Palliative Care
New South Wales

Palliative caring



Information for families and carers who are caring for a person with a life-limiting illness or condition

Acknowledgements

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If you require an interpreter, contact the Translating and Interpreting Service (TIS National)

- 13 14 50
- tisnational.gov.au

If you have a hearing or speech impairment, contact the National Relay Service

- 24 hour relay call numbers
  TTY/voice calls: 133 677
  Speak and Listen: 1300 555 727
  SMS Relay: 0423 677 767
- relayservice.gov.au

Caring for someone as they approach the end of their life can be both rewarding and demanding. It is hoped that this book will help to explain what caring involves, so you are better equipped to make informed decisions which reflect your needs and circumstances.

You matter.

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Introduction

Caring for someone as they approach the end of their life can be both rewarding and demanding. For some carers it proves to be a privilege, strengthening relationships and giving them precious time and memories that they otherwise would not have had.

It is also a role that can be incredibly difficult and exhausting at a time when people are at their most vulnerable. In some instances, the needs of the person being cared for may far exceed the capacity of the carer, in which case, taking on the role may not be appropriate.

It is hoped that this book will help to explain what caring involves so you are better equipped to make informed decisions which reflect your personal needs and circumstances. Rather than giving detailed medical or nursing information, it presents options to consider and references a range of services and supports that might be helpful.

Despite best intentions and good will, the process of dying may not go according to plan. It is important to ask for help and accept it when you need it.

Recognising when your role has changed

Sometimes people do not identify themselves as carers, even when they are filling this role. Most people see themselves in the context of their relationship first, whether it is as a spouse, partner, parent, child, sibling, friend or neighbour. If you are providing more assistance to the one you are caring for than you would normally, then you are a carer. This role is often undertaken by a family member or friend who is closest to the person who is unwell. They are generally referred to as the primary or main carer.

Be assured that it is okay to change your mind – even with the big decisions. Above all, your health and wellbeing as a carer are a priority.

Your role as a carer



Looking after your physical and mental health is important, so be sure to make this a priority.

Caring for yourself

Caring for someone with a life-limiting illness can be both rewarding and challenging. On top of that role, you may have family or work commitments. It is important to find ways to balance your caring role and other responsibilities, so that you maintain a sense of wellbeing.

Looking after your physical and mental health is important, so be sure to make this a priority.

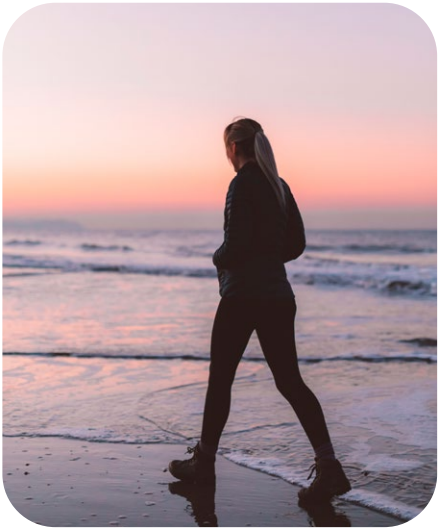
There is no need to feel guilty about caring for you. Many people receiving care feel better if they know their carers are taking time to enjoy themselves and rest.

Get some exercise

Doing something physical will help you remain fit and well and maintain your energy. Try an exercise that you enjoy and can fit easily into your routine. Walking, swimming and daily stretching are good examples.

Get enough sleep

Lack of sleep can become a problem for carers as the person they care for becomes increasingly unwell. Often stress and a busy mind can keep you awake. Limit coffee and alcohol intake, especially in the latter part of the day. Try relaxing with a warm bath or herbal tea before bedtime.



Sometimes listening to soothing music or reading a book can help you unwind. If you find sleeping difficult on a regular basis, see your nurse or doctor. Importantly, try to avoid driving or making important decisions if you are overtired.

Maintain a healthy diet

Try to maintain a well-balanced diet and stay hydrated. Factors such as stress or a disrupted routine may affect your appetite. If your appetite decreases and becomes a matter of concern, seek advice from your doctor.

Be social

Try to maintain social contact with friends, other family members and usual social groups. Keep up your usual activities as much as possible.

Practise your own spirituality or religion

Whether it be meditation, yoga, prayer or discussion with a pastoral worker, maintaining religious or spiritual practice will help you to stay well.

Do something for yourself every day

Consider activities to help clear your mind such as walking, gardening, meditation or listening to music. Take a break – list the things you enjoy that would give you a short break and renew your energy. Do one of these things each day, for example, take time out for a sport, craft or artistic activity.

Tuning in to feelings and emotions

It is normal for carers to experience a range of feelings and emotions, including fear and resentment. You may fear the unknown, or worry you won't be present when the person you are caring for dies.

There are also times when you will see the funny side of things. It's okay to maintain a sense of humour and enjoy a good laugh along the way.

Being aware of your feelings and emotions will help you to cope with the grief, anxiety and sadness that are a natural part of being with someone as they approach the end of life. Recognise your physical and emotional limits.

It is okay to stop being a carer. Even though you may have promised the person who is unwell that you would always look after them, it may not be possible. You may feel distress or guilt at having to say that you are unable to continue. You may find it hard to hand over to someone else. You may also feel a sense of relief. This is ok as well. There is no right or wrong way to feel about giving up this role.

You may find you still want to be involved but in a lesser way.

Asking for help and accepting it

Sometimes carers find it hard to acknowledge that they need help, fearing it is a sign of weakness or that they are not coping.

Often carers do not seek help for themselves because they consider their needs less important than those of the person they are caring for.

Do not be afraid to ask for help. Your wellbeing is vital to your role as a carer. Try to share the load so you don't become overwhelmed and exhausted.

Providing Palliative Care at home is a big commitment which requires the help of family, friends and others close to the person who is unwell. Often family and friends would like to help but are unsure what to do. Practical assistance like making a meal, walking the dog, buying groceries and hanging out the washing can make a big difference to your load.

Consider:

- Making a list of family and friends who could provide practical support. Invite them to choose from a list of tasks so you can lessen your workload. For example, mowing the lawn, taking out rubbish, providing meals or transport and so on.
- Asking a friend or family member to stay overnight, so you can get a good night's sleep.
- Setting up a roster if more than one person is providing care.
- Finding out what local services or community groups provide volunteers or support programs.
- Making contact with your local Palliative Care service to discuss what help is available and how to access it.



Communicating effectively

It is normal for your relationship with the person you are caring for to have ups and downs. The stress of coming to terms with a life-limiting illness, the impact this has on family members, and the physical and mental exhaustion of caring for someone can all take a toll. Your relationship may at times feel strained, or stronger than ever. While caring for someone, it is important to keep communicating, even though talking to them about their illness and dying may be difficult.

It will be useful to have regular conversations with family members so they know what is happening and what to expect as the illness progresses. Sometimes strong opinions about important care decisions can lead to conflict. You might find this distressing, particularly if someone not directly involved in day-to-day care offers unsolicited advice or direction.

It is important for family members to recognise that the person with a life-limiting illness has the right to make decisions about all aspects of their treatment and end-of-life care if they have the capacity to do so.

If communication becomes a problem, consider asking a skilled professional to facilitate a family meeting where all members can share their concerns, problem solve and provide support.

