with disabilities who are affected by life-limiting illnesses?*

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- *How are you going to use this new information in your work role?*

- *Do you see any difficulties using what you have learnt here as part of your work?
If so, what methods can you use to overcome these difficulties?*



Dictionary of Terms

Advance care planning	A process where a person discusses what is important to them and their decisions about future healthcare with their family, friends, carers and healthcare team.
Advocacy	The act of supporting a person, action or belief.
Autonomy	A person's ability to make decisions for themselves. Also known as 'self-determination' or 'sovereignty'.
Bereavement	The reaction to a loss and the process of healing from that loss.
Burnout	Physical or mental collapse caused by overwork or stress.
Care pathway	The ideal way to manage most people with a specific health problem. Care pathways use documents, like flowcharts to outline the steps of care to be followed by members of the healthcare team.
Care plan	A plan made for an individual to meet their specific health needs.
Chronic disease	Long lasting and ongoing health conditions that, in most cases get worse as the person gets older.
Compassion fatigue	The gradual weakening of compassion over time.
Coroner	A person who is responsible for investigating and determining the cause of death for those cases reported to them. In all states and territories, a coroner is a magistrate with legal training, and is attached to a local court.
Curative care	Treatment that is aimed at identifying and treating the source of the illness and promoting recovery.
Dementia	Dementia is a condition or illness that affects the way the person's brain is working. The brain controls everything that we do and so dementia can cause changes in the way the person thinks, their memory, the way they see things and the way they talk.
Down Syndrome	Down syndrome is a condition in which a person has an extra chromosome. Chromosomes are small "packages" of genes in the body. They determine how a baby's body forms and functions as it grows during pregnancy and after birth.

Empathy	The ability to appreciate another's experience, concerns and perspectives with the ability to communicate this understanding.
Empowerment	The ability to mobilise the resources needed to make a person feel in control and have confidence in the goals they are attempting to meet.
End-of-life care	A part of palliative care that focuses on the care people need during the last days or weeks of life.
Existential distress	A person's experience of lack of meaning or purpose in life.
Family	The word 'family' can mean different things to different people. Some people have a 'chosen family' (important people in their life) who they may feel closer to than the family they were born into.
Frail	Weak or delicate.
Grief	A normal reaction to loss. It includes a range of responses: physical, mental, emotional, cultural, and spiritual.
Health passport	A booklet containing information about a person's health and care needs.
Health risk factor	An aspect of a person's health history or habits that make it more likely they will have poorer health.
Holistic care	Care that treats the whole person – body, mind and spirit.
Intellectual disability	A learning and understanding disability where a person has a lower level of intelligence, a reduced ability to cope by themselves, and has difficulties with practical skills.
LGBTIQ+	Lesbian, gay, bisexual, transgender, intersex or queer and other sexuality, gender and bodily diverse people and communities.
Life-limiting illness	An active, ongoing, advanced disease. This term is used to describe a wide range of illnesses where it is expected that death will occur.
Loss	The severing or breaking of an attachment to someone or something, resulting in a changed connection.

Moral distress	Psychological, emotional and physical suffering caused by acting in ways that go against what you believe in.
Palliative care	The comfort and support given to a person and their family when they have a life-limiting illness.
Palliative care specialists	Healthcare professionals who specialise in palliative care (with additional training) and work permanently in that role.
Person (and family) centred care	Care that places the person and their family at the centre of healthcare.
Physical disability	A disability caused by a physical problem or injury that affects a person's ability to move, hear, see, feel or respond.
Primary healthcare	Healthcare provided in the community for people with an initial health concern or need for advice (eg, a visit to the GP for a routine check-up).
Public Guardian	A public official in the state / territory government who is appointed by law to make healthcare and other decisions for a person who is not able to make decisions for themselves.
Quality of life	The standard of health, comfort and happiness that an individual experiences. This is different for everyone and depends on what is important to them.
Self-care	Any activity that is done to take care of mental, emotional and physical health.
Sorry Business	The term that many Aboriginal and/or Torres Strait Islander peoples use to refer to grief and bereavement. It can also refer to a period of cultural practices and protocols associated with death.
Substitute decision-maker	A friend or family member who is chosen by a person to help guide the healthcare team in making decisions about ongoing care if the person is unable to speak for themselves.
Surprise Question	A trigger question used to help identify when a person is approaching the end of life (<i>Would I be surprised if this person were to die in the next 6-12 months?</i>)
Symptom Assessment Scale	An assessment tool that helps a person talk about how they are feeling about their symptoms.
Terminal	A progressive disease where death because of that disease can reasonably be expected within 6 months.

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Record of Participation

This is to record that

Has completed

PEPA Learning Guide for Disability Support Workers

Learning Outcomes

When you have completed this learning guide, you will be able to:

1. Describe the palliative approach to care and outline important points
2. Communicate well with people and their families about palliative care
3. Plan ahead and ensure the necessary care and support is provided
4. Understand the common care needs for people with life-limiting illnesses and how you can help to meet their needs
5. Know what is important to be able to care for someone living with a disability at the end stages of their life
6. Understand ways to support people who are experiencing grief and loss
7. Outline important points of self-care.

Learning Hours*

Date completed

Signature

*Please keep a record of the time taken to complete learning modules and refer to your professional regulating body for allocation of CPD points.



PEPA Program of Experience in the Palliative Approach

PEPA Indigenous Program of Experience in the Palliative Approach

