

DYING AT HOME

Support for **Palliative Care**



Empower,
inform and
encourage
conversations
about dying

 **Home Instead**[®]
To us, it's personal

INTRODUCTION

Let's face it; talking about dying is difficult. Most people do not want to think about death, let alone talk about it. It's also hard to know how to raise the subject, or what to ask. You may not know where to go for information, what support is available, or the different choices you can make for end-of-life care.

This guide aims to empower, inform and encourage individuals, families and friends to talk about dying. If you are faced with a life-limiting illness, it's time to discuss what you need to plan for, and how you can go about it. What support is available and from where? Who will care for you?

Time is precious when faced with a life-limiting illness. Having these conversations and planning ahead will help you maximise the time you have left. You can focus on life-affirming moments and ensure you or your loved one's final days are as meaningful and comfortable as possible. Even if you are already on an end-of-life journey with a family member or friend, it's not too late to start talking about dying.

DYING AT HOME

70% of Australians wish to die at home, surrounded by their friends and families. However, this rarely becomes a reality without advance planning because only 14% of people realise their wish of passing away in their own home.

(Dying Well, Grattan Institute Report, 2014).

If you or your loved one wish to die at home, it is important to discuss this with your family, friends, doctor and palliative care specialists. This will give you the opportunity to put all of the necessary plans in place, to ensure your end of life happens as you wish.

DYING AT HOME

Support for Palliative Care

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WHAT IS PALLIATIVE CARE?

Palliative care is holistic, supportive care for people with a life-limiting illness. It can commence as soon as it becomes apparent that a cure is no longer possible.

It's much more than just straightforward medical care provided during the last days or weeks of a person's life. Palliative care supports the physical, psychological, social, emotional and spiritual aspects of end-of-life care for you, your family, friends and carers.

The primary aim of palliative care is to affirm and maintain a person's quality of life through the normal process of dying, while also providing relief from pain and other symptoms, as well as support for loved ones throughout the end-of-life journey. Palliative care can occur in a range of settings from a hospice, hospital, nursing home, or in your own home.

How to Source Palliative Care

Sourcing palliative care can be as simple as getting a referral from your General Practitioner (GP). Once you have a referral, you can find a service provider in your area by accessing the National Palliative Care Service Directory on the Palliative Care Australia website.

The Directory provides information about different types of palliative care services available in your area, including specialist or general palliative care. It is a great place to start, but it might not list all the services available.

You can also search for palliative care services in your state, city or town to find active local providers. You may be offered a choice, or the options may be limited, but it's your decision to choose the provider that suits you best, after discussing costs and needs. There is also a list of providers and organisations at the end of this booklet.

Home Instead can help you look at all of your options for sourcing palliative care, including funding arrangements and staffing options, depending on your individual needs.

Remember, palliative care is not just accessed in the final stages of life – it can help you live well with a terminal illness. It's never too early to discuss the options that are available when you need them.



PLANNING AHEAD

Discussing the end of life is not an easy task, but it is a very important series of conversations to have with those you love and care for. Talking about your end of life with loved ones will allow you and them to prepare and plan ahead. The end of life is a very emotional journey, but knowing your wishes will reduce some of the stress involved and give your loved ones a greater sense of comfort, control and peace of mind over what the future may hold.

How to Start the Discussion

Initiating the conversation with your loved ones is often the biggest challenge, but like many things in life – it's not as bad as you might have built it up to be. Maybe you're not one to share your personal thoughts and feelings, or you are afraid of upsetting your loved ones. It is almost certainly a conversation you don't want to have, but know you need to.

The toughest step is to start the ball rolling. There is no right or wrong way to bring up the subject of dying, but it can help to make a list of questions. What do we need to talk about? The key is to have these conversations before they are needed, or overdue. Take or make notes of your answers to these questions if you can – they can be helpful to refer back to when you are recording your wishes in legal documents.

Who	<i>Who will care for you? Who do you trust to make health decisions on your behalf? Who do you want to be there at your end of life?</i>
What	<i>What support is available to you? What medical treatment and interventions do you want, or not want?</i>
When	<i>When do you want someone to manage your affairs or make decisions on your behalf?</i>
Where	<i>Where do you want to spend your last months or days?</i>
How	<i>How do you envisage your end of life?</i>
Why	<i>Why are these things important to you? Make it known to others that these things are important to you, and the reasons why.</i>

If you're caring for someone approaching their end of life – take your time, approach the subject delicately and ask open-ended questions. Try to ease into the conversation by talking about the future in general at first, before delving into the topic of dying. Let your loved ones know it is OK to talk about dying, and that you would like to know what they want at their end of life.

REMEMBER:

- Having open, honest conversations about your end of life will make the journey easier for you and your loved ones in the long run.
- You don't have to cover everything in one conversation; take your time but don't keep putting it off.
- Be patient, it may take a while for your loved ones to feel comfortable talking about dying.
- Your loved one may never wish to discuss such matters; if this is the case, their choice needs to be respected.

Getting Your Affairs in Order

Once you have talked about the end of life journey and shared your personal preferences with loved ones, it is important to set these plans in place. It's best to write your wishes down in a legal document, so there can be no confusion.