Involving children

Children and young people often manage stressful situations better if they are told the truth in a way that reflects their level of understanding. They can become distressed if they see adults upset and are not given an honest explanation of what is happening, or their questions are dismissed. Encourage them to ask questions and provide reassurance.

Give children choices about how to interact with them, whether that is face-to-face, drawing pictures, making cards or sending photos, messages or letters.

Try to maintain routines as much as possible and offer children the chance to help with caring.

Managing visitors

You may need to manage visiting times so that you and the person you are caring for have ample time to rest and attend to other tasks as necessary. Sometimes well-meaning visitors stay too long.

Before visitors arrive, suggest a reasonable period of time for their stay. As the time to leave approaches, remind them if necessary.

You might want to prepare the visitors on the state or the appearance of the person they are visiting as they may look quite different.

You might also suggest the best time for visitors to come. For instance, a late morning visit will allow time for an early afternoon rest. A nicely worded sign near the doorbell stating convenient visiting times might also help to minimise poorly-timed impromptu visits. It may become necessary to set up a roster to limit visiting times.



Children and young people often manage stressful situations better if they are told the truth in a way that reflects their level of understanding.

Planning & decision making



It is important that the person you are caring for conveys their preferences while they still have the legal capacity to make decisions.

Advance care planning

A life-limiting illness may remove the capacity to make decisions about important matters in the final months and days of life. Advance care planning is the process of discussing and documenting future health care wishes, values and priorities. It enables doctors, friends, family and carers to understand what a person with a life-limiting illness wants, should they become so unwell that they are unable to speak for themselves.

It is recommended to begin these discussions and planning during the early stages of an illness. It is important that the person you are caring for conveys their preferences while they still have the legal capacity to make decisions.

Advance Care Plan

Advance Care Planning means planning your care in advance of your condition worsening to the point where you are unable to make decisions for yourself. It is how you take control of your future health care decisions and help you live more positively.

The ability to decide what healthcare and health treatments we want is something we take for granted every day. However, there may come a time when illness makes us unable to make clear what we want from our healthcare providers. If you are diagnosed with dementia for example – that time will certainly come and there are other illnesses and conditions that may also make your ability to communicate your wishes impossible.

An Advance Care Plan can be prepared by you or on your behalf by family or medical professionals who know what your wishes are.

Aboriginal Communities

The *Aboriginal Wills Handbook* and its companion booklet *Taking care of Business* aim to enable Aboriginal people to make culturally appropriate planning ahead documents. These can be found on the NSW Department of Health Website.

The **NSW Trustee & Guardian** has information on planning ahead for Aboriginal people:

- tag.nsw.gov.au/wills/make-will/wills-aboriginal-people

Download the *Taking Care of Business* booklet here:

- www.tag.nsw.gov.au/sites/default/files/2020-10/Taking_Care_of_Business.pdf

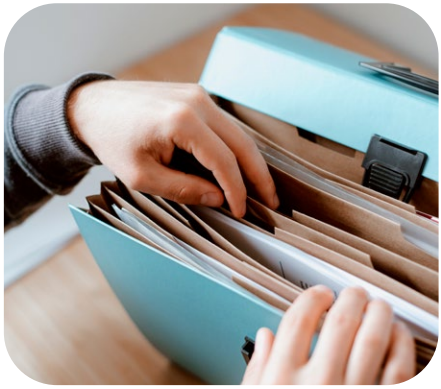
Advance Care Directives

In NSW an Advance Care Directive (or ACD) is a written statement completed by you that records your health and treatment goals of care. There is no set format but you can download a form from the NSW Department of Health.

Although there is no specific legislation for ACDs in NSW, an ACD has authority under common law and must be adhered to as long as it was made voluntarily by a competent adult. An Advance Care Directive is sometimes called a 'Living Will'.

Advance Care Directive forms are available from the **NSW Department of Health**:

- health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf



Enduring Guardianship

An enduring guardian is a person, over the age of 18 who agrees to be appointed by you to make personal and lifestyle decisions and/or medical treatment and healthcare decisions on your behalf only when you are no longer able to do so for yourself.

An enduring guardian legally appointed by you should consider your views both past and present. Your enduring guardian should also consider the views of professionals and other people important in your life at the time then make decisions on your behalf should the need arise.

Your enduring guardian's powers only come into effect and remain while you lack capacity to make decisions. The enduring nature of the power means that the guardian's authority continues while you are incapacitated.

The **NSW Trustee & Guardian** has information about appointing an Enduring Guardian. For more information, contact:

- 1300 109 290
- tag.nsw.gov.au

Enduring Power of Attorney

An enduring power of attorney is a legal document that you can use to appoint a person to make decisions about your property or financial affairs. It is only activated if you lose mental capacity, and ceases upon your death. They do not contribute to future healthcare decision-making.

More information and forms can be obtained from the **NSW Civil & Administrative Tribunal** website:

ncat.nsw.gov.au

Making a Will

Making a Will is the only way you can ensure that when you die, your estate will be distributed according to your wishes.

If you die without a Will, no one knows who you wanted as your beneficiaries. Your assets will be distributed according to a formula set by legislation. This means that certain relatives will receive a defined percentage of your assets, despite what you may have wished.

Dying without a Will is called dying intestate. Life circumstances change, so it's advisable to regularly review your Will to ensure that it accurately reflects your current wishes.

For more information, contact **NSW Trustee & Guardian**:

1300 109 290

tag.nsw.gov.au

You can choose your own executor or nominate **NSW Trustee & Guardian** for impartial and independent services.

Organ and tissue donation

You must be 16 or older to register your donation decision for after your death.

You can list your decision to donate for transplants, including which organs and tissue you want to donate.

It's important to tell your family your decision about being an organ and tissue donor. This is because they'll have the final say.

Your family need to agree to donate your organs and tissue when you die. They may be more likely to follow your wishes if they already know about them.

For more information, contact **DonateLife**:

(02) 8566 1700

donatelife.gov.au

Body donation

A number of universities throughout NSW offer a Body Donation Program through their Faculty of Medicine and Health Sciences. These Programs accept donations of human bodies to provide an invaluable contribution to the training of medical professionals and the advancement of scientific and medical knowledge.

If the person you are caring for intends to be a donor it is important for them to talk to their family. Not all donated bodies are accepted, which then leaves the family responsible for funeral arrangements and costs.

For more information or to register, contact the following universities body donation programs:

University of NSW
(02) 9385 2480

University of Sydney
(02) 9351 2519

University of Western Sydney
(02) 9852 5095

University of Wollongong
(02) 4221 3800

University of New England Armidale
(02) 6773 3087

Macquarie University
(02) 9812 3543

University of Technology Sydney
(02) 9514 9703

Choosing where to die

When asked where they would prefer to die, most people say they want to die at home. Home is what is familiar and comforting.

Encourage the person who is dying to discuss their views and preferences with you, family and friends.

Ideally, you and the person you're caring for will have the chance to discuss this with the GP or other healthcare professional, particularly if any decision depends on you and others to provide care at home. Your capacity to continue in the caring role, the preferences and care needs of the person you are caring for, access to Palliative Care and other practical considerations will help determine the best option. Also, it helps to be prepared if something unexpected happens such as a medical emergency. Other options for consideration include: a Residential Aged Care Facility, Palliative Care unit, hospice, or hospital.

It might be helpful to discuss a Plan A and a Plan B if things do not go as expected. It is important to have support and the capacity to look after yourself as well as your person if the decision is to stay at home.

