

Palliative Care Support for Patients, Carers and Families

CareSearch provides trustworthy information about palliative care for patients, carers and families as well as for health professionals



This booklet provides a starting point to learn about palliative care and the support available. For people approaching their natural end of life many of the issues covered in this booklet may also be relevant.

Visit the [Information for Patients, Carers and Families](#) section at caresearch.com.au to find out more or speak to your health care provider.

Diagnosis and Prognosis

'Illness trajectory' or 'course of illness' are phrases that are sometimes used in medicine to describe what is likely to happen. When someone has a life-limiting illness, it will cover what usually happens from diagnosis to death.

For some, the time from diagnosis to death is very short. This can be a matter of weeks. For others, symptoms will slowly become worse over months or years.

Sometimes with treatment, the progress of your illness will fluctuate. You may feel well for a while, but your symptoms may return. You may have another cycle of being unwell and more treatment until you are stable again.

It is important that you understand your prognosis, that is, whether your disease can be cured or only stabilised for periods. You should also be told the goal of any treatment. Is it to slow progress of your disease, or to treat a symptom or improve your quality of life?

Understanding the path or pattern of your illness can help you make important decisions.

This may be about your job or any legal matters including advance care planning.

Being aware may help with emotional or spiritual issues and prompt you to think about what is important to you now and as things change.



Let health and care professionals know:

- If there is anything you do not understand.
- Who they can talk to about your care.
- If you are comfortable with them talking to your family or friends without you being there.

Being able to talk openly with the people involved in your care will be important.



? Questions to ask your doctor or health professional

- What is the name of my condition?
 - What are my treatment options?
 - Does this treatment aim to help me live longer or control my symptoms?
 - How much longer am I likely to live for?
 - What will happen if I do not have treatment?
 - Are there any side effects of treatment?
- When doctors and health professionals have been providing you with information, it can help to summarise what you think they mean. Start by saying 'So if I've got that right, you mean.....!' or 'So what you are telling me is that...!'

About Palliative Care

Palliative care supports you to live the best life you can with a life-limiting illness. The focus is on quality of life.

Palliative care is person-centred and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die.

Palliative care supports the person and their family. Quality of life can include many things including being pain-free, as independent as possible, and not feeling like a burden.

Palliative care can help with many diseases, including:

- Alzheimer's and dementia
- advanced lung, heart, kidney, and liver disease
- neurodegenerative conditions
- multiple sclerosis
- cancer.

You may receive palliative care at any age and stage of serious illness including while having active treatment. It is about

supporting you to live well while you manage your illness. It is not just about cancer, and not just for care in the last days of life.

You can be involved in any planning of your care. Talk to your doctor if you need support.

? Questions to ask your doctor

- Does referral to palliative care mean treatment will stop?
- Is there anything you can do for me?
- Who are the members of the palliative care team and will this change over time?
- How do I contact the palliative care team?
- Can I receive help at home?
- Do I have to pay to see the palliative care team?

Some members of your palliative care team may include:

Aboriginal and Torres Strait Islander Health Workers: work with other health professionals to provide care that is respectful of culture.

Bereavement support: may be available to assist in managing grief and loss.

Care Workers: provide personal care and support.

Dietitians: can help with eating and drinking problems.

Doctors: a GP, and/or a specialist doctor responsible for care planning and prescribing.

Music therapists: help you with music-based activities to share enjoyable and memorable times.

Nurses: may provide physical care, and advice and support including information about your medications.

Nurse Practitioners: are nurses with an extended role including assessment and prescribing.

Occupational Therapists (OTs): help you to participate in everyday activities including work.

Pastoral Care Workers and Chaplains: provide pastoral and spiritual care for all who want it.

Pharmacists: can help with advice on medicines and health issues and organising a Home Medicines Review.

Physiotherapists: help people to keep moving and to function as well and as comfortably as they can.

Psychologists: help assess and treat psychological distress that you or your family may experience.

Social Workers: help you and your family with personal and practical difficulties, including financial and legal matters.

Speech Pathologists: help manage any communication and swallowing difficulties.





Caring and Support

Carers and those receiving care all need support to cope with the situation. Being prepared for likely changes is important.

Information for patients

Changes over time: When you are seriously ill, changes may occur in all aspects of your life. This includes physical changes such as pain and other symptoms like tiredness or loss of appetite. Changes in your mobility or independence can be especially challenging. You may also have to deal with changing feelings and emotions.

When you have a life-limiting illness there are things you need to consider. You may want to think about:

- your quality of life
- what is important now
- whether you continue to work
- how things are likely to change.

Emotional challenges: It is normal to have changing feelings and emotions. This is especially true if you or someone close are seriously ill or facing the end of life. Sometimes the worry is so great that you may develop symptoms of anxiety. This can include feeling edgy or restless. You may have difficulty concentrating, feel tired, or have difficulty in falling or staying asleep.

If you feel sad, moody, or low for a long period of time you may be experiencing depression. It is natural for anyone facing a serious illness to feel depressed and need time to adjust.

