



# A guide to palliative care in Queensland

For people with a life-limiting condition,  
their families, carers and friends

**24/7 advice for patients and carers**  
**Palliative Support 1800 772 273**



**Queensland**  
Government



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

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

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**If you need more information or advice call PalAssist: 1800 772 273. PalAssist is a Queensland-wide, no-cost, 24-hour palliative care information and support service. Details of other organisations that provide help, as well as useful websites and resources, are included throughout this booklet and listed on page 68.**

# Introduction

This booklet is for anyone who wants to know more about palliative care and how it can improve quality of life, and help you prepare for death.

Finding out that you have a life-limiting condition and making decisions about palliative care can be confronting. This booklet aims to provide information to support and guide you in making decisions about your care. This booklet may also be helpful for your partner, carers, family members or friends.

You don't need to read it from cover to cover. Choose the sections that are most relevant to you right now and skip the ones that don't feel relevant now, or that you're not ready to read yet.

This booklet has been developed by PalAssist with support from Queensland Health, and with input from palliative care health professionals, patients and carers.

We hope it's helpful for you.

Please note: the advice in this booklet is based on palliative care best practice principles. Individual access to palliative care services may vary depending on funding and resources available in your particular area, your illness or condition, the stage of your illness or condition, and other factors.

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# 1. Coping with the news

Finding out that you or your loved one has a life-limiting condition or needs palliative care is tough. Most people do not have experience in dealing with this life stage or talking about death.

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

Many people struggle to accept the news and put off seeking help. Some people think that starting 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 isn't just about dying. Palliative care aims to assist you to have a good quality of life for as long as possible, through managing pain and symptoms.

Take some time on your own or with your partner, a relative or close friend to talk about the news and get the information you need to understand your options. You may find it easier to talk to someone outside your family. You can talk to your doctor or nurse or call **PalAssist on 1800 772 273** to talk things through or find out about services in your area.

“When I was told my husband needed palliative care I thought, what is palliative care? We were given some advice but not in our wildest dreams did we consider what this really meant.”  **Sandy**

## What next?

Read the next chapter, so you understand what palliative care is (and what it isn't) and when and how to access it.

Although the future may be uncertain, it is helpful to plan ahead and make the most of the days when you feel well. There may be important things you want to do and plan such as:

- Choosing where you want to be cared for (see Chapter 3).
- Making plans for your family's and your future, including health, financial and legal concerns (see Chapter 5).
- Creating memories, setting personal goals and priorities, and dealing with unfinished business (see Chapter 6).

### A note about terms

When we use **'you'** we mean a person who is receiving, or is thinking about starting, palliative care.

Some information is highlighted as being **'for carers'**. A carer is anyone who provides unpaid personal care, help and support to someone who needs palliative care. This information is usually helpful for family members and friends too. In this booklet, we have used the

term **'your relative'** to refer to the person you are caring for. We acknowledge that there are many carers who care for someone they are not related to.

**'Palliative care team'** means the people involved in your palliative care, whether that's your GP and community nurses or health workers in your own home, or a team of health professionals at a hospital or hospice.

## Rene

I was diagnosed with throat cancer as a 61-year-old non-smoker. I underwent chemo/radiation treatment, followed by a neck dissection the following year.

After a five-year remission, cancer was discovered last year in my left lung with some further spread to my stomach area. The five-week radiation treatment to my lung proved successful. Initially I was offered chemo but declined. It also meant I could go back to my daily swims, which has been my own therapy program and gave me enjoyment of life.

Later I chanced upon a clinical trial and was accepted into this program. Results have been encouraging, with the main tumours shrinking considerably, giving me an extension of life. I celebrated my 69th birthday and am looking forward to my

70th! Time will tell how my good fortune will hold up. I do my best to not disappoint my swimming mates and just enjoy every day in the pool.

I have had a good life and have no regrets. With a supportive loving wife and son and caring friends throughout the world, I have accepted the situation. It has not diminished my sense of humour or my positive outlook on life. I have talked about death with my family. My affairs are in order which gives me peace of mind, knowing that my family is well looked after when I am gone.

I know palliative care will help me and my family when the final call comes, but in the meantime I just keep on swimming daily and enjoying life to the fullest however long I have got.



## 2. About palliative care

Palliative care is specialised care that helps people with a life-limiting condition to be as comfortable as possible for as long as possible. Palliative care does not seek to prolong life, or hasten death, but it does encourage people to plan for death. The aim is for you to have the best possible quality of life for as long as possible and, when the time comes, to die with dignity.

Where and when you have palliative care, and who provides it, depend on your condition, your preferences, what services are available, and your home situation and carer or family support.



## Key points

- Palliative care is about **quality of life** – allowing you to live as fully as possible for as long as possible.
- The palliative approach to care is **not just for people who are close to dying**. It can help people with a wide range of conditions, and at any stage of an illness.
- Palliative care is **for people of any age** (including children and young people), race, culture, background or religion.
- Palliative care assists people to **plan for death**, including taking care of emotional, financial and legal issues.
- Palliative care also provides **support to help your family and carers** manage during your illness, and after you die.
- **Seek palliative care** as soon as you think you may need it. People often say they wish they had known about and used palliative care services earlier.

“Many people, both patients and carers, are worried that a referral to palliative care will mean a loss of control, when in fact the opposite is true. The purpose of accessing palliative care is to ensure that both patient and carer needs are adequately met, in consultation with them.”

Chris, PalAssist Advisor

## What is palliative care?

Palliative care services can assist at any stage of a life-limiting condition, from the time of diagnosis through to the last days of life. Focusing on a palliative approach to care early in your illness can help you to live as fully as possible for as long as you can.

Palliative care also supports your family and carers. This can include advice about caring for you, help getting equipment or practical support, and emotional support or counselling. Depending on your needs, palliative care may include:

- **Treatment** to relieve pain and other physical symptoms like nausea, breathlessness and trouble sleeping.
- **Information and advice** to help you make decisions about treatment and care options.
- **Help with emotional and social needs**, like dealing with fear and other feelings, and communicating with your family and friends.
- **Help to access practical support**, like financial assistance, equipment and visits from care providers so you can live comfortably at home for as long as possible, if that is your choice.
- **Guidance to meet spiritual needs or concerns.**
- **A support system** to help you live as actively as possible and to assist your family and carers to manage during your illness and after you die.

You may receive palliative care from a GP and specialists as an outpatient, in your home, a residential aged care facility (nursing home), palliative care unit, hospice, or in hospital, or some combination of these. See Chapter 3 for more information.

### Palliative care is for...

- Managing physical symptoms.
- Giving the best possible quality of life.
- Meeting your 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.
- Ending your life sooner or an attempt to prolong life artificially.
- Only for people with cancer, or who are near the end of life.