Planning the funeral

Whilst it may be a difficult conversation, it would be helpful to have conversations with the person you are caring for regarding their preferred funeral arrangements.

It may also be appropriate to have discussions with key members of the family and important friends to clarify their expectations and what role they may wish to take.

Issues for consideration include:

- The type and style of funeral service e.g. family led, private committal, church, cemetery chapel, graveside, memorial or other
- Burial, cremation or entombment
- Coffin or casket
- Death notices, mourning vehicles and flowers
- Audio/video recording
- Poetry, music, readings, photo presentations or memorabilia
- Preferences of deceased, family and friends
- Minister, celebrant or friend to officiate
- Ashes placement
- Cost implications.

There are several options for funerals including natural funerals, cardboard coffins and so on. Cost can be a burden on families so you may want to do some research on alternatives. Of course you can always talk to a traditional funeral director who can guide you through the planning process and explain your options.

Making preferences known

Encourage the person you are caring for to:

- Let loved ones know what is important to them.
- Talk with their GP and other health care professionals caring for them about their health care treatment preferences.
- Give copies of their advance care planning documents to their health care providers, including their GP, medical specialists, Palliative Care team, hospital or aged care provider.
- Upload their advance care planning documentation to their electronic My Health Record.

For more information regarding **My Health Record,** contact:

1800 723 471

myhealthrecord.gov.au

Palliative Care



Palliative Care is care and support provided to people who have a progressive, life-limiting illness.

What is Palliative Care?

Palliative Care is care and support provided to people who have a progressive, life-limiting illness. Palliative Care aims to improve the quality of life for patients, their families and carers by addressing their many needs; physical (including treatment assessment and management of pain and other symptoms), emotional, social, cultural and spiritual needs.

The care offered may include:

- Medical treatment
- Relief of pain and other symptoms e.g. vomiting, shortness of breath
- Access to resources such as equipment needed to aid care at home
- Assistance for families to come together to talk about sensitive issues
- Nursing care
- Links to other services such as home help and financial support
- Support for people to meet cultural obligations
- Support for emotional, social and spiritual concerns
- Counselling and grief support
- Referrals to respite care services.

Does Palliative Care signal the end?

It may be devastating to hear that your family member or friend is considering referral to Palliative Care services. Understand that being referred to Palliative Care is not in itself a prognosis. Some people receive Palliative Care for a few weeks or months, while an increasing number of people receive it over a number of years. Palliative Care does not try to end life sooner nor prolong life expectancy.

Some people opt to continue treatment while also accepting Palliative Care, but generally it represents a change in focus – from trying to find a cure, to living with an illness and managing symptoms in order to achieve the best possible quality of life.

Quality of life means different things to different people, but it might include:

- Being comfortable and pain free
- Being able to socialise and spend time with loved ones
- Being as independent as possible
- Not feeling like you are a burden on others
- Feeling emotionally well.

Who can benefit from Palliative Care?

Palliative Care is for people of any age who have a serious illness that cannot be cured. This includes people with dementia, cancer, motor neurone disease or other neurological conditions, or end-stage kidney, heart or lung disease.

Palliative Care is also family- centred, offering families and carers practical and emotional support.

When to start Palliative Care

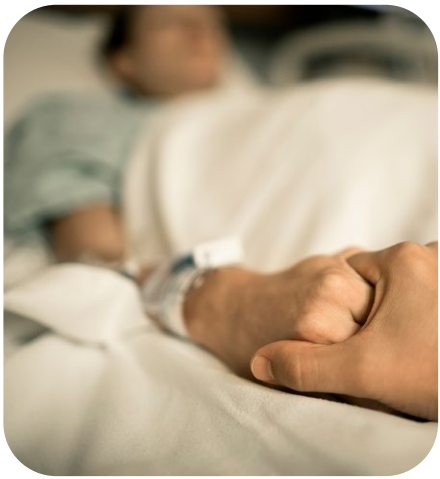
The decision about when to contact a Palliative Care service provider rests with the person who is unwell, their GP and/or medical specialist. Some people may benefit from receiving Palliative Care services from the time they are diagnosed with a life-limiting illness. Others may find comfort in just connecting with a Palliative Care service during the early stages of their illness, so they know services will be available when they are required.

If their health stabilises or improves, then Palliative Care services can be stopped and accessed again later if required.

Myths and misunderstandings

There are some commonly held myths about Palliative Care, so it is important to clarify the facts.

- People can continue medical treatment while also receiving Palliative Care. They do not have to cease all treatment options.
- Palliative Care focuses on more than just the last days and hours of life. It helps to achieve the best possible quality of life right from the early stages of illness.
- Palliative Care does not shorten or extend life through the use of medications, machines or technology. Rather, it focuses on providing comfort, support and respect.



Who provides Palliative Care?

Palliative Care may be provided by a range of different health and allied care specialists depending on the needs of the person you are caring for, your needs and the resources of your family and friends. In many cases Palliative Care is provided by your doctor (GP and/or specialist) and nurses.

Your Palliative Care team may include:

- Your GP
- Specialist Palliative Care doctors and nurses
- Specialists specific for the condition e.g. cardiologist, neurologist
- Nurses
- Occupational therapists
- Physiotherapists
- Speech pathologists
- Social workers
- Pharmacists
- Counsellors
- Pastoral care workers
- Dietitians
- Personal care assistants
- Volunteers
- Administrative assistants and ancillary staff.

Palliative Care health professionals work in a range of settings, including outpatient clinics, community nursing teams, consultation teams (facilities and hospitals) and specialist Palliative Care units located in metropolitan, rural and remote areas.

The services provided vary with most, but not all, requiring a referral from your GP. Call your local Palliative Care Service to find out if you need a GP referral. The specialist Palliative Care teams liaise with GPs and primary healthcare teams to provide specialist advice and treatment based on the needs of the patient, their carer(s) and family.

People providing Palliative Care recognise that every person has different physical, emotional, practical and spiritual needs and that a holistic and an interdisciplinary approach is best. It is important that you and the person you are caring for discuss what services and supports are needed, and when and how they are delivered.

For more information visit:

health.nsw.gov.au/palliativecare/Pages/palliative-care-in-NSW.aspx



Complementary, alternative and integrative therapies

Many people receiving Palliative Care explore therapies outside of conventional medicine and find them beneficial. It is wise to discuss these options with health professionals already managing conventional treatment or management so any potential side effects or undesirable interactions with medication are understood. Be careful not to presume that because something is deemed natural, it won't cause harm.

Complementary therapies aim to enhance quality of life and improve wellbeing. They are generally used in addition to conventional medical treatment. Many Palliative Care nurses and volunteers incorporate complementary practices into care, including massage, acupuncture, therapeutic touch, Reiki, music therapy, art therapy, visualisation, meditation and aromatherapy.

Alternative therapies are usually treatments which may be offered as an alternative to conventional treatments, although they are frequently used in addition. They include diets, and herbal and homeopathic therapies. There are varying levels of evidence for these therapies and some have been found to be harmful.

Integrative therapies offer a holistic approach that aims to provide co-ordinated care, utilising a variety of approaches.

The **Cancer Council NSW** website has a directory of complementary therapies and other helpful information:

- cancercouncil.com.au/cancer-information/living-well/complementary-therapies

Psychosocial care needs

The person you are caring for will have both physical and psychosocial needs which are equally important to be addressed.

