



# **A guide to palliative care in Queensland**



**For people with a life-limiting illness,  
their families, carers and friends.**

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### Disclaimer

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### Cancer Council Queensland

Cancer Council Queensland is a not-for-profit, non-government organisation that provides free information and support for people with cancer and their families and friends throughout Queensland. These services are made possible through the generous donations of Queenslanders and we thank them for their continued support.

If you would like to know more about the information and support services provided by Cancer Council Queensland, call **13 11 20** Monday to Friday, 9am to 5pm, excluding public holidays or visit [cancerqld.org.au](http://cancerqld.org.au)

## Introduction

This booklet provides information on palliative care and how it can improve quality of life. It will help you to prepare for the end of life, navigate the health care system and find grief and bereavement support. Choose the sections that are most helpful and skip the ones that are not relevant, or that you are not yet ready to read. This booklet has been produced by PalAssist, with support from Queensland Health, and with input from palliative care health professionals, consumers, and carers.

**Please note:** the information in this booklet represents palliative care best practice principles. Access to palliative care services depends on funding, location, illness, the stage of illness, and other factors.

# 1. Coping with the news

Finding out that you, or your loved one, has a life-limiting condition or needs palliative care is hard. Many people do not have experience in dealing with dying or talking about death.

You may feel sad, angry, worried, or numb. There may be questions about what this means for you and your family. You may have trouble thinking. All these reactions are normal.

Many people struggle to accept the news and put off seeking help. Some people think that palliative care means that they will die soon, or that they are giving up hope. While palliative care can provide comfort at the end of life, it is not only about dying.

Take some time in solitude or with someone else to talk about the news. When ready, seek the information you need to understand the options. It may be easier to talk to someone outside of the family. You can talk to a doctor or nurse, or call PalAssist on **1800 772 273** to talk things through or find out about local services.

## What next?

Read the next chapter to understand what palliative care is (and what it is not) and when and how to access it.

Although the future may be uncertain, it is helpful to plan ahead. This may include:

- choosing where you would like to be cared for (see chapter three)
- making plans for the future, including decisions concerning treatment, finances and legal concerns (see chapter five)
- creating memories, setting personal goals, and dealing with unfinished business (see chapter six).

## A note about terms

The term 'you' refers to you, the reader. You might be the person with the life-limiting illness, this person's carer, family member or friend.

Some information in this booklet is directed to carers. A 'carer' is an individual who provides unpaid ongoing care, help and support to someone with a life-limiting illness.

'Palliative care team' means the people involved in palliative care. This can be a GP, community nurses or health workers in the home, those providing care in a residential aged care facility, or a team of specialist palliative care professionals at a hospital, in the home or in a hospice.

## 2. About palliative care

**Palliative care is care that focuses on improving the quality of life and quality of care for people with a life-limiting illness, as well as their families. Palliative care does not aim to slow down or speed up the dying process.**

Where and when someone receives palliative care, and who provides it, depends on the illness, what services are available, the home situation and level of carer or family support.

### Key Points

- Palliative care is about quality of life – allowing someone to live as fully as possible for as long as possible.
- Palliative care is not just for people who are close to dying. It can help people at any stage of an illness.
- Treatment does not need to stop to receive palliative care.
- Palliative care is for people of any age (including children and young people), ethnicity, culture, background or religion.
- Palliative care helps people to plan for death, including taking care of emotional, financial, and legal issues.
- Palliative care supports not only the person with a life-limiting illness, but their family and carers too.
- Exploring the possibility of a referral to palliative care sooner rather than later is advised. People often say they wish they had known about and used palliative care services earlier.

### What is palliative care?

Palliative care services provide assistance at any stage of a life-limiting illness, from the time of diagnosis to the last days of life. Early palliative care can help a person live as fully as possible, for as long as they can.

Palliative care also supports families and carers. This can be by providing information about caring, getting equipment or practical support. Palliative care services can also help with accessing respite care and emotional support or counselling. Depending on the individual's needs, palliative care may include:

- medications to help manage pain, nausea, breathlessness, trouble sleeping and other symptoms
- information and advice to help make decisions about treatment and care options
- emotional and social support, like managing fear and how to talk with family and friends
- practical support, like financial help, mobility equipment and home visits from care providers
- help to meet spiritual needs.

Someone may receive palliative care from a GP and from specialists as an outpatient, in their home, a residential aged care facility (nursing home), palliative care unit, hospice, or in hospital, or some combination of these. See chapter three for more information.

### Palliative care is for:

- managing physical symptoms
- enabling the best possible quality of life
- meeting emotional, social, and spiritual needs
- people with many different conditions, at any stage of an illness.

### Palliative care is not:

- just about pain relief
- giving up hope
- euthanasia or voluntary assisted dying
- ending life sooner or keeping someone alive for longer
- only for people with cancer, or who are near the end of life
- only for older people
- only for people who are in the last hours, days or weeks of life.

## Pain and symptom management

People with a life-limiting illness can live with many symptoms, which may change over time. Common symptoms include:

- pain
- nausea (feeling sick)
- lack of appetite (not wanting to eat)
- trouble swallowing
- trouble breathing or breathlessness
- constant tiredness (fatigue) or difficulty sleeping.

Pain and symptom management is one of the key goals of palliative care. The health care team can work together to assess and help manage any physical symptoms, to assist the person receiving care to be comfortable and maintain quality of life for as long as possible.

## Emotional and spiritual issues

It is normal for a person who is seriously ill to feel a range of emotions. This emotional response is also frequently experienced by carers. You may feel worried, overwhelmed, anxious or even depressed. You will, understandably, need time to adjust. People in this situation may question their beliefs, contributions and the decisions they have made at various times in their life. Talking with someone experienced in palliative care may help. Call PalAssist on **1800 772 273** if you would like to talk about how you are feeling.



## Who is palliative care for?

Palliative care may be appropriate for anyone with a life-limiting or terminal condition, which has little or no possibility of cure. Palliative care is for people of any age, ethnicity, culture, background, or religion.