Talking to others about the adjustment may help. Your doctor or a psychologist may help you to understand your feelings and manage any emotional problems.

Changes that may affect your quality of life include:

- being uncomfortable or in pain
- being unable to socialise or spend time with loved ones
- loss of independence
- feeling that you are a burden.

Financial challenges: Most palliative care services are free, but there may be some costs associated with hospice and hospital care. You may need to pay extra for medications and equipment.

Continuing to work: For some people, work is very important to their sense of identity and independence. Your illness will affect not only you but also the people you work with. The seriousness of the illness needs to be acknowledged and talked about.

Planning: You may just want to live as well as possible within the limitations of your illness. There may be conversations that you need to have or issues you want to resolve. Think about the choices that matter to you. Consider preparing an advance

care plan, a will and even planning your funeral.

Spirituality: Spiritual needs can become very important at the end of life. For many people religion and faith are part of their spirituality, but spirituality is not the same as religion. Spirituality can involve love, hope, joy, dignity, or humour. Pastoral care workers and chaplains can offer spiritual support.

Information for carers

Carers may be a friend, neighbour, extended family member, spouse, sibling, child, or parent. You may not think of yourself as a 'carer'. Caring may not be something that you thought you would ever have to take on. You may take it on willingly, or it may be more of an obligation. Some people just cannot do it at all. It is ok to say no. It can be helpful to find and use support services to help you continue as a carer.

Family carer role: Caring for someone at home at the end of life is complicated and you may find it challenging. The intensity of the caring situation can be hard to deal with.

To work out what your needs are as a carer ask your doctor or health professional about the Needs Assessment Tool for Carers (NAT-C) tool.

Managing daily life: Ask health professionals for advice. Balance your carer role with other responsibilities. Maintain a social life. Keep yourself physically and emotionally well.

If you are caring for someone at home, there can be many other people involved. Having so many people around can be reassuring, or it can sometimes feel intrusive.

Family conflict in caring: Sometimes family members disagree with care directives or decisions. Families are not always close, and there may be general communication problems. If this happens to you, talk to a health professional such as your community nurse about a family meeting to talk about what is happening.

Respite: Respite is a chance for a break for you and the person you are caring for. A range of respite support services are available such as in-home

respite, centre-based respite, community access respite, or residential respite care (see www.carergateway.gov.au).

The cost of respite care depends on the care provider, the length of time involved, and the type of care.

Things you can do:

- Let your partner, relative or friend know that you have the time to sit and listen.
- If the person tells you their fears or worries, it is important to let them be sad or upset.
- Sometimes your company in silence is all that is needed.
- Leave a message on your phone to let people know what is happening eg, "Mary is home again and is feeling tired but appreciates your messages."
- Share an online calendar with family and friends so that they know where and when you need help. Organisations like 'Gather my crew' can help you with this.

Symptoms

A symptom is a physical or mental feature of a disease or illness that you experience.

Experienced by many people, these may not be the same from person to person. They may be mild in some cases or more severe in others.

A symptom diary can be used to record any symptoms you have had. This could include when they occurred and what was done. Let your carer know what you are feeling.

Medical language:

Understanding the language used by health professionals can help you to understand what is happening.

Some common symptom terms include:

- **anorexia** - poor appetite
- **anxiety** - anxious is when a person feels scared or worried about something. Anxiety is when these feelings do not go away
- **dysphagia** - difficulty swallowing
- **dyspnoea** - trouble breathing or breathlessness
- **fatigue** - tiredness
- **nausea** - feeling that you want to vomit.



Questions to ask your doctor or health professional

- What can be done to improve my symptoms?
- Can you help to control my pain?
- What is the cause of my symptoms?
- Who can I call in the middle of the night for medical help?



Medicine

The more health issues you have, the more medicines you are likely to take. Your medicines may come in many forms, including tablets, patches, and injections.

Your medicines may be given regularly to manage a symptom such as pain or nausea. This may include medicines which are prescription-only, non-prescription (over the counter) or complementary medicines.

Palliative patients take on average five regular medicines and two 'just in case' medicines.

Medicine interactions: Some combinations of medicines may make your medicines less effective, cause unexpected side effects, or increase the action of a medicine. Food and alcohol may also interact with medicines. Check with your doctor or pharmacist to see if a new medicine may interact with your current ones.

Side effects: All medicines can cause side effects. This could be a reaction to a medicine such as a rash or diarrhoea.

Discuss all side effects with your doctor or pharmacist.

Cost of medicines: The Pharmaceutical Benefits Scheme (PBS) subsidises many medicines registered for use in Australia.

This means that you can get them at a lower cost from your local pharmacy.

You may need to get a lot of prescriptions filled, and this can become costly. If you or your family use a lot of medicines, the PBS Safety Net helps with the costs. Once you have reached a certain limit, you and your family can receive medicines more cheaply for the rest of the calendar year.



More information:

- Discuss with your doctor or pharmacist.
- Call the free National Prescribing Service 'Medicines Line' on **1300 MEDICINE (1300 633 424)** from anywhere in Australia.
- Your doctor or pharmacist can arrange a Home Medicines Review (HMR).