They may experience some intense feelings that are not easy to describe or understand. This is a normal response to their circumstances. People will be affected in very different ways and this may change over the course of the illness.

Fear is a strong human emotion and this unknown experience can be very frightening. Asking questions of health staff and gathering information from a range of credible sources can be comforting.

People with a life-limiting illness may experience:

- An urgent need to get their personal affairs in order.
- The desire to spend as much time as possible with family and friends or withdrawal from these networks.
- Anxiety and depression.
- A reduced ability to process information and make rational decisions.
- A reduced sense of influence and control within the family.
- Guilt regarding the impact of illness and care on others.
- Frustration at changing physical and mental ability.
- A desire to explore spiritual perspectives, religious beliefs and meaning-of-life issues.
- A sense of regret, a desire to reflect and possibly resolve issues from the past.

As a carer, it might help to:

- Take time to help them work through complex decisions.
- Encourage them to talk matters through with family and friends.
- Provide opportunities for them to try breathing techniques and other relaxation methods.
- Ensure they get regular sleep and exercise, and have social contact.
- Connect with a support group of people in similar circumstances.

If anxiety and depressive symptoms persist, seek medical advice or suggest professional counselling support. Try to ensure that care provided by family and friends is seen as a demonstration of love and respect and not a burden.

Providing care at home



If you decide to care for someone with a life-limiting illness at home, it is important to recognise your limits.

Getting support

If you decide to care for someone with a life-limiting illness at home, it is important to recognise your limits and only do what you can reasonably expect of yourself at this time. You may reach a time where the person you are caring for has physical needs that are beyond your capacity. This may necessitate having additional care support come into the home or for care to be given in a different environment such as a care facility or hospital. It may be better for everyone if physical care can be delivered by skilled professionals so that you have more time to offer your love, and personal and emotional support.

There are number of service providers offering in-home support that also provide specialist Palliative Care. In addition to providing nursing care, a community nurse visiting can provide guidance and advice to you and person you are caring for as well as help coordinate care from other services, health and allied professionals.

Preparing the home

Caring for someone at home may necessitate the need to rearrange rooms, use additional fittings and equipment or even make some structural changes.

Changing the home can be disruptive to other family members, so having a discussion to consider everyone's needs first is important. The arrangements you make may need to change as the person's condition changes.

It is best to discuss your needs with a healthcare professional as you may be eligible to loan equipment through a local service provider.

They can also make referrals to physiotherapists or occupational therapists who are well-placed to review the physical needs of the person you're caring for and suggest what will make the home safe for everyone.

An occupational therapist can identify strategies to make your caring role easier, safer and maintain quality of life for the person you are caring for. Occupational therapists have expertise in changing the way you do important daily activities and manage fatigue, pain, breathlessness or memory changes by education,

task redesign, prescribing specialised equipment and creating a more accessible home environment for the patient and carers. They may also help minimise the risk of falls, manual handling injuries and pressure injuries.

They may suggest hiring equipment, such as:

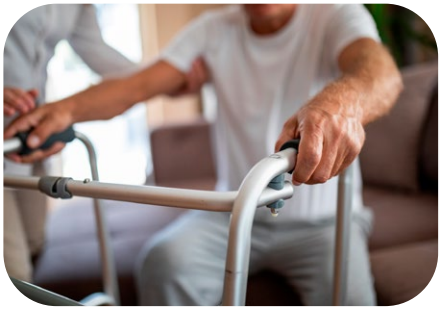
- Walking frames or walking sticks
- Wheelchairs
- Ramps and handrails
- Shower chairs or commodes
- Toilet raisers and surrounds, to assist with getting on and off the toilet
- Pressure relieving products, such as an air mattress
- Bed rails, for ease of movement and preventing falls
- Tables designed to sit over the top of the bed
- Washable incontinence sheets to protect the mattress
- Bedpans and urinal bottles
- Hospital beds
- Hoists to assist with getting in and out of bed.

Setting up the bathroom and toilet

Ensure there is easy access to a toilet and ideally a bathroom close to where the person you are caring for spends most of their time. You may need to ensure there is room for a bedside commode if they cannot get to the bathroom.

Space can be tight in a bathroom when you are helping someone to shower. If you have a drain hole in the bathroom floor, you might find it easier to shower them seated on a plastic shower chair or stool outside of the shower cubicle using a flannel and warm water. Another space saver is changing the way the bathroom door swings, so it opens out of the room rather than into it.

Non-slip mats can make floor tiles safer, particularly if they are slippery when wet. A raised toilet seat with hand rails can make it easier to sit down or get up from the toilet.



Setting up a space for the bed

Consider where the person you are caring for will sleep or spend most of their time. If they are mostly in bed, they might enjoy having their bed set up somewhere aside from the bedroom, where they can still feel part of everyday life. If the person can move around safely from their bedroom, think about setting up a comfortable chair or day-bed in the living room, ideally with a garden outlook or another interesting view.

If they start finding it difficult to get into or out of bed, seek advice on what specialised equipment might make it safer and easier. For your benefit and theirs, reduce trip hazards and make getting around easier by removing unnecessary furniture and floor rugs away from the bed.

A small table that can be positioned over the bed is useful for meals and other activities. If they are confined to bed reduce how often they may need to call on you for help by ensuring they can reach items such as a drink, telephone, television and radio controls. Having a radio, music centre, computer or television will help to maintain contact with the outside world and provide entertainment.



A small chair near the bed is useful for visitors and for the person to sit on while you make their bed. You may need a small table or drawer for medical equipment or dressings to keep them clean and dry, and a convenient place for medications that is safely out of the reach of any children.

You are unlikely to be sitting with them the whole time, so it can be reassuring for them to know they can reach you for help if they need it. A simple bell or baby monitor alarm, which you can hear from any part of the house or garden, might bring you both peace of mind.

Providing personal care



The person you are caring for may, or may not, want to be bathed or showered each day, so ensure their preferences are heard and respected.

Bathing, showering and toileting

If you are caring for someone at home and providing personal care, you will understand how important it is for this to be done with respect and concern for their dignity. Showering and toileting someone who is unwell may be confronting for you as a carer, as well as the person you are caring for.

If either of you is finding this difficult, consider accepting help from friends and family members who may be willing to share these caring roles.

Lifting and moving

If the person you are caring for needs assistance to move around, make sure you are shown how to do this correctly and that you are provided with the correct equipment. This is important to make sure both of you avoid being injured, so look to your nurse for practical advice.

Mouth care

The person you are caring for needs to have their mouth cleaned at least once a day. If they cannot chew or swallow properly and small amounts of food are left in their mouth, this can lead to oral infections.

If a toothbrush works, choose a soft one. If not, offer mouth wash or oral swabs. Swabs, which have a soft foam or cotton heads on the end of a stick, can be purchased untreated or impregnated with a flavoured paste.

If they are not eating or drinking, use a moist swab to wet the lips and tongue every hour or two during the day and whenever you attend to them at night. Your nursing service may be able to provide mouth swabs to assist you. Lip balms can relieve uncomfortable, dry lips.

If a sore or dry mouth is causing discomfort, consult your pharmacist or visiting nurse for further advice.

Hair care

It is possible to wash a person's hair when they are confined to bed though it will be easier if someone can help you. Dry hair shampoo can make the job easier and it may be worth seeing if there is a mobile hairdressing service available in your area.