Palliative care can help people with a wide range of conditions including (but not limited to):

- cancer
- organ failure (heart, liver, kidney)
- lung or chronic airway disease
- renal disease
- heart disease and stroke
- dementia
- motor neurone disease
- multiple sclerosis (MS)
- Huntington's disease
- muscular dystrophy
- HIV/AIDS
- dying of old age
- other degenerative or deteriorating conditions relating to ageing.

Often, the GP or specialist can continue to manage care together with the specialist palliative care team. The specialist palliative care team may be more directly involved with people who have advanced illnesses or who are at end of life.

## Palliative care for children and young people

### Children

When a child has a life-limiting illness, there can be much uncertainty. Some life-limiting illnesses may be able to be managed as chronic illness, others may not. Children may have palliative care at the same time as active treatment. This can improve their comfort and maintain their quality of life.

Children's palliative care teams understand how a child develops and that their needs are different to an adult. They have skills in both the medical treatment of children and palliative care. They understand that each family has different preferences and will work with families to help make informed decisions.

### Adolescents and young adults

It can be very difficult for a young person to grapple with the news that they may not have a long life. There can be a lot of anger and sadness. It is important that they have support to carry out their wishes and to have their emotional needs addressed.

Adolescents and young adults receiving palliative care experience a unique range of issues that differ from children and older adults, as the timing of their life-limiting illness coincides with a period of critical growth and development.

They need the chance to talk about death and make plans but may also want to get on with living the life they have to the fullest. There may be things they want to do or accomplish. Palliative care can help adolescents and young adults plan and achieve their personal goals.

### Paediatric palliative care in Queensland

Queensland's Paediatric Palliative Care Service is based in Brisbane at the Queensland Children's Hospital and works state-wide. A referral is needed to access this service. The team at the Queensland Children's Hospital will work in partnership with parents and the child's GP or paediatrician.

Call **07 3068 1111** or visit [www.childrens.health.qld.gov.au](http://www.childrens.health.qld.gov.au) for more information.

Palliative Care Australia's Paediatric Palliative Care website provides information to help people prepare for situations they may face during a child's illness. [www.palliativecare.org.au/children](http://www.palliativecare.org.au/children)

For more information about palliative care services for children and teens in Queensland and support for families, contact PalAssist on **1800 772 273**.

## When to access palliative care

If someone has a life-limiting illness, they may want to talk to a doctor about palliative care at the earliest opportunity.

Finding out about palliative care services and support earlier, may reduce stress later. It may provide more time for a person to better understand and manage any physical symptoms, make plans, and get help meeting practical, emotional, and spiritual needs.

### For specific illnesses

Palliative care services can help at any stage of illness. However, the person receiving care may have individual needs due to the symptoms associated with their condition.

For example, it is important for people with dementia to make advance care plans early (see chapter five). Likewise, if an illness can affect speech (like motor neurone disease), palliative care should be discussed early while the person can talk about their wishes.

## How to access palliative care

Most people with a life-limiting illness will continue to have their usual care managed by their GP, who will also consider the need for home support. A GP may refer the person to a specialist palliative care service.

If someone is **65 years old** or over, the GP may also refer them to My Aged Care to access further community care support. If someone is **under 65 years old**, they may be referred to the Queensland Community Support Scheme for more care support. If someone is an inpatient in hospital, they may also be seen by a specialist palliative care team within the facility.

Many people also contact local hospitals, health services or community palliative care services to see what is available. Most providers need a referral to access their services. Providers may also charge for some services. It is always best to ask if there will be any costs involved.

To find a service in any area of Queensland, call PalAssist or go to [www.palassist.org.au](http://www.palassist.org.au)

## What is a referral?

A referral is a written request from one health professional to another health professional or health service, asking them to treat someone for a certain condition. A referral can also be called a doctor's letter. A person might require a referral if they need to be linked with a community palliative care team or a specialist palliative care team within a hospital.



## Who provides palliative care?

Palliative care may be provided by many different health professionals, depending on a person's individual needs, and the needs of the family or carers.

Often, palliative care is provided by a doctor (GP or specialist) and community nurses. They may communicate with palliative care specialists to ensure the individual receives the care and support they need.

A palliative care team may include:

- a GP
- specialist palliative care doctors and nurses
- specialist doctors for a certain illness, for example: oncologist, cardiologist, neurologist, respiratory physician
- nurses
- social workers
- personal care assistants
- physiotherapists
- occupational and speech therapists
- pharmacists
- psychologists
- spiritual carers or pastoral care workers
- Aboriginal and Torres Strait Islander health workers
- professional interpreters
- trained volunteers.

## 3. Where to access palliative care

Palliative care may be delivered at home or in a residential aged care facility, a hospital, a palliative care unit or a hospice. Where someone receives care depends on their needs, the stage and progression of their illness, their preferences, available services, and whether family or friends can help.

Health professionals will assess people's needs and work together with individuals and their families to plan where someone might receive palliative care. It is important to ensure the doctor knows about any specific choices that an individual may have. These may be written in an Advanced Health Directive or Statement of Choices. These choices can change over time as illnesses or needs change.

It is important to remember that while the team will try to honour a person's first care choice, such as in-home care, sometimes other options, like residential aged care, must be considered.

### Key points

- Many people with a life-limiting illness prefer to be at home, or on Country, but whether this can happen depends on the illness and circumstances.
- If needs are more complex, and specialised care is available, the person may have to be cared for in a palliative care unit or hospice.
- Needs and preferences may change over time. People can move in and out of different settings. They might need a short stay in hospital to get symptoms like pain under control, and then return home if possible.
- Wherever someone is cared for, the intent of palliative care is to improve or maintain quality of life and help the individual get the care needed to ensure that symptoms are well controlled.
- If you need more information about local options and would like to ask questions, talk to a GP, palliative care team or call PalAssist.