Practical ways to manage medicines:

- Keep a list of what medicines you have and why you are taking them.
- Take your list to appointments.
- Make sure you have enough medicines to last over weekends and public holidays.
- Ask your doctor or pharmacist about your medicines including any changes.
- Return any unwanted medicines through your local pharmacy.



Last days

Information for patients

Place of care, place of death:

Many people want to be cared for and die at home. Others want to be cared for at home but to spend their final days in a hospice or hospital. If you find that you are in a hospice or hospital, you may want to go home to die.

Sometimes people die unexpectedly and not where they planned. Your preferences and choices can change over time and home can have different meaning for different people.

There may need to be continuing discussions about what is the best place for care or place of death. This will often depend on what care is available in any place, and where symptom control and comfort can be best provided. Sometimes a change in the place of care is unavoidable. Ask questions if things seem to be changing or unclear.

? Questions to ask your palliative care team

- Are treatments and medications still helping?
- Is it time to stop some treatments that are no longer adding to comfort?
- Does your carer need more help?
- Is it feasible for me to die at home?

Preparing for the end: You can make decisions about how you want to be cared for as you move towards the end of your life. You may have already written this in an advance care directive or plan. Or you may have discussed your wishes with your carer or family. Where possible, join discussions about your care and treatments.

Information for carers

As an illness progresses, you may need to provide more care. Being free of symptoms like pain and nausea is important.

Ability to move will change over time. It can take more effort for the person to walk or stand up from a chair or the toilet. An occupational therapist or physiotherapist can help.

Questions to ask your palliative care team

- What do I say when the person I am caring for asks 'Am I dying?'
- What should I do if the person I am caring for does not want to eat?
- What changes will I notice at the time of death?

Immediately after death: You should have a discussion with the health care team about what needs to be done after death. It may help if you have a list of things to do, with names and phone numbers. Consider who you will want to phone.

An expected death is not an emergency. You do not need to call for the police or an ambulance.

Ring the community nurse or the doctor to let them know what has happened. A doctor will need to come and verify the death. If the person was expected to die this is not urgent.

If the doctor has seen the person recently and they die at home during the night, you can wait until morning to call the doctor. You may want to spend quiet time with the person who has died before you ring anyone.

Bereavement

Many people are quite shocked by the death even when it was expected and followed a long illness.

Those who are grieving will react differently to the loss. For some it can take a long time to recover. Everyone reacts differently when someone dies and there is no right or wrong way to grieve.

Grief and sadness: You may remain in shock in the weeks following the death of a loved one. For some, it may lead, at least for a time, to overwhelming grief and sadness. Coping with grief and loss often requires effort. It can be both emotional and physical.

Support from your family and friends is important when someone has died. Tiredness and grief can make it difficult for you to remember some things. Sometimes talking about the final days can help you to work through your experience of grief.

After someone has died, some people may avoid talking about them for fear of causing you distress. Sometimes it is better to take the lead. Talking about a loved one will let your family and friends know that it is okay.

Children and grief and loss: Children grieve in a different way from adults. Grief will affect each child or teenager differently. Their behaviour may change; they may need support or someone to talk to. It is important to be available and talk at the level they are able. If this is difficult for you, talk with your GP, community palliative care service or school about supports for your child.

Loss of a child: The loss of a child is devastating. Nothing can prepare you or others for when it happens.



Parental grief has been described as more intense than other grief. This is regardless of the age of the child. You may have been providing care for months or even years.

When your child has died, this caring role ends. It is a period of great change and conflicting emotions. Health care teams will no longer be as involved. Ask who is available to help you and those affected.

Remembering: Following a death, you may spend time to reflect and acknowledge the person's life. In this way the person who has died will still have a voice, a story, or a connection that remains with

you. You may feel sad and at a loss but still want to recall and remember good memories.

There are many ways you could do this, such as a remembrance service or celebration of life, or a memory box or scrapbook.

If you are having trouble with your grief, talk to your **GP** or **Ring Lifeline on 13 11 14**.

Questions to ask your palliative care team

- What support is available for families after the person dies?

Talking about Death and Dying

If we are to help people in our community who are dying, caring or grieving, we need to be able to talk naturally about death and dying. But many of us find it hard to do.

Sometimes books, music, and movies can help us start to have important conversations about death and dying.

CareSearch has asked members of the Australian community for suggestions. Below are

their Top 10 books, films, and songs. We hope they start many conversations and help us all feel more comfortable talking to each other about death, dying, living and caring.

Books

Tuesdays with Morrie by Mitch Albom

Being Mortal by Atul Gawande

When Breath Becomes Air by Paul Kalanithi

The Lovely Bones by Alice Sebold

The Book Thief by Markus Zusak

Die Wise: A Manifesto for Sanity and Soul by Stephen Jenkinson

Top Five Regrets of the Dying by Bronnie Ware

The Prophet by Kahlil Gibran

Dying to Know: Bringing Death to Life by Andrew Anastasios

Smoke Gets in Your Eyes by Caitlin Doughty



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