## Who is palliative care for?

Palliative care may be considered 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, race, culture, background or religion.

Palliative care can help people with a wide range of conditions including:

- Cancer
- Organ failure (heart, liver, kidney)
- Lung or chronic airway disease
- Renal disease
- Dementia
- Motor neurone disease
- Multiple sclerosis (MS)
- Huntington's disease
- Muscular dystrophy
- HIV/AIDS
- End-stage dementia
- Dying of old age
- Other degenerative or deteriorating conditions relating to ageing.

## Your life, your care

Palliative care services can be helpful at any stage of your illness and the principles are the same regardless of your illness. However, you may have some individual needs due to the particular symptoms or problems associated with your condition.

For example, it is important for people with dementia to make advance care plans early (see Chapter 5). If an illness has a high chance of affecting speech (like motor neurone disease), end-of-life care should be discussed early while the person can communicate their wishes on their own behalf.

In many cases, your GP or specialist will continue to manage your care, in consultation with a specialist palliative care team. If your illness is advanced, or life expectancy can be measured in weeks to months, or less, the palliative care service may be more directly involved.

### **Pain and symptom management**

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

- Pain
- Nausea (feeling sick)
- Lack of appetite
- Trouble swallowing
- Trouble breathing or breathlessness
- Constant tiredness (fatigue).

Pain and symptom management is one of the key goals of palliative care. Your doctor and palliative care team will work together to assess and help you to manage any physical symptoms, as well as emotional and spiritual issues, so that you can be comfortable and maintain quality of life for as long as possible.



# Palliative care for children and young people

## Children

When your child has a life-limiting illness there is often uncertainty about how it will progress. Life-limiting conditions with a long life expectancy (several to many years) may be managed as chronic illness. In other cases, children may have palliative care while receiving treatment aimed at curing their illness. This can improve their comfort, and reassure you that everything is being done to maintain their quality of life.

Children's palliative care teams have specialised skills in paediatrics (medical treatment of children) as well as palliative care. They understand how your child's stage of development affects their needs for physical, practical, emotional and spiritual support.

Children's palliative care teams understand that each family has different preferences and will work with your family to help you make informed decisions.

### Paediatric palliative care in Queensland

Queensland's Paediatric Palliative Care Service is based in Brisbane at the Lady Cilento Children's Hospital and works within a network of health care providers across the state. The team at the Lady

Cilento will work in partnership with you and your child's GP or paediatrician.

Call 1800 249 648 or visit [childrens.health.qld.gov.au](http://childrens.health.qld.gov.au) for more information.



## Teenagers

It can be very difficult for a young person in your family 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.

They need the chance to talk about death and make plans, but they also may 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 them plan and achieve their personal goals.

### More information

Palliative Care Australia's booklet *Journeys* provides information to help you prepare for situations you may face during your child's illness.

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 you have a life-limiting condition (or incurable or progressive disease), talk to your doctor about palliative care at the earliest opportunity. People often say they wish they had known about and used palliative care services earlier. You might use palliative care for a few weeks, over several years, or until your condition stabilises.

Finding out about palliative care services and support now, will reduce stress on you and your family later. It will give you information and time to better understand and manage any physical symptoms (such as pain or nausea), make plans and get help meeting your practical, emotional and spiritual needs.

## How do I get palliative care?

In most cases, your general practitioner (GP) or a community nurse will continue to manage your care using home support services as needed. Your GP may also refer you to a specialist palliative care service. You may also be referred to a specialist palliative care team while being treated for your condition in hospital.

You or your family can also contact your local hospital, health service or community palliative care service directly to see what services are available. You will likely need a referral to access these services, and if you are in the early stage of an illness, there may be costs involved.

To find a service in your local area call PalAssist or visit [palliativecare.org.au/directory-of-services/](http://palliativecare.org.au/directory-of-services/).

## Who gives palliative care?

Palliative care may be provided by a range of different health and related care specialists, depending on your needs, and the needs and resources of your family or carers.

In many cases palliative care is provided by your doctor (GP or specialist) and community nurses. They get advice and support from palliative care specialists to ensure you get the care and support you need.

Your palliative care team may include:

- Your GP
- Specialist palliative care doctors and nurses
- Specialist doctors for your illness, for example: oncologist, cardiologist, neurologist, respiratory physician
- Nurses
- Social workers
- Personal care assistants
- Physiotherapists
- Occupational and speech therapists
- Pharmacists
- Counsellors
- Spiritual carers or pastoral care workers
- Trained volunteers.

### 3. Where to access palliative care

You may have palliative care at home, in a residential aged care facility, or in a hospital, palliative care unit or hospice. Where you receive care depends on your needs, the stage and progression of your illness, your preferences, services available in your area, and whether you have family or friends who can help.

Your doctor or palliative care team will assess your needs and recommend the place they think is best for your care. Make sure you tell your doctor about any specific choices, needs and concerns that you may have. This can change over time as your condition or support needs change.



## Key points

- Many people with a life-limiting illness **prefer to be at home**, but it depends on your condition and circumstances.
- If you have more **complex palliative care needs**, and specialised care is available, you may have to be cared for in a palliative care unit or hospice.
- Your **needs and preferences may change** over time. You can move in and out of different settings. You might need a short stay in hospital to get symptoms like pain under control, and then return home if possible.
- Wherever you are cared for, the **intent of palliative care** is to help you get the care you need and to ensure that your symptoms are well controlled.
- If you **need more information** about the options in your area and things to consider when choosing where to have palliative care, talk to your GP or palliative care team or call PalAssist.

“My mum was very clear that she wanted to be cared for in a palliative care unit even though our family were wanting her to die at home. She said she would be feel safer there. As it was her choice, we totally supported her decision and involved ourselves in her care in that setting.”  Sharon

## At home

For many people, palliative care is provided in their home by a community palliative care service. “Home” could be the house you’ve lived in for most of your life, a residential aged care facility (nursing home) or a special place that has personal, cultural or spiritual meaning.

Advantages of staying at home might include being in familiar surroundings, feeling more in control, and being with family or friends.

Your doctor or palliative care team will respect your wishes if possible, but receiving palliative care at home depends on many factors including:

- The level of care required for your illness or condition.
- Your home environment.
- How much support you have from family or carers or in your community.
- Whether there is someone at home to care for you.

If you are able to be at home, your GP or palliative care team will organise the services and support you and your carers might need, like special equipment or home nursing (see Chapter 9).

## Caring for someone in the home

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

However many people who have done it say it can be rewarding and a time of great closeness. The key is getting the advice, help and support you need (see Chapter 9).