### At home or on Country

Some people may have palliative care in their own home, or on Country, with help from a community palliative care nurse. 'Home' could be the house someone has lived in for most of their life, a residential aged care facility (nursing home) or a special place that has personal, cultural, or spiritual meaning. 'On Country' refers to the traditional homelands of Aboriginal and Torres Strait Islander peoples. The advantages of staying at, or returning to, home or Country might include being in familiar surroundings, feeling more in control, and being with family, friends, or community.

Healthcare professionals will respect wishes as much as possible, but receiving palliative care at home or on Country depends on many factors including:

- the level of care required for the individual
- the home environment
- how much support is available from family or carers in the community
- whether there is someone at home to be a carer.

### Caring for someone in the home

Many people have little or no experience being with someone who is dying. The thought of caring for someone at home can be frightening.

However, people who have cared for a dying person say it can be rewarding and a time of great closeness. The key is getting advice, help and support (see chapter nine).

Over time, the person receiving palliative care may change and the carer may feel that they don't have the skills or emotional strength to continue with their duties as a carer. It is okay to ask the GP or palliative care team for more help or other options such as a hospice or hospital. This doesn't mean the carer has failed or given up; it's about ensuring care needs are met. It also means the carer can focus on spending time with, or simply being with, the person receiving care.

### In a nursing home

Public and private residential aged care facilities (nursing homes) may offer respite or permanent care for people needing palliative care. Many nursing homes are familiar with palliative care. In some areas of Queensland, specialist palliative care services may visit the nursing home if more complex care needs have been identified.

More information about moving a person requiring palliative care to a nursing home can be found by contacting My Aged Care on **1800 200 422**.

### In a palliative care unit or hospice

A palliative care unit provides full care for people with a life-limiting illness and is usually attached to a hospital. A hospice is often a standalone facility that is less like a hospital, and more like an ordinary house.

A person may go to a palliative care unit or hospice for:

- a short stay to get symptoms under control
- emergency (or respite) care for a day or a few days if a carer is unwell
- end-of-life care if they cannot be cared for at home or do not want to die at home.

Hospices can be different from hospitals. Often, they are quieter, visiting may be easier, and holistic care is usually the focus. To find out if hospice care is available in your area, phone PalAssist.

### In hospital

Some people may want to return to hospital when they need full-time nursing care. Whether this is possible will depend on the hospital.

Hospitals are intended for short term stays. If someone cannot return home and needs long term care, the care team can talk to individuals and their carers about options for ongoing care. Depending on the person's illness and needs, this may include a residential aged care facility (nursing home).

## 4. Costs and financial assistance

The financial cost of life-limiting illnesses can be stressful. Some palliative care services are provided at no cost, but there is usually a cost for medicines or equipment. This section provides information about financial help and support.



### Key points

- Some palliative care services are provided at no cost.
- There is usually a cost for medicines, equipment, and services like in home nursing.
- Private specialists, hospitals and other health care services may also charge fees.
- Financial help may be accessed through Centrelink, charities, local councils, or church groups.
- Queenslanders may access medical aids and equipment through the Medical Aids Subsidy Scheme (MASS). Talk to a doctor about applying.
- It may be useful to see a financial advisor or accountant to help sort out financial and tax matters.
- Early access to superannuation or an insurance payout may help with costs.

### How much does palliative care cost?

Most public palliative care services are free for Medicare-eligible patients and are funded by the federal and state governments.

However, there are usually costs associated with the following:

- hiring or buying specialised equipment to use at home
- medication
- nursing staff if the individual chooses to stay at home and needs 24-hour care
- respite services
- home help services
- private health professionals
- complementary therapies
- services received if the person with the life-limiting illness is not eligible for Medicare.

Private therapists, private hospitals, and some hospices charge fees. If a person has private health insurance, they should check for palliative care cover.

If unsure, ask a doctor or treatment team about costs.

## Financial assistance

There are several programs providing financial assistance to people with a life-limiting illness and their carers.

### Government allowances

You may be eligible for benefits from the Australian Government.

For more information, call Centrelink on **136 240** or visit [www.servicesaustralia.gov.au/individuals/centrelink](http://www.servicesaustralia.gov.au/individuals/centrelink).

To access the Medical Aids Subsidy Scheme (MASS), talk to a doctor or health professional, or phone MASS on **1300 443 570**.

Charities, local councils, and church groups may offer financial or practical support. Some banks and utility companies may also have hardship or compassion programs. People may choose to contact their providers to ask about allowances.

For more information about accessing financial support, call PalAssist on **1800 772 273**.

### Financial advice and planning

Getting professional financial advice may help if you are stressed. Sorting out finances and tax can give people peace of mind and may reduce the stress and financial burden.

Talking to a trusted family member, financial advisor, financial counsellor, or accountant may help a person:

- consider the impact of a carer stopping work
- check insurances and update beneficiaries
- sort out their assets and bank accounts
- make a financial plan, particularly if the person with a life-limiting illness has a partner or dependent children
- gain advice on whether tax deductions can be claimed
- organise financial information and documents so they are safe and easy to find.

For financial counselling, call National Debt Helpline on **1800 007 007** or visit [www.ndh.org.au](http://www.ndh.org.au), [www.moneysmart.gov.au](http://www.moneysmart.gov.au) or [www.financialfirstaid.org.au](http://www.financialfirstaid.org.au).

Speak to a social worker (if available) or call PalAssist on **1800 772 273** for further information.

## Superannuation and insurance

### Early release of superannuation

In some circumstances, people with a life-limiting illness, or their carers, can get an early release of their superannuation.

To find out more, contact the relevant superannuation fund.

### Insurance

Financial help may also come from a person's insurance policies, like income protection, total and permanent disability, or life insurance.

Life insurance, also known as death cover, will pay a lump sum to a person's beneficiaries after death. Some people use this to pay off their mortgage, other debts or provide an income for their dependents.

The individual should contact their insurer or financial advisor to find out what can be claimed.



## 5. Sorting things out - making plans

Thinking about and planning for dying can be distressing. It can be tempting to put things off or to avoid difficult conversations. However, making plans early may provide everyone involved with comfort as it gives each person the chance to discuss their concerns.