Nail care and grooming

Keep nails clean and trimmed. If toenails are hard and thickened you may need a podiatrist's assistance.

Try to maintain their normal personal grooming routine such as shaving or applying makeup.

Bed linen

If the person is confined to bed, change the sheets as often as required. Ask a nurse to show you how to change the sheets while the bed is occupied.

When changing the bed, you can reduce washing by placing the top sheet on the bottom of the bed and placing a clean sheet on top every day or two.



If you are caring for someone who is incontinent, use incontinence aids and a plastic sheet to protect the mattress. Make sure they are not lying directly on the plastic.

For longer term use, ask your visiting nursing service about how to access incontinence supplies such as pads at reduced cost through schemes such as CAPS or EnableNSW.

For more information about the **Continence Aids Payment Scheme** (CAPS), visit:

- health.gov.au/our-work/continence-aids-payment-scheme-caps

Find out about **EnableNSW** services:

- enable.health.nsw.gov.au

Clothing

It is important for clothes to be comfortable and practical, as you need to be able to dress and undress them with ease.

Tracksuits or t-shirts made of soft, stretchy fabric are likely to be less restrictive than more formal, fitted clothing.

Aim to have them change out of pyjamas each day if it makes them feel fresher and they enjoy the normality of this routine.



Meals

Providing food is one of the ways we show love and concern. It is important to understand that nutritional needs of someone with a life-limiting illness will change over time, and their appetite will lessen as their illness progresses towards the end of life. They are likely to become more particular about their food, and to eat smaller portions or not want to eat at all. Try not to be disheartened if food is rejected. This is a common response and not necessarily an indication that the person you are caring for is being difficult.

There are no special rules or diets, so you can be guided by their personal preferences. Serve them what they want to eat, encouraging them to eat as much – or as little – as they like, whenever they want to.

- Offer a selection of small, nutritionally dense portions of food as often as desired during the day.
- Illness can dull the sense of taste. Different flavour combinations or using herbs and spices (if tolerated) may help.
- Cooking smells may be off-putting, so use the extractor fan or open windows to disperse odours.
- If they have a dry or sore mouth, they may prefer soft food. Try blending it or straining it through a sieve, keeping individual components of the meal separate. Food is likely to lose its appeal if everything is blended together.
- Ready-made or canned food like soups, yoghurts and custards are a nutritious option without being time-consuming to prepare.
- Soups and milky drinks are tasty and nutritious options for people who can only eat fluids.
- Supplements designed as meal replacements are sometimes more palatable if chilled.
- Fortifying food with dried milk, cream, ice cream, eggs, honey, and nutrition supplement powders can add nourishment.
- Referral to a dietician may be helpful if swallowing problems exist, or for advice about liquid replacements.

Symptoms



The way we feel pain is affected by many other factors in our life such as stress, anxiety, sleep and our past experiences of pain.

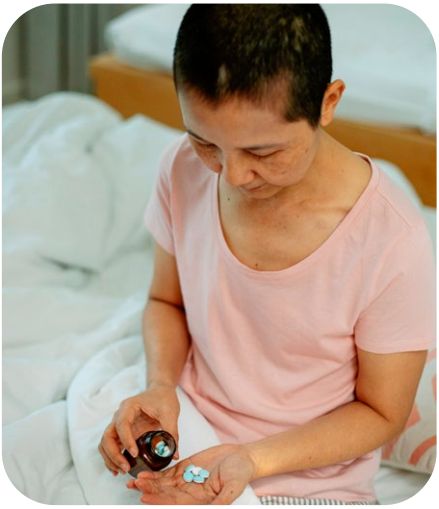
Pain

The symptom most feared by people with a life-limiting illness is pain. Although it is a common symptom in some conditions, not everyone with a life-limiting illness experiences pain.

To manage pain effectively, it is important for your Palliative Care team to consider and discuss all the factors that are affecting the pain experienced by the person you are caring for.

A holistic management plan can then be developed, which may involve setting realistic goals, exercise, mobility and positioning aides, hobbies and discussions with a counsellor or social worker.

Taking medications is usually part of the pain management plan.



Medications to manage pain are called analgesics. There are many analgesics, and the doctor will consider the type of pain and its severity when prescribing. Taking the right analgesic in the right dose will assist the person you are caring for to continue doing the things that are important to them.

In general, people with a life-limiting illness will take analgesics at the same times each day in order to manage constant or background pain. Additional doses of medication can be taken when the regular dose is not enough to manage a flare in pain, termed breakthrough pain, which may occur after showering or exercise.

Analgesic medications come in various forms including tablets, syrups, suppositories, injections or skin patches, and may include morphine or similar strong analgesics.

Constipation

Constipation is a common problem in people with a life-limiting illness. It can be caused by reduced physical activity, a changed diet, reduced fluid intake and analgesic medications including morphine.

It is normal to need laxatives to keep the bowel working well. Encourage the person you're caring for to drink plenty of fluids, keep as mobile as possible and take laxatives regularly.

Nausea and vomiting

There are many reasons for nausea and vomiting. Medications can be prescribed to help but you may also consider reducing exposure to various triggers such as strong smells (perfumes or cooking).

Nausea may be reduced by simple measures such as fresh air, adjusting the body position or by sipping cool fluids such as lemonade, sports drinks, juices or cordial. Providing mouth care may also help.

Weight loss and decreased appetite

Loss of appetite in life-limiting illness is common and can be distressing for carers. Attempting to increase food consumption may be difficult and cause unnecessary tension, particularly if the person you are caring for has no appetite. They may want to avoid looking in the mirror if they find the change in their body size upsetting.

Avoiding regular weight checks is also recommended as weight loss can still occur even when eating. Buying new clothes or adapting existing items so they fit may help them feel better. You may also find adding extra padding to the bed or chairs makes them more comfortable, and that they need more clothing, bedding or heating than normal in order to stay warm.

Fatigue

Fatigue is a debilitating symptom of a life-limiting illness which is often described as an overwhelming feeling of exhaustion. It is normal as the disease progresses for the person to need to spend more time sitting in a chair or more time in bed.

Some people find supplements or vitamins helpful in building their energy levels. Light activity or exercise, if possible, may also help.

Prioritise activities that are most important for the person – this might mean choosing to save energy for family or friend visits by showering every second day.

Encourage the person you are caring for to balance periods of activity with periods of rest before they get tired. Offer help and a chair for some activities. Arrange items used daily between waist and shoulder height so they are easy to reach. Allow a little more time to get things done and cut out unnecessary tasks or steps to conserve energy.

Confusion

Confusion or delirium is not uncommon in people with a life-limiting illness. It is not a sign of mental illness or dementia. It may be caused by a number of factors, including medications or medical conditions.

You can help to lessen confusion by keeping to a routine and having familiar things and people around. Try to have the house light during the day and dark at night and have a clock in view. Keep the surroundings quiet and calm.

Consider whether familiar music may be comforting. If they are disorientated they may need to be reminded where they are and supervised when walking. Night-lights in the hallway and toilet may help prevent falls. An assessment by your visiting health professional is recommended for ongoing or severe confusion.



Breathing problems

Difficulty breathing, also called dyspnoea, is a common symptom and often increases as the end of life approaches. It can be very distressing for the person with the condition and for the carer to observe.

It may help to open windows, be outside or have a fan blowing gently near the person's face. Medications are sometimes useful.