Over time, the needs of the person you are caring for may

change or you may feel that you don't have the skills or emotional strength to continue looking after them. It's okay to ask the GP or palliative care team for more help or options for your relative to be cared for in a hospice or hospital.

This doesn't mean you've failed or are giving up; it's about ensuring their care needs are met, and that your needs are also met. It also means you can focus on spending quality time with your relative.

“All my husband wanted to do was come home, so provision was made with installing more rails on the staircase and his room fitted out to accommodate what he would need. We got a chair for the toilet and a seat for the shower and a walker.” **Sandy**

## In a nursing home

Public and private aged care facilities (nursing homes) may offer short-stay or long-stay care for people needing palliative care. Many nursing homes are as well-equipped to manage palliative care as hospital palliative care units. In some areas, specialist palliative care services may visit the nursing home if more complex care needs have been identified.

Talk to your GP, community nurse or palliative care team about arranging this if you think it might be the right setting for you as there are sometimes long waiting periods.

## In a palliative care unit or hospice

A palliative care unit provides comprehensive care for people with a life-limiting condition, and is usually attached to a hospital.

A hospice is more often a standalone facility that is less like a hospital and more like an ordinary house.

Palliative care units and hospices have staff who are experts in controlling symptoms, like pain, and providing emotional support.

You may go to a palliative care unit or hospice for:

- A short stay to get your symptoms under control.
- Emergency (or respite) care for a day or a few days if a carer is unwell.
- End-of-life care if you can't be cared for at home or don't want to die at home.

Hospices are very different from hospitals. They are quieter, visiting is usually not as restricted, and they are very focused on holistic care for patients and families which may include counselling, spiritual care, complementary therapies and bereavement support. Hospice care may not be available in all areas.

## In hospital

If you have spent time in and out of hospital during your illness, you may want to go back to hospital when you need full-time nursing care. Whether this is possible will depend on the hospital.

Some hospitals have palliative care teams that include specialist nurses and doctors, and in most you will have access to allied health professionals including social workers and counsellors to support you and your family.

It may not be the most peaceful place to be if the ward is busy, and it may be difficult to have the personal or holistic care you'd like because of hospital routines.

Hospitals are designed for short-term stays. If you cannot return home and require care for several months or more, the palliative care team will talk to you and your carers about options for your ongoing care. Depending on your condition and support needs, this might include a residential aged care facility (nursing home).

## 4. Costs and financial assistance

The financial burden of a serious illness – including treatment costs and loss of income – can be stressful for you and your family.

While most palliative care services are free, there may be costs for things like medicines or equipment. This section provides some information about financial assistance and support that may be available to you or your carer.



## Key points

- The majority of core palliative care services are **provided free of charge**.
- A **fee may be charged** for medicines, specialised medical equipment, and other services such as in-home nursing.
- **Private specialists,** hospitals and other health care services also charge fees.
- You may be able to access **financial assistance** through Centrelink, charities, local councils or church groups.
- The **Medical Aids Subsidy Scheme (MASS)** provides funding for medical aids and equipment to eligible Queenslanders.
- **A financial advisor or accountant** can help you sort out your financial and tax matters to reduce stress on you and your family.
- You may be able to get your **superannuation early** or an **insurance payout** to help with costs.

““ *At a time when people are struggling with medical and emotional issues, the attendant financial concerns can seem almost overwhelming.*”” **Chris, PalAssist Advisor**

## How much does palliative care cost?

Most palliative care services are free. Core services are funded by the federal and state governments so that they are free, whether you receive care at home or in a public hospital or hospice.

However there may be some costs for equipment, medicines or special services such as:

- Hiring or buying specialised equipment to use at home.
- Paying for medications at home.
- Paying for your own nursing staff if you choose to stay at home and need 24-hour assistance.
- Using respite services that charge a fee.
- Paying the fees for home help services such as cleaning or meal delivery.
- Paying the fee of a private health professional, such as a psychologist, that isn't fully covered by Medicare.
- Paying for complementary therapies, such as massage therapy and acupuncture.

Private therapists, private hospitals and some hospices charge fees. If you have private health insurance, check if you are covered for palliative care and any excess payable. Your private health insurance may include cover for home nursing, meaning you could be treated by a nursing service as a private patient.

If you are unsure, ask your doctor or treatment team about likely costs.

## Financial assistance

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

### Government allowances

The Australian Government offers special payments and provisions for people with a long-term illness and their primary carers. These include: sickness allowances, the disability support pension, carer payments and allowances, and carer supplements.

For more information, call Centrelink on **13 27 17** or contact your local **Centrelink** office to discuss your situation.

### Other financial support

The Medical Aids Subsidy Scheme (MASS) provides funding for medical aids and equipment to eligible Queensland residents so that they can live at home. You may be eligible if you hold a pensioner concession, health care or Queensland Government Seniors card. To find out more, contact **MASS 1300 443 570** or talk to your doctor.

Many charity organisations, local councils and church groups may offer financial or practical assistance to you and your carer. Some banks and utility companies (that provide electricity, gas, water, phone) have hardship or compassion programs offering concessions or extended time to pay.

For more information about accessing financial support ask your social worker or call PalAssist.

## Financial advice and planning

It might be helpful to get some expert advice about your financial situation, especially if it's causing you stress. Sorting out your finances and tax can give you peace of mind, while also reducing the stress and financial burden on your partner or children.

Talking to a trusted family member, professional financial advisor or your accountant about your finances can help you:

- Consider the impact of you/your carer stopping work.
- Check your insurances (health, life, income protection) and update your beneficiaries if you need to.
- Sort out your assets and bank accounts.
- Make a financial plan for the future, particularly if you have a partner or dependent children.
- Advise if you can claim a tax deduction for expenses such as medical treatments, hospital fees and home nursing.
- Organise all your financial information and documents so they are safe and available to the person managing your estate.

For information about financial counselling, call Financial Counselling Australia on **1800 007 007** or visit **[financialcounsellingaustralia.org.au](http://financialcounsellingaustralia.org.au)**. Call Money Smart on **1300 300 630** or visit **[moneysmart.gov.au](http://moneysmart.gov.au)** for free and impartial financial guidance. Speak to your social worker or call PalAssist if you would like further information on how to access financial advice.

# Superannuation and insurance

## Early release of superannuation

In some circumstances, people with a life-limiting illness or who have a dependent with a life-limiting illness can get an early release of their superannuation savings (retirement fund). This may be to pay for medical treatment, palliative care, or expenses related to a dependant's death, funeral or burial.

To find out more, contact your superannuation fund, call the Department of Human Services on **1300 131 060** or visit **humanservices.gov.au** and search for 'superannuation'.