### Key Points

- Planning and recording preferences for future care and what happens after death allows the person with a life-limiting illness to feel confident their wishes are known. Family or carers will also know what is wanted.
- Advance care planning means thinking about what kind of treatment and care is wanted in the future.
- An Advance Health Directive is a legal document that details a person's wishes for medical treatment.
- The person receiving care can appoint someone they trust to make important decisions in the future if they are unable to do so. This is called an Enduring Power of Attorney.
- It is important to have a valid Will to ensure property and possessions are distributed in accordance to a person's wishes.
- Funeral preferences may be considered and written down, so the person with a life-limiting illness can choose how they would like to be remembered.
- Organ donation can also be considered.

### What to consider

Even though it may be complex and emotionally difficult, it is important to think about future care, end of life, and what happens after death.

Things to think about include:

- place of death (home, hospice, hospital, or on Country)
- visitors and company while someone is dying
- medical treatment at the end of life
- trustworthy people to make decisions when the person being cared for cannot.

People may wish to discuss their choices with their family, carers, GP, or palliative care team.

Making plans for the end of life does not mean giving up. It's about being prepared and ensuring everyone involved is aware of the wishes of the person receiving care.

If anyone is struggling to talk about death or dying, let the palliative care team or GP know.

### Advance care planning

Advance care planning involves thinking about what is important and deciding on appropriate care. It may involve:

- Discussing wishes with close, trustworthy people.
- Documenting preferences for future care and treatment in an Advance Health Directive or Statement of Choices.

Advance Health Directives and Statement of Choices forms are documents that can be used to record a person's wishes. Contact the Office of Advance Care Planning for more information [www.metrosoth.health.qld.gov.au/acp](http://www.metrosoth.health.qld.gov.au/acp).

- Appointing a 'substitute decision maker'. This is someone who will make decisions when the person receiving care loses ability. In Queensland, people complete an Enduring Power of Attorney form for this.

Queensland law also recognises a statutory health attorney – someone with automatic authority to make health care decisions for a person if they become unable to make them because of illness or incapacity. A statutory health attorney does not need to be formally appointed – this person automatically acts in this role when the need arises because of their relationship with the person who is ill or incapacitated.

Visit [www.advancecareplanning.org.au/resources/Queensland](http://www.advancecareplanning.org.au/resources/Queensland) or call PalAssist on 1800 772 273 for more information.



## Stopping active care

In Queensland, people who can make decisions themselves have the right to refuse medical treatment. They can stop treatment even if this may cause death or make it happen sooner. This is an automatic right of every person and is legal.

If someone makes an Advance Health Directive, they can include instructions about particular treatments, and whether they want treatments that keep them alive, such as tube feeding, ventilation, or resuscitation.

## Making a Will

A Will is a legal document that records what happens to a person's money, belongings, and other assets when they die. It names beneficiaries and who is to administer the estate of the deceased. If there are dependent children, it should also contain details about who has guardianship of them if both parents die.

A Will must be in writing and signed in front of witnesses, so it is best to get help from a solicitor or community legal service.

If a Will has been made before a person's diagnosis, it should be reviewed in case any wishes have changed.

## Planning a funeral

It can be confronting to think about, but the person receiving care may want to consider the kind of funeral they would like and talk about it with their loved ones.

If it is too hard to talk about funeral plans, the palliative care team may be able to help.

A funeral director can help plan a pre-arranged or a pre-paid funeral. Alternatively, if planning in detail is not something that can be faced just yet, the person receiving care may find it helpful to instead tell family and friends their wishes, or write them down. This may include considerations such as the following:

- whether they would rather be buried or cremated
- where they would like to be buried or have their ashes placed
- whether they want a religious service or not
- whether they would like particular songs or flowers
- if they would like donations given to a charity
- who they would like invited
- what clothes they want to wear.

It isn't necessary to have a funeral. Some people choose to have a gathering or ceremony instead, or would prefer not to mark the occasion.

## Organ and tissue donation

Having a medical condition does not prevent someone from donating organs or tissue, but it may affect what can be donated. Donation may also be difficult in some rural and regional areas.

If a person makes the decision to donate, it is helpful to share this information with family or close friends. Family or friends will be asked to confirm the person's wish to donate before donation for transplantation can proceed.

If someone is a potential donor, the quality of care at the end of life will never be compromised by the potential for organ and tissue donation.

For more information, visit the Australian Government's DonateLife website: [www.donatelife.gov.au](http://www.donatelife.gov.au).

## 6. Life matters

Many people with a life-limiting illness often find that setting personal goals and spending time with those who are important to them can be very meaningful. They can plan to use the time to make memories, communicate with family and friends, and to think about spiritual needs.

This chapter includes some suggestions on how to plan quality time, based on activities that others facing the end of life have found fulfilling. People receiving palliative care may wish to use this as a guide to develop their own list.

### Key points

- Sharing memories and creating legacy items is a great way to leave a message for loved ones.
- Making the most of the time someone has means doing what is important and meaningful.
- It is normal for anyone in this situation to feel a wide range of emotions. Find ways to express them and know it is okay to get professional help.
- Talking with family and friends about plans, feelings, and fears can be helpful and rewarding. Doctors, social workers, psychologists, or a telephone support service like PalAssist can also be engaged in these conversations if it's preferable.
- If talking is hard, creative activities like music or art can help express feelings.
- At the end of life, people might feel more religious or spiritual and start thinking about big questions like the meaning of life. Try talking with an Aboriginal and Torres Strait Islander health worker or liaison officer, a religious leader or a pastoral care worker. These people can discuss spirituality-related questions, feelings and fears.
- Ensure family and the palliative care team are aware of any special cultural or religious rituals, food requirements or end of life practices the person receiving care may need.