Finding ways to relax and reduce anxiety caused by breathlessness can also help. Ask your doctor or Palliative Care team for assistance.

Depression and anxiety

Identifying depression can be difficult due to the changes of advancing disease. However, if the person you are caring for shows signs of persistent low mood, irritability, insomnia, expressing fears and feelings of loss of control, loss of dignity or being a burden and a general pervasive sense of hopelessness and helplessness, they may be suffering from depression and/or anxiety.

It is important to share these concerns with the person you are caring for and seek help from your doctor or Palliative Care team.

Medicine safety



Carers who are supported with education and resources can manage and administer medicines to relieve symptoms in home-based patients.

- Store all medicines in a cool, dry and clean place.
- Store all medicines safely away from children, visitors and pets.
- Keep an updated list of medicines (including vitamins, over-the-counter and herbal products). Take the list with you to all doctors' appointments and ask them to review and update it at each visit.
- Make sure your doctor, nurse and pharmacist know about any allergies or reactions to medicines.
- Take the right medicine at the right time. Check with your pharmacist, nurse or doctor if you are not sure how the medicines should be taken, or if you have any questions about the medicines.
- If a dose of medicine is missed, contact your pharmacist, doctor or nurse for advice: it may be important to take the missed dose now or to wait until the next time the dose is due.
- If there are any side effects from any medicine, contact your pharmacist, nurse or doctor for advice.
- Take the medicine list and all current medicines (including medicines such as vitamins, herbal products and cough medicines) with you when you go to hospital.
- Never share medicines with other people. Medicines are potentially dangerous if taken by other people for whom they were not prescribed.
- Some medicines, particularly pain medicines, can affect one's ability to drive safely. It may be necessary to stop driving when first starting some medicines.
- It is important to talk with your doctor about safety to drive when taking prescribed medicines.

Research has shown that carers who are supported with education and resources, tailored to their needs, can confidently, safely and competently manage and administer subcutaneous medicines to relieve breakthrough symptoms in home-based Palliative Care patients.

caring@home resources are available for community service providers and health professionals to support carers to help manage breakthrough symptoms safely using subcutaneous medicines if that is something they want to do.

For more information:

1300 600 007

caringathomeproject.com.au

Adapted from: *Palliative Care Medicine and Symptom Guide*, produced by WA Cancer and Palliative Care Network, with support from Bethesda Hospital © Department of Health 2015.

Accessing respite care

If you wait until you are exhausted, you may need a longer break.



As a carer you should try to take regular breaks from your caring role. Such breaks are known as respite. Taking a well-deserved break may help relieve stress for both you and the person receiving care.

Leaving the person in someone else's care is a major emotional hurdle for many carers. The carer worries about their loved one, who may be uncomfortable with intimate care from someone else.

It is sometimes difficult to explain your need for time out to the person who is unwell. If this is the case for you, ask a member of the care team to help. If you take regular time out from the start, the person will get used to other carers.

Respite care can be provided by family or friends, or by a respite service. You may choose respite at home or a centre-based service. Different types of respite services are available but availability may vary depending on services provided in your area.



In-home respite

A care worker provides care in the home or may organise to take the person you care for on an outing. In-home respite can also be overnight.

Centre-based respite

Held at a centre or club that organises group activities for the person you care for, allowing them to meet other people.

Community access respite

Provides activities out in the community to encourage the person you care for to maintain a sense of independence and social interaction.

Residential respite care

A short stay in a residential care home can be organised for the person you care for.

Consider planning a break in advance to avoid stress build up and avoid waiting lists. Emergency respite care may be available if the unexpected happens and you need help at short notice.

Contact **Carer Gateway** for information about planned and emergency respite as well as access to other carer support services available in your area:

- 1800 422 737
- carergateway.gov.au

You may also be able to access respite or other supports through the National Disability Insurance Scheme (NDIS) if the person you care for is under the age of 65 or My Aged Care if 65 years and over.

Some condition-specific organisations such as Dementia Australia NSW, MS and Cancer Council NSW offer respite services. Refer to the useful contacts section on page 54.

What is the cost of care?

Some services are free, others are not. The cost of treatment, care and equipment will depend on government subsidies through various care packages (if eligible), whether care is provided at home or in a public hospital, the service provider, the length of time involved, and the type of care needed.

Before engaging services, be sure to ask about what the services provide free of charge and the cost of other services to reduce the risk of receiving an unexpected bill.

If you are experiencing financial difficulties, a social worker may be able to assist with identifying potential sources of support.

It may also be a good time to seek financial counselling or the advice of a financial advisor so you can factor in the cost of care over the caring journey, particularly if your income has been impacted by loss of wages or you are experiencing financial difficulties. Carer Payments or Carer Allowance paid by Centrelink may also be available to you (see details here).

Sources of financial support

Carer allowance

You may be entitled to Carer Payment and/or Carer Allowance if you give constant care to someone who has a severe disability, illness, or an adult who is frail.

Visit **Services Australia** to find out more about the carer allowance:

- 132 717
- servicesaustralia.gov.au/carer-allowance

Home support

If the person you care for is over the age of 65 you may be eligible for entry-level support at home through the Commonwealth Home Support Program, or if needs are more complex, the Home Care Packages Program (4 levels) available through My Aged Care.

Eligibility for these services is determined through an aged care assessment. There are two types of assessments:

- **A basic assessment** with a member of the Regional Assessment Service (RAS) for entry level support at home.
- **A comprehensive assessment** with a member of an Aged Care Assessment Team (ACAT) for more complex support at home.

There is no cost for the assessment, though you are expected to contribute to the cost of care where your personal circumstances allow.

You may need to complete a formal income assessment by Services Australia before you can receive services.

To check eligibility and apply for assessment to receive services, refer to **My Aged Care**:

- 1800 200 422
- myagedcare.gov.au

Veteran and war widow support

Eligible veterans and war widows may be entitled to financial support for services, equipment and medications.

For more information, contact the **Department of Veteran Affairs**:

- 1800 838 372
- dva.gov.au

Disability support

The National Disability Insurance Scheme (NDIS) provides access to services and supports people under the age of 65 living with a permanent and significant disability, their carers and families.

For more information on the **National Disability Insurance Scheme**:

- 1800 800 110
- ndis.gov.au

Medications

Many of the medications used by people receiving Palliative Care are listed on the Pharmaceutical Benefits Schedule, which means they are subsidised by the federal government.

Insurance & health cover

Many superannuation funds offer life and other insurance benefits that will be paid out on diagnosis of a life-limiting illness.

If the person you are caring for has private health insurance with ancillary cover, check whether it covers the cost of private nursing or personal care services provided by nursing agencies.

Cancer support

If you are caring for someone with a cancer diagnosis, the NSW Cancer Council can provide some financial assistance to pay utility bills up to $350.

NSW Cancer Council:

- cancercouncil.com.au/get-support/financial-assistance



Transport

The Taxi Transport Subsidy Scheme (TTSS) supports NSW residents who are unable to use public transport because of a severe and permanent disability.

More information on eligibility and to apply for the **Taxi Transport Subsidy Scheme**, visit:

- service.nsw.gov.au/transaction/apply-for-the-taxi-transport-subsidy-scheme

Patient Transport Service (PTS) is available for patients who meet eligibility criteria. Within greater metropolitan Sydney, transport is undertaken by qualified patient transport officers or, when required, under the supervision of an enrolled or registered nurse. Patient transport may be undertaken by NSW Ambulance in some regional areas.