## Insurance

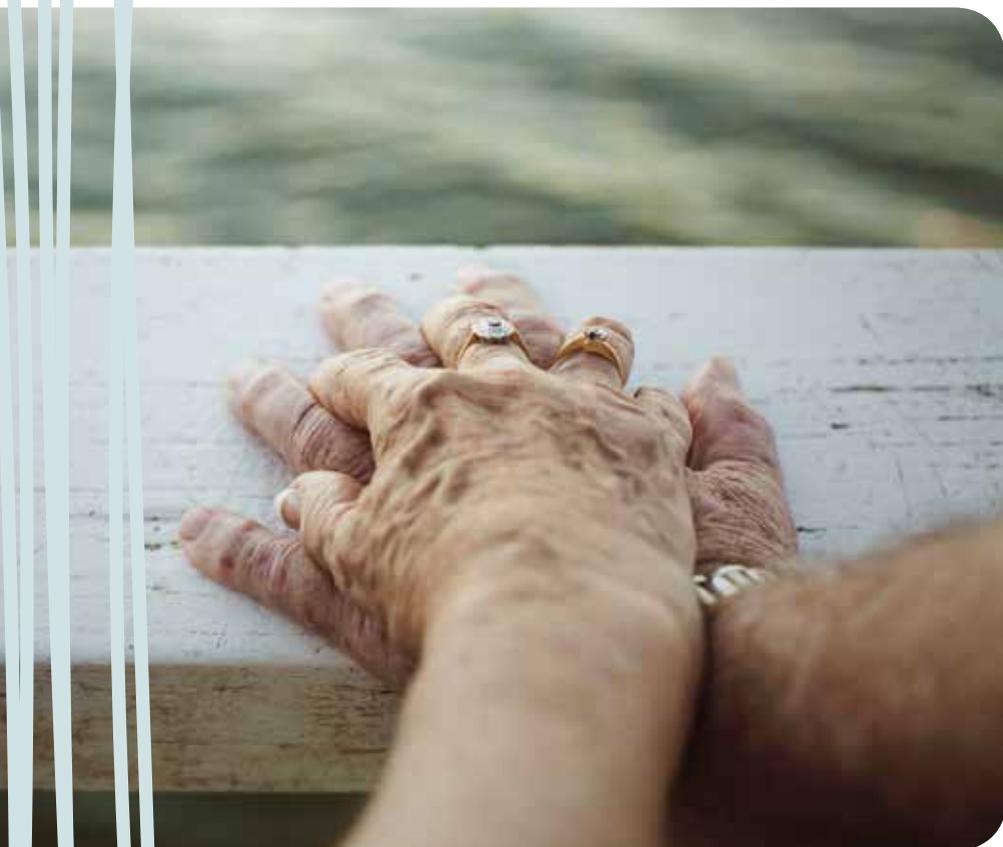
Financial help may also come from any insurance policies you have, like income protection, total and permanent disability or life insurance.

Life insurance, also known as death cover, will pay a lump sum to your beneficiaries after your death. This could be used to pay off your mortgage or other debts or provide an income for your dependents. Check if you have life insurance cover with your superannuation fund.

If you are unsure what you can claim contact your insurer, super fund or a financial advisor.

## 5. Sorting things out - making plans

Thinking about and planning for dying can be stressful and even upsetting. It can be tempting to put things off or to avoid difficult conversations. But making plans now can provide comfort for you and those around you. If you can find a way to express your wishes for end of life, you may feel more in control. It can also give others the chance to discuss their concerns.



## Key points

- **Planning and recording your preferences** for your future care and what happens after your death means you can feel confident your wishes will be considered. It also means your family or carer will know what you would have wanted.
- **Advance care planning** means thinking about what kind of treatment and care you want in the future.
- An **Advance Health Directive** is a legal document that details your wishes for the medical treatment you do or don't want to have.
- You can appoint someone you trust to make important decisions for you (a **"substitute decision-maker" or Enduring Power of Attorney**) in the future if you are unable to do so.
- It's important to have a **valid will** to ensure that your property and possessions go to the family members, friends and/or charities of your choice.
- Take the time to think about the **kind of funeral** you would like, and write down some ideas or preferences.
- If you have not already registered, now is the time to decide about **organ donation** and tell your family your decision.

## It's your life

Even though it may be complex and emotionally difficult, it's important to think about your preferences for your future care, end of life, and after your death.

Things to think about include:

- Where you would like to die (home, hospice, hospital).
- Who you want with you when you die.
- What medical treatment you want, and what you don't want, at the end of life.
- Who you trust to make decisions about your care if *you* can't.

You may wish to discuss your choices with your family or carer, GP and palliative care team. You can also write down your preferences in legal documents including a will and an Advance Health Directive or Statement of Choices form (see page 35) to ensure your wishes are respected.

Making plans for the end of life doesn't mean you've given up. It means you can feel confident that your preferences will be considered and that your family or carer won't have to make difficult decisions without knowing what you would have wanted.

If you find it difficult to talk about death or dying, or if your cultural practice is for your family to make these decisions, let your palliative care team know.

## Advance care planning

Advance care planning means thinking about what's important to you to decide what care you want in the future. It may involve:

- Discussing your wishes with the people closest to you.
- Documenting your preferences for future care and treatment in an Advance Health Directive or Statement of Choices.
- Appointing a 'substitute decision maker' – someone you trust who will make decisions for you if at some point in the future you are not able to. In Queensland this is done by completing an Enduring Power of Attorney. To do this, simply download and print the form from the web page listed below.

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

## Stopping active care

In Queensland, as long as you have the capacity to make decisions you have the right to refuse medical treatment, even if this may cause your death or make it happen sooner. This is an automatic right of every person and is recognised by the law. A social worker can provide support to ensure you make an informed decision, and advocate on your behalf.

If you make an Advance Health Directive you can include specific instructions about medical treatments, such as whether or not you want to receive treatments aimed at keeping you alive – such as tube feeding or resuscitation.

## Making a will

A will is a legal document that records what you would like to happen with your money, belongings and other assets (your estate) when you die. It names who you want your possessions given to (your beneficiaries) and who you would like to administer your estate when you die (your executor). If you have dependent children, it should also contain details of who will take legal guardianship of them if both parents die.

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

If you wrote a will before your illness, you should review it in case your wishes have changed.

## Planning a funeral

Though it can be confronting to think about, you may want to consider the kind of funeral you would like, and talk to family or friends about it.

If you find it too hard to talk about funeral plans with the people closest to you, your palliative care team can help.