## Making memories

One way to emotionally prepare for death is by creating memories and making special items for loved ones. The most important thing is that the person receiving palliative care does whatever feels meaningful and right for them. This may include doing the following for the special people in their lives:

- writing letters or cards
- buying or bequeathing meaningful gifts
- making a hand or footprint cast
- making an audio or visual recording
- writing down the family history for the next generation
- making a photo album or scrapbook
- compiling a collection of favourite recipes
- writing a song or a poem, painting a picture, or making a collage
- writing an obituary
- creating a memory box with messages or letters, photos, special jewellery, mementoes or a present to mark a special birthday.

Some care services and organisations have trained volunteers to help with these activities. Ask a social worker, psychologist, or a member of the palliative care team.

## Making the most of life

Making the most of life involves doing what is important and meaningful.

This may be:

- spending time with loved ones
- relaxing in nature
- 'bucket list' activities and achievements
- simple pleasures like sitting in the sunshine
- celebrating a special event
- recording memories
- seeing an old friend
- visiting a special place
- enjoying an art or craft activity
- working.

A person may also consider reconnecting with people who have previously been an important part of their life, with whom they have since lost touch. Tying up 'loose ends' can help provide closure, acceptance and reconciliation.

The palliative care team may provide support and recommendations. A social worker, psychologist, Aboriginal and Torres Strait Islander health worker or liaison officer, or spiritual advisor can help individuals to identify what is most important, plan activities and work out goals. Health professionals such as physiotherapists, occupational, speech, music and art therapists can also help.

## Communication and expression

It is normal for people to have a range of feelings when receiving palliative care. They may feel shocked, afraid, sad, or angry. Some days people may feel hopeful; other days they may be frustrated or anxious.

There is no right or wrong way to feel. It is normal to feel sad, however, if someone is feeling sad all the time, losing interest in things they used to enjoy, having difficulty sleeping, or not wanting to get up in the morning, talk to a doctor. Counselling and/or medication may help.

### Talking to family and friends

Talking to family or friends about going through palliative care can be difficult. It can be hard to admit fears, worries and emotions.

Talking to children about someone's illness and death is even tougher. Try to be open with them. Many children are aware of what is happening. Ask a social worker, counsellor or PalAssist for advice on talking to children of different ages about death.

Some people see the end of life as an opportunity for reconciliation. The palliative care team may suggest ways to talk with family and friends when a breakdown in a relationship has occurred, so conflicts and unresolved issues can be addressed.

### Talking to people outside of the family

There are health professionals to talk to outside of the family. These could be:

- a doctor or nurse
- a counsellor, social worker, or psychologist
- an Aboriginal and Torres Strait Islander health worker or liaison officer
- a religious leader or pastoral care worker
- a telephone and online support service like PalAssist.

It is important to talk with a doctor or someone in the palliative care team. They can discuss feelings, fears, and emotions, and can help with decision making, as well as medical needs and concerns.

The palliative care team or PalAssist can offer advice on how to find a counsellor or psychologist who has experience helping people with a life-limiting illness, their carers, and family.



### Other means of emotional expression

If talking about feelings and fears is difficult, creative activities like music and art can help express feelings.

Music and art therapy can help to relieve anxiety, depression, and insomnia. These types of therapies may be used to create gifts or legacy items – like a song or painting – for loved ones.

Ask a social worker or any of the therapists in the team to help find a group or options to do something creative.

### Cultural considerations

Palliative care is also about acknowledging and supporting the diverse cultural practices around care at end of life, death and dying. People from Aboriginal and Torres Strait Islander backgrounds and other cultures or language groups, may have values, beliefs, rituals, and perspectives about a palliative care situation that differ from the standard approaches of palliative care services in Queensland. Standard palliative care approaches may be unfamiliar to, and inconsistent with, usual practices within the families and cultural beliefs and practices of some Queenslanders.

Palliative care teams will want to work with individuals to ensure that the care provided is appropriate and in line with their culture. It is important to speak with the team about rituals, traditional preferences, and specific cultural practices to allow these practices to be incorporated into care.

Information may be confusing or confronting for some people. Ask to speak to an Aboriginal and Torres Strait Islander health worker, nurse or social worker if support is needed to clarify information, or to translate it into another language.

### Spiritual concerns

Awareness of religious beliefs, or questions about spiritual issues like the meaning of life, suffering and hope may be things a person receiving palliative care wants to talk about.

Some people find meaning in faith or religion while others question it when they are suffering. Some people express spirituality through personal relationships, meditation, nature, music, art, or community.

A person's palliative care team may include a pastoral care worker to help them find whatever is meaningful to them and talk about thoughts, feelings, and fears from all viewpoints. A priest, rabbi, reverend, imam, or other religious leader may also be arranged. The team will respect personal spiritual, cultural and communication needs. Talk to them about any special rituals, food requirements or end of life practices or issues.

## 7. End of life

At the end of life, some people may experience emotional and physical changes. Many people say they do not fear death as much as they fear the unknown. This fear may never disappear, but knowing about changes can help people prepare for, and manage, end of life.

### Key points

- Each person's experience is different.
- Knowing the physical changes that may happen can take some of the fear and anxiety away.
- Palliative care can relieve pain and other symptoms.
- Palliative care aims to make death peaceful, when the time comes, and support carers and families.
- If the person receiving care is at home, more help from the palliative care team may be needed.
- The palliative care team will communicate what to expect and recommend practical things to do to keep the person with the life-limiting illness comfortable.
- Keeping contact numbers handy will reduce stress.

## End of life signs

It can be helpful to talk to the palliative care team about what to expect at the end of life. No one can say exactly what will happen, or how quickly, but knowing the changes that usually occur can take some of the fear and anxiety away.

For many people, death is not sudden and is peaceful. Usually they become weaker, have little energy, and spend more time sleeping.

### It is common for people near the end of life to:

- need to spend most, or all, of the day in bed
- eat and drink less
- sleep a lot and feel drowsy when awake
- be disorientated
- find it difficult to concentrate on their surroundings and even close family ('withdraw from the world').