More information about the **NSW Health Patient Transport Service** can be found here:

- health.nsw.gov.au/pts/Pages/info-for-patients.aspx



The person you are caring for may be eligible for a Companion Card if they have a significant and permanent disability and require attendant care support to participate at community venues and activities.

Participating businesses will recognise the Companion Card and issue the cardholder a second ticket for their companion at no charge:

For more information about the **Companion Card**, visit:

- companioncard.nsw.gov.au/cardholders/where-can-i-use-my-card

Heading into the last days of life



When someone with an advanced illness approaches death, it is usually a gradual and peaceful process, with pain and suffering kept to a minimum.

How can you tell when an illness or condition is advancing?

You may notice that the person you are caring for has a change in symptoms and may require more support from you and others.

Perhaps they are beginning to consider end-of-life issues and are feeling anxious, frustrated and helpless, as well as the need to get organised and be prepared.

Psychosocial care needs

As the end-of-life approaches the person you are caring for may begin to reflect on their life, consider their spiritual or religious beliefs, plan where they would like to die, who they would like to have with them and how they would like it to happen.



Spiritual and religious beliefs

Spirituality means different things to different people. It can include religious beliefs or practices, their personal view of the world or a connection to something bigger than ourselves that helps them make meaning of life. With impending death, belief systems often become more important.

Some people seek spiritual support from their priest, elder, minister, rabbi, or imam. Others find comfort in meditation or prayer and the knowledge that others are praying for them.

Others may find their illness or condition has challenged their beliefs and need to talk this through with family, friends or a pastoral care worker. People with no faith or religion may wish to explore this.

Those with a personal philosophy on life may wish to share this through conversation, by writing their thoughts down or recording them in another way.

Intimacy

It is important to recognise that when someone is dying they still experience normal feelings and emotions. Being physically close and touching another human being is a basic need which may become even stronger during the last days of life.

This may include physical intimacy with a partner, but also includes time with children, parents and other loved ones.

When someone is dying, priorities can shift and often relationships and connection become their first priority.

Massage is one form of touch that can facilitate feelings of closeness and connection as well as improve physical comfort. However some people may withdraw from intimacy, touch or social contact. There is no right or wrong way for a person to feel.

Indications of approaching death

It is difficult to predict when someone is about to die, so you may need to prepare yourself for the person you are caring for dying earlier or later than you expected.

Even if you have witnessed death before, it is important to ask questions of the health care professionals involved in care so you feel as informed and supported as possible.

Everyone's death is different. Indications that death is approaching are listed below, but not everybody experiences these changes and they do not occur in any particular order.

Sleeping more and eating less

The person you are caring for may become drowsy and sleep a lot. You can move their position in bed if you think they are uncomfortable, but in the last few hours there is often no need to move them at all.

This inactivity reduces their need for food and fluid, so they may stop eating or drinking altogether. This usually does not cause them any discomfort and is a normal part of the body's preparation for death.

Becoming vague, confused or restless

Sometimes people can become restless in the 24–48 hours before they die. This is not necessarily the result of pain, particularly if they have not experienced any pain prior. Try to reassure them by explaining who you are, speaking calmly, softening lighting and playing their favourite music. Have someone stay beside them as much as possible, holding their hand if this is calming. They may be easily startled if someone enters the room, so use a gentle introduction when someone comes in to indicate their presence. If restlessness is distressing, speak with your visiting nurse or medical service for an assessment in case a cause can be identified.

Changes in vision and hearing

They may experience clouded vision, a faraway look in their eyes, or seem unable to focus on anything or anyone. Although they may not be responsive to conversation, they may find familiar voices calming, as hearing is believed to be the last sense that is affected. Encourage family, friends and other visitors to talk with the person who is dying and one another so the person is aware they have company.

Incontinence

Loss of bladder and bowel control may occur when the person is very near death, but their reduced food and fluid intake means excreta is likely to be minimal. You may need incontinence pads to maintain comfort and hygiene and a draw sheet to protect the bed.

Breathing

When someone is approaching death usually their breathing pattern changes. You may notice gaps in breathing of several seconds or several minutes. This is normal and does not require treatment. Sometimes the dying person may make sounds as they breathe which can be distressing to hear. This is caused by saliva and secretions collecting at the back of their throat, because of their reduced ability to swallow. It is not distressing for the person who is dying. Sometimes elevating or repositioning their head or laying them on their side can reduce these noises, or a doctor may prescribe an injection to reduce the secretions, but this is not always effective.

Changes in colour and temperature

As blood circulation slows, the dying person's arms and legs become cool to the touch and may look mottled and dark. Their face may look pale and their nose may feel cold. Their skin may be clammy and mark easily, bearing the imprint of clothing, bedding or fingers as you provide personal care. Adding a sheet and a couple of warm blankets should be sufficient to make them comfortable, but too much bedding or an electric blanket may make them restless.

Mixed emotions

As death approaches, you may find that you experience a range of emotions, including being angry that this is happening, scared about what lies ahead, sad at the imminent loss of someone you care for and maybe relieved that soon their suffering will be over. The process may also leave you thinking about your own life and mortality.

You may feel that you just want it all over and done with. Most people in this situation have times when they feel like this, reflecting the strain they are under. It is a very understandable reaction, so it is important to talk so you do not feel guilty about these thoughts.

These responses are all normal and to be expected in such a stressful situation.

It is important for you to take time to talk through these emotions with friends, family, the Palliative Care team or a trusted health care professional such as your GP.



Saying goodbye

Caring for someone with a life-limiting illness can allow you time to say goodbye in ways that feel most meaningful to you. This may take the form of an intimate conversation with them, telling them what they mean to you and how you might remember them. You might choose to listen to favourite music together or just hold hands in silence. You might choose to say goodbye in a variety of different ways over a number of days. This is a personal experience so do what feels most appropriate for you.

Preparing your family

As a community, we are generally not comfortable talking about death and dying. It might be useful to start having these conversations with family and friends when the dying person's symptoms change in frequency and severity.

Even if the person who is dying is unable to talk or respond, encourage family to talk to them and tell stories, or explain what they mean to them.

It is important to ensure children are given a choice about visiting the person who is dying, and options for their involvement and interaction.

Some people feel awkward about what to say or do when visiting someone who is dying, so it might help to:

- Focus on listening rather than talking.
- Encourage the dying person to talk about their life, as talking about memories will help reinforce that their life mattered and that they will be remembered.
- Ask gentle questions that maybe encourage sharing e.g. is there something you would like to talk about?
- Try to converse as normally as possible by sharing what is happening in their life.
- Watch television, listen to music, or just sit in comfortable silence; company may be just as soothing as talking.

Crying is a natural way of expressing grief, so reassure visitors that there is no need to be embarrassed about it.

Death and bereavement



You need to be able to express your grief, remembering that there is no right or wrong way to do this.

Signs the person has died

The following signs typically indicate that death has occurred:

- Breathing ceases
- No heartbeat
- No response to loud talking
- Eyes are fixed, pupils dilated, eyelids may be open
- Jaw relaxes and mouth remains open
- The person may be incontinent.

What to do next

You do not have to do anything immediately after the person dies and there is no need to call police or an ambulance.