If you do want to plan your funeral, you can talk to a funeral director about a pre-arranged funeral (planning what kind of funeral you want), or a pre-paid funeral (where you organise and pay for it in advance).

If you don't want to plan in detail, it still might be helpful to tell your family or write down your wishes about things like:

- Whether you would rather be buried or cremated.
- Where you would like to be buried or have your ashes placed.
- Whether you want a religious service or not.
- If you'd like a funeral, whether you'd like particular songs or flowers or donations given to a charity, who you would like invited, and what clothes you want to wear.

## Organ and tissue donation

If you have not already registered your decision about organ and tissue donation, now is the time to consider it.

Having a medical condition doesn't mean you can't donate organ or tissue, but it may affect what you can donate. Donation may also be difficult in some rural and regional areas.

Once you have made your decision, share it with your family and close friends. They will be asked to confirm your

wish to donate before donation for transplantation can proceed.

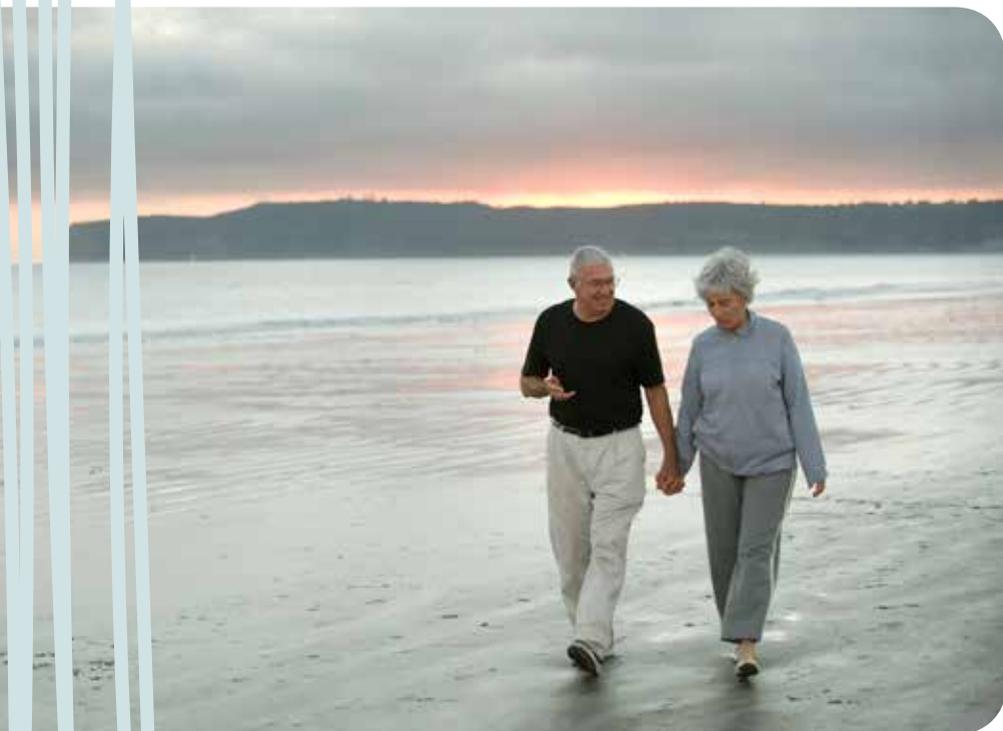
If you are a potential donor, the quality of care at the end of your life, and the wishes of your family, will remain key considerations and will never be compromised by the potential for organ and tissue donation.

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

## 6. Life matters

Setting personal goals, spending time with people who are important to you, and focusing on what is meaningful to you can help you enjoy the life you have left. You can plan to use the time you have to make memories, communicate meaningfully with your family and friends, and to think about your spiritual needs.

We have made some suggestions on the following pages, based on activities that others have found fulfilling. You may wish to use this as a guide, or a starting point to develop your own list.



## Key points

- **Sharing memories** and creating legacy items are a great way to leave a message for your loved ones.
- **Making the most of the time you have** means doing what is important and meaningful to you. Your palliative care team can provide support and recommendations.
- It's normal to be feeling a **wide range of emotions**. Find ways to express them and know the signs that you might need some professional help.
- **Talking openly** with your family and friends about your plans, feelings and fears can be helpful and rewarding. You might prefer to talk to people outside your family like your doctor, a social worker, psychologist or a telephone support service like PalAssist.
- If talking is hard, **creative activities** like music or art can help you express feelings.
- Often at the end of life **people feel more religious or spiritual** and might be thinking about big questions like the meaning of life. You can talk with a religious leader, or with pastoral care workers who can discuss your questions, feelings and fears from religious or non-religious viewpoints.
- Make sure your family and palliative care team are **aware of any special religious or cultural rituals**, food requirements or end-of-life practices you want performed.

## Making memories

One way to emotionally prepare for death is creating memories and making special items for your loved ones. The most important thing is to do whatever feels meaningful and right for you.

### You could:

- Write letters or cards to people who are special to you or who you have not seen for a long time.
- Buy gifts for your children and grandchildren.
- Make a hand or footprint cast.
- Record a CD, video or DVD to be given to loved ones after you die.
- Write down your family history for the next generation.
- Make a photo album or scrapbook for your children or grandchildren.
- Compile a collection of your favourite recipes.
- Write a song or a poem, paint a picture, or make a collage.
- Write your own obituary.
- Create a memory box with messages or letters, photos, special jewellery or mementoes or a present to mark a special birthday.

Some care services or organisations have trained volunteers to help you with these activities. Ask your social worker, psychologist or other member of your palliative care team if you need help or ideas.



## Making the most of life

This means doing what is important and meaningful to you.

This may be:

- Spending time with people you love.
- Relaxing in nature.
- ‘Bucket list’ activities and achievements.
- Simple pleasures like sitting in the sunshine.
- Celebrating a special event.
- Recording your memories.
- Seeing an old friend.
- Visiting a special place.
- Enjoying an art or craft activity.
- Working.

As well as enjoyable things, you may want to deal with difficult relationships or emotional ‘loose ends’.

Your palliative care team can provide support and recommendations. A social worker, counsellor or spiritual advisor can help you plan what’s most important to you and work out your personal goals. Health professionals such as physiotherapists, occupational, speech, music and art therapists can help you to achieve them.

## Communication and expression

It's normal to have a range of feelings when you are receiving palliative care. Many people feel shocked, afraid, sad or angry. Some days you may feel hopeful; other days you may be frustrated or anxious.

There's no right or wrong way to feel. It's normal to feel some sadness. However, if you are feeling sad all the time, losing interest in things you used to enjoy, or not wanting to get up in the morning, talk to your doctor. Counselling or medication may help.