### In the final days, it is usual for people to:

- stop eating and drinking altogether
- have a change in skin colour (more blue, grey, or white) and body temperature (very cold and moist hands, feet, and skin)
- have changes in breathing patterns, with breathing sometimes becoming noisy and irregular
- some people may become restless or agitated, even shouting or jerking the body (called 'terminal restlessness').

## Pain and symptom management

In the last few weeks of life, there are some physical changes that usually occur, regardless of disease or condition.

Symptoms may be more severe or frequent, or there may be new symptoms.

### Common physical concerns at end of life include:

- constant tiredness and lack of energy
- trouble sleeping
- pain
- feeling sick and vomiting
- loss of appetite and weight loss
- trouble breathing or breathlessness
- mouth problems (dryness, ulcers, or an infection)
- coughing and wheezing
- incontinence (losing control of bladder and bowel)
- fluid build-up causing swelling (oedema)
- bladder problems (urine retention)

Many of these symptoms, including pain, can be controlled with medications, other therapies, or medical aids. Palliative care aims to help people die in comfort and with dignity.

If a person is receiving palliative care at home, the palliative care team will support carers and families to ensure they know how to manage symptoms and provide comfort for the person. Keeping all relevant contact numbers on hand will help to reduce stress in this situation and allow support to be gained quickly, when it is needed. For more information on carer support, see chapter nine.

## 8. Question checklist

Questions the person beginning palliative care may wish to ask a doctor:

- ☐ If I am receiving palliative care, can I still get treatment for my disease?
- ☐ How long will I need palliative care for?
- ☐ What is my prognosis?
- ☐ What if my condition unexpectedly improves?
- ☐ Who will be a part of my palliative care team?
- ☐ Who will coordinate my care?
- ☐ Which doctor or health professionals will I see regularly from now on?
- ☐ Where can I access palliative care?
- ☐ How much will it cost?
- ☐ If I am at home, what kind of help will be available?
- ☐ If I am receiving treatment in a city or town away from where I want to live and/or die, will I be able to return there?
- ☐ How will you ensure that my cultural needs and practices are met before and after I die?
- ☐ Can my family or carers get respite care or other support?
- ☐ If I have pain or other symptoms, what can be done to control them?
- ☐ Can I go to a hospital or hospice for a while to get symptoms under control and then go home again?
- ☐ Can I call the palliative care team at any time?
- ☐ Can you help me talk to my family about what is happening?
- ☐ Are there any complementary therapies that might help?

Questions to ask the person starting palliative care/for them to consider:

- ☐ Is there anything you want to do before you get too ill?
- ☐ Are there any issues you want to sort out with particular people?  
See page 29.
- ☐ Have you thought about what care and medical treatment you do and do not want, and documented it in your Advance Care Planning?
- ☐ Have you thought about where you want to die? For example, at home or on Country? Have you informed your carer, family and palliative care team?
- ☐ Have you chosen someone to make decisions for you if the time comes when you cannot make them for yourself?
- ☐ Have you made a Will (or updated your Will, if you made it a while ago)?
- ☐ Do you want to plan your funeral, or talk to your family about what you would like?
- ☐ Have you considered organ or tissue donation?
- ☐ Have you sorted out your financial and tax issues, and found out about financial help that you or your carer may be eligible for?
- ☐ Do you need help to plan or achieve any personal goals, or to create memories for your loved ones?
- ☐ Have you had the conversations you want to have with the people most important to you?
- ☐ Have you told your carer, family and palliative care team about any spiritual or religious practices at end of life that are important to you?

## 9. Carer support

**Facing a life-limiting condition and making decisions about palliative care can be challenging for carers too. There may be times when carers feel like they do not know what to do, what to say, or how to cope.**

They do not need to go through it alone. There are many sources of practical and emotional support for carers. The first step in getting support is knowing what is available, who to contact, and when.

### Key points

- If you are a carer, it is important to get as much support as you need.
- If you are caring for someone at home, the doctor or palliative care team will assess the patient's needs and help organise equipment, home nursing and/or practical help.
- It is also important to look after yourself. It may help to talk about your worries and concerns with friends, a counsellor, a social worker, an Aboriginal and Torres Strait Islander health worker or liaison officer, or other carers.
- If you are caring for someone at home, respite care is available to give you a break.
- Make sure you know who you can contact at night and on weekends if you have worries or queries, and who to contact in an emergency.

### Getting support

Caring can be hard work. For many people, it is a full-time responsibility, on top of jobs, parenting, and other roles. PalAssist and many other national and state services provide palliative care information and support for carers. There is a list with contact numbers and websites on page 45.

### In home care

Carers managing at home may need help with practical aspects of caring, like organising medicines or arranging transport. Gaining advice about coping and self-care is also encouraged.

### Getting equipment and home help

Equipment and other aids may be needed for comfort, independence and safety. This might be:

- a special mattress or chair cushion
- an electric recliner chair
- a walker
- a commode, urinal, bedpan, or incontinence sheets
- grab rails, a raised toilet seat and other equipment for the shower or bath
- a hoist or sling
- a bed with adjustable head and foot sections
- a wheelchair or ramp
- stair rails.

Usually, a community nurse or allied health team member will assess the needs of the person receiving care and organise equipment. They may also explain and demonstrate how to move or lift someone, and shower or wash them. As care needs change, different aids and equipment may be needed, so ask for a re-assessment at any time.

### Nursing and home help

Government services and community organisations may provide help and support to people caring for someone at home, including nursing care, help around the house, meal and food services and transport. Home nursing may be available through community nursing services or local palliative care services. There also may be a fee involved.

Other practical and home help may be provided by the local hospital, council, various community services and health centres, and charities. The palliative care team may organise home nursing and home help.

If the patient is 65 years old or over, phone My Aged Care on **1800 200 422**. If the patient is under 65, phone Queensland Community Support Scheme on **1800 600 300**. Alternatively, contact PalAssist on **1800 772 273** for information about services in the local area.



## Emotional support and help coping

To provide the best care, it is important for carers to also look after themselves.