Their body can remain at home for several hours to allow time for family and friends to say goodbye. You may wish to talk to the funeral director if you wish the person to remain at home. However this will depend on the condition of the body at the time of death and you will need to be able to keep the body cool by lowering the room temperature etc. The body should be positioned so the person is lying on their back with their head and chest very slightly elevated, on pillows with their hands on their chest. It is natural for their jaw to drop, but you can roll up a towel and tuck it under their chin if you wish to close their mouth. Your community or Palliative Care nurse may be able to help with these preparations.

A doctor, paramedic and some Registered Nurses can attend to confirm the death and organise a death certificate. After this, your chosen funeral director can attend to the body and begin funeral arrangements.

Caring for yourself

It can be a time of great sadness for you when the person you have been caring for dies. Grief is a natural response to the loss of someone special and can affect every part of your life, including your thoughts, behaviour, beliefs, emotions, physical health and relationships with others.

You may have mixed reactions including anger, anxiety, depression, disbelief, relief, guilt or numbness. These reactions can be unsettling, particularly if they are not expected. Not everyone will experience these emotional responses and there is no set order for those who do. The length of time the grieving process takes will vary from person to person.



You need to be able to express your grief, remembering that there is no right or wrong way to do this. You may need support during this time from family, friends, a religious figure or a professional bereavement counsellor. A social worker may also be able to help guide and support you with the practical tasks and questions after death.

It is a common myth that people get over grief. The reality is that you will always grieve your loved one but over time the pain will lessen. There may still be things that trigger your grief, months or years later and this emotional response is normal.

Suggested approaches for bereavement self-care include:

- Delaying major decisions if possible
- Finding a creative way to express your thoughts and feelings, such as keeping a diary or journal, writing letters or poems, or creating artwork
- Creating a physical memorial in honour of your loved one
- Allowing yourself to cry
- Exercising, which can help you feel better through the release of natural endorphins
- Drawing on your religious or spiritual beliefs
- Limiting your alcohol and caffeine intake, particularly before sleep
- Sharing memories and stories with others
- Asking for help and accepting support from others.

Caring for your family

Grieving members of your family may need support from you but they may also need space. Everyone has to work through their grief in their own way. The most important thing is to make sure that your family members know that you care. Just being there can be comforting.

One of the greatest gifts you can give someone who is grieving is time and a listening ear. You may find that some people wish to talk repeatedly about the same events and issues, which is quite normal. However, listening to and sharing someone else's pain can be exhausting and it is important to recognise that you too are grieving. Make sure you are conscious of your own needs and responding to them; that being supportive is not inhibiting your own capacity to grieve. You might encourage a grieving relative to seek help from other sources and not be totally reliant on you. They may be able to seek a listening ear from other family members and friends, link into support groups, use the internet to access support material or access counselling or other professional support.

Supporting children

Like adults, children and young people will experience grief in different ways, depending on their age, developmental stage, personality and past experiences. Although most adults will want to be protective of the younger members of their family, it is almost impossible to shield them from the facts and you may be surprised how much they work out for themselves.

One approach to discussing a loved one's death is asking them what they know and inviting any questions. Answer their questions honestly and consistently. They may have an increased curiosity about death, have changes in behaviour and eating patterns, and feel angry towards anyone connected to the death – such as medical staff.



In simple terms, young children tend to worry about three things: Can I catch it? Did I cause it? Who is going to take care of me? You may need to provide reassurance for each of these concerns.

Children and young people sometimes fear they have caused a death through something they said or did. It is important to clarify that they are not responsible in any way. You may need to repeat answers their questions many times.



It is important to use appropriate language with younger children. Use the words 'has died' instead of 'gone to sleep' or 'gone away' as this may illicit fears when the child goes to sleep at night, or if someone goes away on holiday.

Some children will experience a loss of concentration, have dreams and nightmares. As with adults, children's responses will vary.

Some may experience a delayed response as they take time to absorb the loss and its meaning. It is important to take time to talk to them and to listen. They may benefit from creating memories of their loved one, by sharing stories, visiting their grave and creating a memory box.

Where possible, give children some control by allowing them to make decisions they are comfortable with when it comes to seeing their loved one's body or attending a funeral. Try to pose a number of scenarios so they can choose options they feel most comfortable with.

Who to advise of the death

The following list provides a starting point of who you might need to contact to advise of a recent death:

- Australian Taxation Office
- Centrelink
- Medicare
- Australian Electoral Commission
- Public Trustee
- Executor of the will
- Funeral director
- Funeral insurance
- Health insurance fund
- Superannuation fund
- Hospital
- General Practitioner
- Local government
- Social worker
- Post office
- Religious advisor
- Solicitor
- Accountant
- Support services (Commonwealth Home Support Program, Aged Care Assessment Team, etc.)
- Banks and credit unions
- Clubs
- Department of Veterans Affairs
- Employer
- Friends and family
- Landlord or tenants
- Utility companies for gas and electricity.

Services Australia has information in different languages about what to do following a death:

servicesaustralia.gov.au/death-loved-one

Useful contacts

Australian Indigenous Health InfoNet
(08) 9370 6336
healthinfonet.ecu.edu.au/learn/health-system/palliative-care

Cancer Council NSW
13 11 20
cancercouncil.com.au

Carer Gateway
1800 422 737
carergateway.gov.au

Carers NSW
(02) 9280 4744
carersnsw.org.au

Caresearch
(08) 7221 8233
caresearch.com.au

Centrelink
13 27 17
servicesaustralia.gov.au

Dementia Australia NSW
1800 100 500
dementia.org.au

GriefLine National
1300 845 745
griefline.org.au

Leukaemia Foundation
1800 620 420
info@leukaemia.org.au
leukaemia.org.au

Lifeline
13 11 14
lifeline.org.au

My Aged Care
1800 200 422
myagedcare.gov.au

My Health Record

- 1800 723 471
- myhealthrecord.gov.au

National Disability Insurance Service (NDIS)

- 1800 800 110
- ndis.gov.au

National Stroke Foundation

- StrokeLine: 1800 787 653
- strokefoundation.org.au

NSW Trustee & Guardian

- 1300 109 290
- tag.nsw.gov.au

Palliative Care NSW

- (02) 8076 5600
- palliativecarensw.org.au

Relationships Australia

- 1300 364 277
- relationships.org.au

Services Australia

- servicesaustralia.gov.au/individuals/contact-us/phone-us
- servicesaustralia.gov.au

The Department of Veteran's Affairs

- General enquiries: 1800 838 372
- Counselling Service: 1800 011 046
- dva.gov.au

If you require an interpreter, contact the Translating and Interpreting Service (TIS National)

- 13 14 50
- tisnational.gov.au

If you have a hearing or speech impairment, contact the National Relay Service

- 24 hour relay call numbers
  TTY/voice calls: 133 677
  Speak and Listen: 1300 555 727
  SMS Relay: 0423 677 767
- relayservice.gov.au

Access our Palliative Care Guidance service

The Palliative Care Guidance Manager provides non-clinical advice to carers, family members and health professionals on how to access appropriate services to meet end-of-life and palliative care needs.

(02) 8076 5604
pcguide@palliativecarensw.org.au

Palliative Care NSW recognises the joys and demands of your role. We provide resources and useful links to networks to help you do your best in your carer's role.

palliativecarensw.org.au

Palliative Care
New South Wales

Palliative Care NSW
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