### Talking to family and friends

Talking to your family and friends about what you're going through can be difficult. It can be hard to admit your fears, and you may have to deal with their worries and emotions too.

Talking to children or grandchildren about your illness and, when the time comes, your death, is even tougher. Try to be open with them. Even young children can be aware of what's happening. Ask a social worker for advice on talking to children of different ages about death.

If you've had difficult relationships with someone in the past, or if there are tensions in the family, it's likely that communication may be even harder. If you need support, your palliative care team can suggest ways to talk with your family and friends and to deal with any conflict or unresolved issues.

## Talking to people outside your family

You might prefer to talk to people outside your family about what you're feeling. This could be:

- Your doctor or nurse.
- A counsellor, social worker or psychologist.
- Your religious leader or spiritual advisor.
- A telephone support service like PalAssist.

It's important to talk openly with your doctor or someone in your palliative care team you feel comfortable with. Tell them not just about your medical needs and concerns, but also how you are feeling and any fears about what might happen in the future.

Your palliative care team or PalAssist can advise you how to find a counsellor or psychologist who has experience helping people with life-limiting illness, their carers and families.

## Other ways to express yourself

If talking about feelings and fears is difficult, creative activities like music and art can help you express your feelings and feel better in yourself.

Music and art therapy are proven ways to help relieve anxiety, depression and insomnia. You can use them to create gifts or legacy items – like a song or painting – for your loved ones.

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

## Spiritual concerns

Most of us avoid thinking too much about the end of life. But when you have a life-limiting illness, you may start to think seriously about death and dying.

You may become more aware of religious beliefs or question spiritual issues like the meaning of life, your identity and values, or suffering and hope.

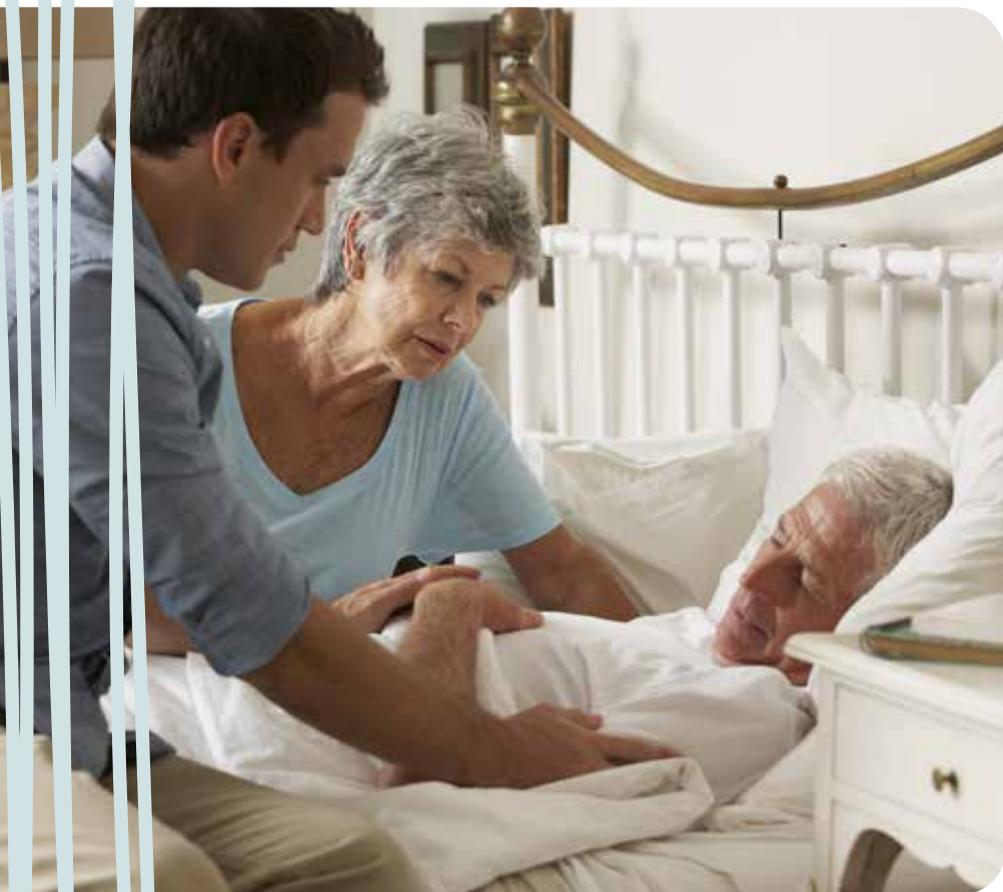
Some people find meaning in their faith or religion; others question it, especially when they are suffering. Some people express their spirituality through close personal relationships, meditation, nature, music, art or community.

Your palliative care team may include a pastoral care worker who is trained to help you find and focus on whatever is meaningful to you and talk with you about your thoughts, feelings and fears from all religious and non-religious viewpoints. Your team can also arrange for you to talk with a religious leader such as a priest, rabbi, reverend or imam.

Your team will respect your 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 you may experience different emotional and physical changes and symptoms. Many people say they don't fear death as much as they fear the unknown. While this fear may never completely go away, knowing about likely changes can assist you and your carer and family to prepare for and manage end of life.



## Key points

- Death is an **inevitable part of being human**.
- **Each person's experience** leading up to their death is different, but in most cases there are common changes that indicate a person is dying.
- Knowing the **physical changes** that may happen can take some of the fear and anxiety away.
- Palliative care can **relieve pain** and other symptoms.
- With good palliative care, **death is usually peaceful** and your carer and family will be supported.
- If you are caring for someone at home, it's normal to **need more support** and help from the palliative care team at this time.
- The palliative care team will tell you **what to expect**, and practical things you can do to keep your relative comfortable. Know who you can contact at any time of the day or night.

“ I would have liked it if I could have been more informed of what actually was happening. I know no one can tell you exactly when a person is going to die, but to be informed of the stages that the patient will go through would have been a help. ” **Sandy**

## How will I know?

Most people have little or no experience of being with someone at the end of life. It can be helpful to talk to the palliative care team about what to expect. No one can tell you 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 very peaceful. Usually you'll gradually become weaker, have little energy and spend more time sleeping.

It's 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's 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 possibly moist hands, feet and skin).
- Have changes in breathing patterns, with breathing 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 your 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 you to die in comfort and with dignity.

## Feelings

It's natural to feel lots of different emotions at the end of life including worry, anxiety, anger, resentment, uncertainty, sadness and fear.

It may seem easier to avoid talking about dying and your fears and concerns. But it can be a relief – for you and your loved ones – when someone starts the conversation. Your family members and friends are probably unsure what to say. Being open with them about how you are feeling and your worries might help them to talk about their feelings and concerns too.