It may help to talk about worries and concerns with friends, a counsellor, social worker, Aboriginal and Torres Strait Islander health worker or liaison officer, or with other carers. They may give advice on coping, how to get some 'you' time and take care of health and relationships. There are several carers organisations that provide advice, support groups or online discussion groups and counselling (see page 45).

## Respite care

Respite care may be available to give carers a break from their role. Respite care may be provided in someone's home, in a residential aged care facility, a respite care centre, hospital, palliative care unit or hospice. It may be for a few hours, overnight or for several days. Depending on the location, respite may be accessed for a range of reasons, such as a carers own health concerns or wellbeing.

Ask a doctor or palliative care team to help organise respite care. Alternatively, contact My Aged Care on **1800 200 422** or the Carer Gateway on **1800 422 737** for information about local carer support services and respite options, including what costs may be involved.

## Emergency and after-hours support

Ask the GP, community nurse or palliative care team about who to contact if there are any worries or questions after hours, at night or on weekends, and who to contact in an emergency.

Keep the numbers in a safe and obvious place.

## Condition-specific support

Palliative care is available for a wide range of life-limiting illnesses. While many people live with these illnesses for years, often they require the additional care and support that palliative care provides.

There are benefits to starting palliative care at the same time as having treatment for an advanced disease.

PalAssist can provide details of national and Queensland organisations that provide information and support for people affected by specific illnesses. Call **1800 772 273** or visit [www.palassist.org.au](http://www.palassist.org.au) to find out more.

## End of life

Some carers have never seen anyone die and may be afraid of what will happen.

The physical signs described on page 34 are part of the normal, natural process of the body gradually shutting down. If any carer notices any worrying signs or changes, contact the GP, community nurse or palliative care team.

The palliative care team may tell carers practical things they can do to help the person nearing end of their life remain comfortable, such as keeping their mouth moistened. Carers give great comfort just by being with the person they are caring for, holding their hand, and talking to them. Even if they do not respond, they can probably still hear.

## 10. Coping after death

Death is never easy to deal with, even when it is expected. Losing a family member, a friend, or someone you have been caring for, can bring up a range of emotions: sadness, anger, fear, or even relief. This is normal. Everyone grieves differently.

There are also many practical tasks that need to be taken care of after someone dies. It can be helpful to know what to do ahead of time.

### Key points

- Death can be a shock, even when it is expected. It can bring up a range of emotions. This is normal.
- After someone has died, there are several legal and practical things to take care of, such as organising a funeral and informing family and friends.
- There may be government payments and financial advice that can help during this time.
- Grief is a normal response to loss. Bereavement is when you are grieving for someone close who has died.
- There is no right or wrong way to grieve.
- Most people find that with the support of their family and friends, they can learn to cope with their loss.
- Talking to a bereavement counsellor or social worker can also be very helpful.

### Practical and legal things to organise

When someone dies, there are many things that family members or friends may need to do, including:

- organising a funeral, ceremony or gathering
- informing people (family and friends)
- informing organisations like Centrelink, Medibank, banks, insurance company, etc.
- organising mail redirection
- shutting down any social media accounts.

There may be government payments and financial services that can help during this time. Call Centrelink on **13 23 00** or contact your local Centrelink office to find out if you are eligible for the bereavement payment or allowance.

### Grief and bereavement

Grief is a normal response to loss, especially the loss of a loved one. It is more than sadness. People may also feel:

- numbness and disbelief
- anger
- anxiety and distress
- loneliness.

There is no right or wrong way to grieve, and no timeline for how long it will last. Grief can also be delayed and appear later, sometimes long after a loss.

Everybody grieves in their own way. Some people are expressive and cry; others don't want to talk about it and prefer to keep busy or keep to themselves. Often people mourning for the same person may grieve in very different ways and may not understand ways of managing grief that are different from their own.

## Reconnecting

Being a carer for someone with a life-limiting condition can be quite isolating and exhausting. After the person has died, carers may find it very difficult to go back to their work, groups, clubs, or the activities they previously enjoyed. Inviting a friend or volunteer for support the first few times may make it a little easier.

If grief feels overwhelming or there are concerns about how low someone is feeling, talk to a GP or palliative care team about grief and bereavement counselling. Support can also be accessed by calling PalAssist **1800 772 273**, or Lifeline **13 11 14**.

The organisations and websites listed on page 45 can provide more information and help on coping with loss and grief.

## Tips for coping with loss

- Accept that there are many ways to grieve and feel, and that this is normal and natural.
- Let health professionals or Aboriginal and Torres Strait Islander health workers know if you would like spiritual or emotional support.
- Be patient. People may feel – or other people may say – that someone should be ‘back to normal’ or ‘over it by now’, but grief can be ongoing and can change.
- Find someone to talk to. If it is too difficult to talk with family and friends, ask a doctor or the palliative care team to recommend a bereavement counsellor or service.
- Take care of yourself: rest when you need to, accept help, try to eat well, do some light exercise.
- It is normal to feel angry at times. Try to find healthy ways to express it – go for a run, scream in the shower or hit a pillow.
- It may help to create a memorial (at home or online) to honour your loved one.
- Take your time rather than rushing into making any big decisions or major changes.
- Consider joining a support or grief group (face to face or online) to connect with other people who have had a similar experience.

## Resources and websites

**PalAssist** • 1800 772 273 • [palassist.org.au](http://palassist.org.au)

### PALLIATIVE CARE ORGANISATIONS AND DIRECTORIES

**Palliative Care Australia** • 02 6232 0700 • [palliativecare.org.au](http://palliativecare.org.au)

**Palliative Care Queensland** • 1800 660 055 • [palliativecareqld.org.au](http://palliativecareqld.org.au)

**National Palliative Care Service Directory** • [palliativecare.org.au/directory-of-services](http://palliativecare.org.au/directory-of-services)

**CareSearch** • [caresearch.com.au](http://caresearch.com.au)

### FOR CARERS

**Carers Queensland** • 1800 242 636 • [carersqld.com.au](http://carersqld.com.au)

**Carers Australia** • 1800 242 636 • [carersaustralia.com.au](http://carersaustralia.com.au)

**Carer Gateway** • 1800 422 737 • [carergateway.gov.au](http://carergateway.gov.au)

**Centrelink – Carer payments & allowances** • 132 717 • [humanservices.gov.au](http://humanservices.gov.au)

**Australian Centre for Grief and Bereavement** • 1800 642 066 • [grief.org.au](http://grief.org.au)

### OTHER

**Queensland Community Support Scheme** • 1800 600 300 • [qld.gov.au/qcss](http://qld.gov.au/qcss)

**Advance Care Planning Australia** • [advancecareplanning.org.au](http://advancecareplanning.org.au)

**My Aged Care** • 1800 200 422 • [myagedcare.gov.au](http://myagedcare.gov.au)

**Cancer Council Queensland** • 13 11 20 • [cancerqld.org.au](http://cancerqld.org.au)

**Lifeline** • 13 11 14 • [lifeline.org.au](http://lifeline.org.au)

**Medical Aids Subsidy Scheme (MASS)** • 1300 443 570 • [health.qld.gov.au/mass](http://health.qld.gov.au/mass)

## GLOSSARY

### Advance care planning

When an individual thinks about their future health care and discusses their wishes with their family, friends and health care team. The written record of these wishes may be called an advance care plan or advance health directive.

### Allied health professional

A tertiary-trained professional who works with others in a health care team to support a person's medical care. Examples include psychologists, social workers, occupational therapists, physiotherapists and dietitians.

### Bereavement

The period of grief following the death of a loved one.

### Carer/caregiver

A person who provides unpaid personal care, help and support to someone who needs help because of a disability or illness.

### Community nurse

A nurse who provides primary health care to people in their homes and communities and may coordinate their palliative care. Community nurses usually work for local health services.

### Complementary therapies

Supportive treatments that are used in conjunction with conventional or palliative treatment. They can improve general health, wellbeing and quality of life, and help people cope with the effects of illness and treatment.

### Depression

A persistent sadness or very low mood that lasts for long periods of time and includes a lack of interest or pleasure in previously rewarding or enjoyable activities. It can cause physical and emotional changes.

### End-of-life care

Health care provided in the final days and hours of life.

### Grief

A reaction to any loss or major change that is painful. Intense sorrow caused by a major loss in a person's life.

### Holistic care

Care that incorporates different types of therapies and services to ensure that physical, emotional, spiritual and practical needs are met.

### Hospice

A health care facility that provides care for sick or terminally ill patients in a home-like environment.

### Life-limiting condition

When an illness is unlikely to be cured and will cause death at some stage in the future. A person with a life-limiting illness may live for weeks, months or years.

### Palliative care

The holistic care of people who have a life-limiting illness, their families and carers. It aims to improve quality of life by addressing physical, emotional, spiritual and practical needs. It is not just for people who are about to die, although it does include end-of-life care.

### Palliative care nurse

A nurse who has specialised in the field of palliative care nursing. They provide support to the patient, family and carers, and may coordinate the palliative care team.

### Palliative care specialist (physician)

A doctor who has specialised in palliative medicine. The palliative care specialist prescribes medical treatment for pain and other symptoms, and also supports and advises other members of the palliative care team, the patient, family and carers.

### Palliative care unit

A place that provides comprehensive care for people with a life-limiting illness. This may include inpatient medical care, respite care and end-of-life care for people who are unable to be cared for at home. Also known as a hospice.

### Palliative treatment

Medical treatment for people with a life-limiting illness to manage pain and other physical and emotional symptoms.

### Primary health care provider

A health professional, such as a GP or community nurse, who provides the first point of contact for a person with the health care system and helps them with a range of health-related matters.

### Prognosis

The likely outcome of a person's disease.

### Quality of life

A person's comfort and satisfaction, based on how well their physical, emotional, spiritual, sexual, social and financial needs are met within the limits of their illness.

### Respite care

Care given to a sick person to give their regular carer a break. Respite care can be given in the home or in a respite care centre, hospital or palliative care unit.

### Specialist palliative care team

A multidisciplinary team of health professionals who offer a range of services to meet a person's needs and improve their quality of life. A palliative care nurse usually coordinates the team.

### Substitute decision-maker

A person who makes decisions on your behalf if you become incapable of making them yourself. Documents used to make someone a substitute decision-maker may be called enduring power of attorney, enduring power of guardianship, or appointment of enduring guardian.

### Terminal illness

An illness that is unlikely to be cured and will eventually result in a person's death. It may also be called a life-limiting illness.

### Can't find a word here?

For more words related to palliative care, visit:

**End of Life Essentials** [www.endoflifeessentials.com.au/tabid/5311/Default.aspx](http://www.endoflifeessentials.com.au/tabid/5311/Default.aspx)

**Caresearch** [www.caresearch.com.au/caresearch/tabid/1801/Default.aspx](http://www.caresearch.com.au/caresearch/tabid/1801/Default.aspx)

**Palliaged** [www.palliaged.com.au/tabid/4341/Default.aspx](http://www.palliaged.com.au/tabid/4341/Default.aspx)

PalAssist is a Queensland-wide, accessible online and telephone service for palliative care patients, carers, family and friends seeking practical information and emotional support. The service is available between the hours of 7am to 7pm, 7 days a week.

Our charter is to provide accurate information, referral advice and compassionate support to those dealing with a life-limiting or terminal illness.

PalAssist is operated by a team of nursing and allied health professionals. We understand that every person's journey is different and offer individualised support and advice to our clients.

The service is funded by Queensland Health and provided by Cancer Council Queensland. We are here to offer trusted advice, or simply to listen.



**1800 772 273**  
**palassist.org.au**



**Queensland  
Government**



**Cancer  
Council**  
Queensland

Funded by Queensland Government. Provided by Cancer Council Queensland.