Some people prefer to talk to a health professional or counsellor. If you would like to talk to a counsellor or psychologist, ask your GP or palliative care team for a referral. Talking to a religious or spiritual advisor can also be helpful even if you're not religious.

“ I felt I had an opportunity to get to know my mother in a new light during her seven weeks in palliative care. We cried, we laughed and we even planned her funeral together. I am so grateful for the gift of those weeks. ” Sharon



# 8. Question checklist

## Questions for your doctor - to help you make decisions about palliative care

- If I'm having 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'm at home, what kind of help will be available?
- 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 for you - things to think about or do when you start palliative care

- Is there anything you want to do before you get too ill? Any issues you want to sort out with particular people? See page 42.
- Have you thought about what care and medical treatment you do and don't want, and documented it in an Advance Health Directive?
- Have you chosen someone to make decisions for you if the time comes when you can't make them for yourself?
- Have you made a will (or updated yours 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 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?
- Does your carer, family and palliative care team know where you want to die? Have you told them 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 is challenging for carers too. There may be times that you feel like you don't know what to do, what to say, or how to cope. You don't need to get through it alone.

There are many sources of practical and emotional support for carers. The first step in getting the support you need is knowing what's available, who to contact, and when.



## Key points

- If you are a carer, it's 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 your relative's needs** and help organise equipment, home nursing and/or practical help.
- It's also important to **look after yourself**. It may help to talk about your worries and concerns with friends, a counsellor, a social worker 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** if you have worries or queries at night or on weekends, and who to contact in an emergency.

““ You're no assistance to your loved one unless you support and take great care of yourself. Only do what you can manage. ””

**Jacinta**

## Getting support

Caring can be hard work, both physically and emotionally. For many people it is a full-time responsibility, on top of work, parenting and other roles. In addition to PalAssist, there are many national and state services and organisations that provide palliative care information and support for carers. There is a list with contact numbers and website addresses on page 68.

## In home care

If you are caring for a relative at home, you will probably need help with the practical aspects of caring, like managing medicines or arranging transport. But you should also get advice about coping and how to get some time out for yourself.

## Getting equipment and home help

You may need some equipment and other aids to make your relative more comfortable and independent, and help you provide care more safely. This might be:

- A special mattress or chair cushion.
- 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, occupational therapist, physiotherapist and/or speech therapist will assess your relative's needs and organise equipment or tell you what you need. They can also explain and demonstrate how to safely move or lift your relative, and shower or wash them. As your relative's needs change, different aids and equipment may be needed, so ask for a re-assessment at any time.

Organisations in Queensland that hire or sell care aids and equipment are listed in on the PalAssist website [palassist.org.au](http://palassist.org.au). There is information about the Medical Aids Subsidy Scheme to help with the costs of equipment on page 29.

## Nursing and home help

Government services and community organisations 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 may be a fee involved.

Other practical and home help may be provided by your local hospital, council, various community services and health centres and charities.

Your palliative care team can organise home nursing and home help for you, or contact **PalAssist on 1800 772 273** for information about services in your area.

## Emotional support and help coping

In order to provide the best care, it is important to look after yourself.

It may help to talk about your worries and concerns with friends. Or you can talk to a counsellor, social worker or other carers. They can give you advice on how to cope, get some 'you' time and take care of your health and relationships. There are several carers organisations that provide advice, support groups or online discussion groups and counselling (see page 68).

## Respite care

Respite care is available to give you a break if you are caring for someone at home. Respite care for your relative may be provided at your home, or your relative may go to a respite care centre, hospital or palliative care unit (hospice). It may be for a few hours, overnight or for several days. Depending on where you are located, you may be able to access respite care for a range of reasons, such as looking after your own health and wellbeing, or visiting friends or other family members.

Ask your doctor or palliative care team to help you organise respite care, or contact the **Commonwealth Respite and Carelink Centres on 1800 052 222** 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 you can contact if you have any worries or queries and questions after hours (at night or on weekends), and who you should contact in an emergency.

Keep the numbers in a safe and obvious place and make sure any other caregivers have them too.

## Financial help

Information about financial assistance for carers of people with palliative care is on page 29.

## Condition-specific support

Palliative care can help people with a wide range of life-limiting conditions. While many people live with serious illnesses or conditions for many years, there comes a time when you may require the additional care and support that palliative care provides.

For most people, there are benefits to starting palliative care at the same time as you are having treatment for advanced disease.

PalAssist can provide details of national and Queensland organisations that provide information and support for people affected by particular diseases. Call **1800 772 273** or visit **palassist.org.au**

## End of life - for carers

If you have never seen anyone die you may be afraid of what will happen.

The physical signs described on page 48 are part of the normal, natural process of the body gradually shutting down. If your relative has symptoms like pain or restlessness these can be managed to make them more comfortable. If you notice any other signs or changes that worry you, contact the GP, community nurse or palliative care team.

If you are caring for someone at home, it's normal to need more support and help from the palliative care team at this time. Make sure you know which doctor or nurse you can call at any time.

The palliative care team will tell you practical things you can do to keep your relative comfortable, such as keeping their mouth moistened. You can give great comfort to your relative just by being with them, holding their hand and talking to them. Even if they don't respond they can probably hear you.

It can be helpful to know ahead of time who you should contact if your relative dies at home. This may be your GP, community nurse or palliative care team. They can provide assistance or give you advice by phone.

“It can be a long journey waiting for death – it’s very easy to allow the whole process to take over your life. Try and take every day as it comes and if it’s possible, share the responsibility. If someone offers to help, accept it. I learned, the hard way, that accepting help from another opens both parties to love. And remember: it is a privilege to be there for someone as they depart from this life.

●● **Jacinta**

## 10. Coping with death and loss

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, and the feeling of loss will usually reduce over time.

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 a number of **legal and practical** things to take care of, such as organising a funeral and informing family and friends.
- You may be entitled to **government payments** and financial advice to help you adjust.
- **Grief is a natural response** to loss. Bereavement is when you are grieving for someone close to you 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.

““ My mother and sister died within four months of each other. Whenever I thought of one of them, my eyes would fill with tears. Instead of stopping it or distracting myself, I just allowed it to be and the sadness lifted until the next time. Now, over two years later, these moments have become less and less. ●● Sharon

## Practical and legal things you need to do

When someone dies, there are many things that you and/or family members or friends will need to do including:

- Organise a funeral.
- Inform people (family and friends).
- Inform organisations like Centrelink, Medibank, banks, insurance company, etc.
- Organise mail redirection.
- Shut down any social media accounts.

For more information go to **humanservices.gov.au** and search for 'what to do following a death'.

You may be entitled to government payments and financial services to help people adjust to life after a partner or relative has died. 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, natural response to loss, especially the loss of a loved one. It is more than sadness. You 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 hit you 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 and 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

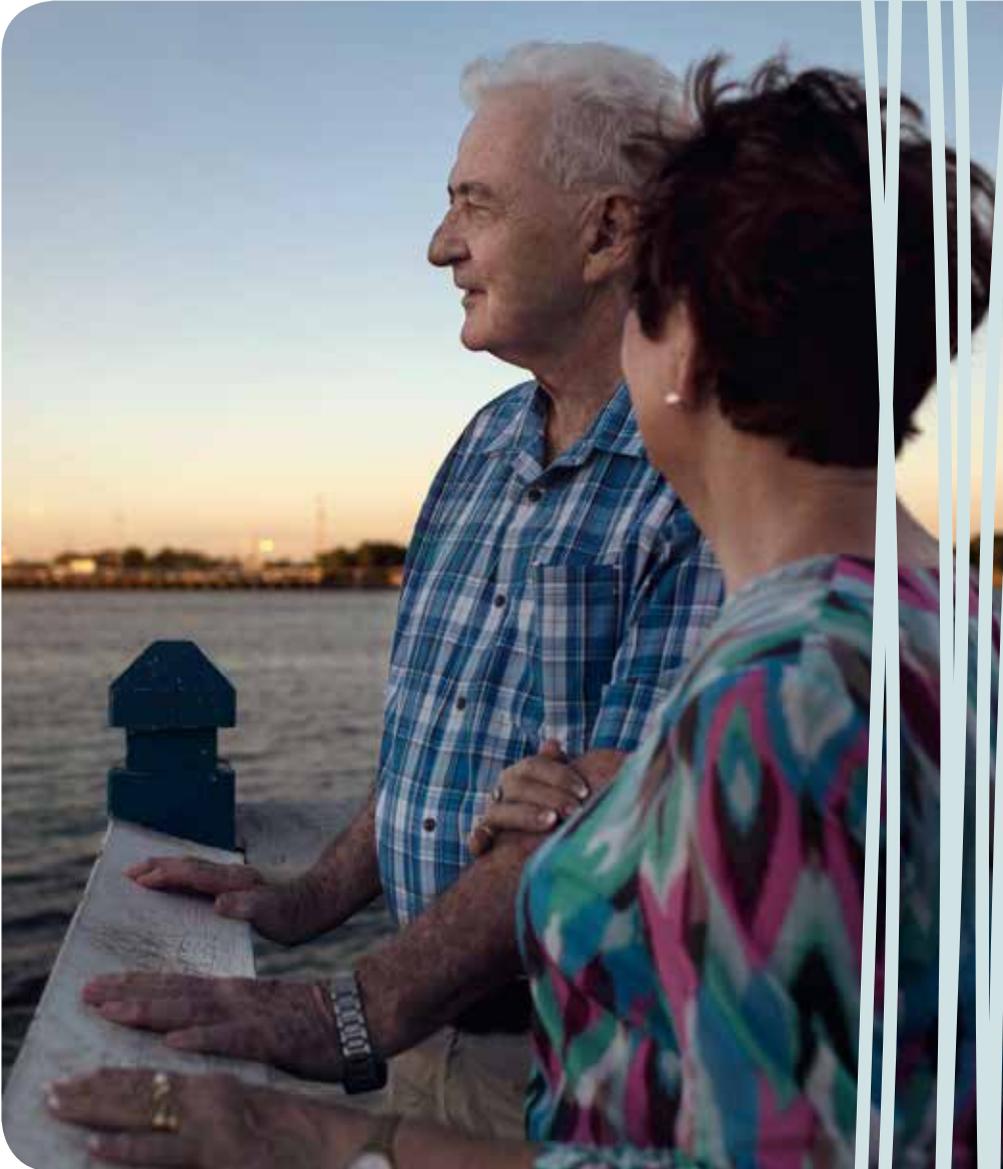
Being a carer for someone with a life-limiting condition can be quite isolating and exhausting. After the person has died, you may find it very difficult to go back to the work, groups, clubs or activities you previously enjoyed. Inviting a friend or volunteer to go with you the first few times may make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

If your grief feels overwhelming or you are concerned by how low you are feeling, you may need professional help or counselling. Talk to your GP or palliative care team about grief and bereavement counselling, or call **PalAssist 1800 772 273** or **Lifeline 13 11 14**.

The organisations and websites listed on page 68 can provide more information and help coping with loss and grief.

## Tips for coping with loss

- **Accept that your feelings**, and your way of grieving, are normal and natural.
- **Be patient.** You may feel – or other people may tell you – that you should be ‘back to normal’ or ‘over it by now’, but grief can be ongoing and can change.
- **Find someone you can talk to.** If it’s too difficult to talk with family and friends, ask your doctor or 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, 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

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**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)  
**My Aged Care** 1800 200 422 [myagedcare.gov.au](http://myagedcare.gov.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)  
**Advance Care Planning** [advancecareplanning.org.au](http://advancecareplanning.org.au)

## For carers

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**Carers Queensland** 1800 242 636 [carersqld.asn.au](http://carersqld.asn.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 [www.grief.org.au](http://www.grief.org.au)

## Other

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

## **Alternative therapies**

Unproven therapies that are used in place of conventional treatment, often in the hope that they will provide a cure.

## **Bereavement**

The sorrow you feel or the state you are in when a relative or close friend dies.

## **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**

Very low mood and loss of interest in life, lasting more than two weeks. 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 your 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 illness**

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 even years.

## **Multidisciplinary care**

A system where all members of the treatment team collaborate to discuss a patient's physical and emotional needs as well as any other factors affecting their care. The team meets to review cases and decide on treatments.

### **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. Provides 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.

# PalAssist 1800 772 273

**palassist.org.au**

*We're here and we care*

PalAssist is a Queensland-wide, no-cost 24-hour telephone and online service for palliative care patients, carers, family and friends seeking practical information and emotional support.

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 health professionals with nursing, social work and counselling experience. We understand that every person's journey is different, and offer individualised support and advice to our clients.

The 24-hour service is funded by Queensland Health and provided by Cancer Council Queensland. We are always here to offer trusted advice, or simply to listen.



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.



If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.  
[www.relayservice.gov.au](http://www.relayservice.gov.au)



**Queensland  
Government**



Funded by Queensland Government. Provided by Cancer Council Queensland.

Palliative care support and advice 24/7.  
Chat to us anytime **1800 772 273** or visit **[palassist.org.au](https://palassist.org.au)**