1. Document your exact wishes in writing, as there may come a time when communication is compromised and no longer possible.
2. Make a Will. This is a legal document that details how an individual's assets and belongings will be distributed after their death. You can write or update your Will with a solicitor or the Public Trustee.
3. Power of Attorney (POA), Enduring Power of Attorney (EPOA) or Enduring Guardian. This is the legal appointment of someone to manage your financial and/or medical health affairs when you ask them to, or when you are deemed to not have capacity to make your own decisions. Generally, it's recommended to appoint your own trusted POA or EPOA before you lose the capacity to make your own decisions. In the absence of a designated POA or EPOA, the court system can appoint a Guardian to manage your affairs. Your solicitor or the Public Trustee would be best placed to offer more specific advice relating to your individual circumstances.
4. Develop an Advance Care Plan and/or Advance Health Directive. This important document can be prepared by you with your GP and a Justice of the Peace – you can read more about this on the next page.



Planning ahead allows you to have a say in your end of life. It means you have given appropriate consideration to your choices, and it ensures your wishes are followed, even if you are no longer able to make decisions or have the capacity to communicate. Whether you choose to inform a family member or friend of your wishes, it is important that it's someone you trust. You must be confident they will make sure directions are followed, based on your wishes.

Talking about and planning for dying can be difficult, but dying at home on your terms with your beloved family members present can be a beautiful and fitting end to a life well-lived.

Remember, palliative care is a service that is here to help you. It can be a positive and dignified experience if planned well, with the right support in place.

Advance Care Planning & Advance Health Directives

Advance Care Planning (ACP) is a process to guide your thinking about how you wish to be medically cared for, in the event you cannot make decisions or communicate. These wishes are formally documented in an Advance Health Directive (AHD) – a document that is signed by you, your GP and a Justice of the Peace.

Advance Care Planning gives those caring for you the opportunity to understand and respect your choices. The types of questions to be considered are:

1. Who do I trust to make health decisions on my behalf?
2. What medical treatment do I want to receive, or not want to receive?
3. Where do I want to spend my last months and days?

You don't need to consult a lawyer to complete an AHD, but it is important to talk to your doctor to fully understand your future health needs. Your doctor can discuss the range of care and treatment options available to you, and the potential outcomes of each, to assist you in your decision making.



An AHD can be changed at any time, provided you have the mental capacity to do so. If you no longer have the capacity to communicate your wishes, a Substitute Decision Maker (SDM) can legally make decisions on your behalf. You can formally nominate a SDM through the legal framework in your State or Territory. If you have a formal decision maker in place such as a POA / EPOA for health matters, make sure they are aware of your AHD.

Palliative care services provide assistance with Advance Care Planning and can facilitate family case conferences if you request or require it.

It's important to note that the legislation surrounding Advance Care Planning varies in every State and Territory. For more information about Advance Health Care Planning visit www.advancereplanning.org.au

Funeral Planning

When a loved one dies, there are many things that need to be attended to and many decisions that need to be made. The funeral is a very important part of the grieving process for family and friends. It is a time when they can come together as a group, to remember and honour the life of their loved one.

If you have been diagnosed with a life-limiting illness, you have an opportunity to plan or articulate what funeral arrangements you want in advance. Many Funeral Directors offer the option to pre-pay for funeral packages or can tailor a payment plan in advance to help ease any future financial responsibility or stress for loved ones.

Family and friends can draw great comfort knowing they are able to carry out your wishes exactly as you requested.

When discussing or planning a funeral, consider:

- **Do you want to be buried or cremated?**
- **What type of service would you like?**
 - This can be very personal and involve favourite songs, hymns, readings, flowers and other items special to you and your loved ones.
- **Who should be there?**
 - Do you want an intimate service with close friends and family?
 - Do you want to welcome everyone who has shared in your life?
 - Do you want a notice in the local paper of your passing?
 - Who should give your eulogy or other readings?
- **Where and when would you like the service?**
 - It is a common belief that a funeral must take place within a few days of death. This doesn't have to be the case. Take your time and proceed at a pace that is comfortable and suitable for you, your family and friends.

Funerals are an important celebration of a life that has passed, with the loving support and presence of family and friends.

Most importantly, a funeral should honour any specific requests of the person whose life is being celebrated, reflecting their values, personality, life experiences, achievements and hopes.

Speech
pathologist

Community support
organisations

Palliative care nurses

Dietician

Medical
specialists

**Professional
CAREGivers**

Counsellors

Allied health professionals



Family carers

Social workers

Occupational therapist

Family

Specialist palliative care services

CARING AT HOME

If you want to spend your last days at home, it is important to put plans in place to ensure you receive the care and support you need to make your end of life as comfortable as possible.

At some point, you may require care services to support you at home, and this may vary from a few hours a week, a few hours a day, up to 24-hour care in some cases. Consider who can best support your care needs. Family members and friends may be able to support you initially, but as your needs change, you may need nursing, allied health and/or professional home care services to support you.

Talk to your support team, who will assist you to develop a palliative care plan, and guide you through what may be required during your end of life at home. They will also be able to help with local home support, health services and resources.

Your support team may include some or all of the following:

- Specialist palliative care services including doctors, nurses, social workers, counsellors, allied health professionals such as occupational therapists, physiotherapists, speech pathologists, dieticians, chaplains etc.
- Palliative care nurses who can visit you regularly at home, help you manage your symptoms, plan and coordinate your clinical care needs with other members of your support team.
- Your local General Practitioner can be an invaluable support. Your GP will be able to assist you to understand your diagnosis, the likely progression of the disease, and liaise with specialist medical staff and allied health professionals. Many doctors provide home visits. Speak to your doctor about who you can contact if you cannot visit the practice, or if you require out-of-hours support.
- Support services may also be available in your local community from not-for-profit, carer or disease-specific organisations.
- Home care services can be arranged privately or through government funded programs (subject to assessment and eligibility). Volunteers and/or professional CAREGivers can provide palliative care support at home. Home Instead CAREGivers can support you with a range of daily living activities such as showering, dressing, bed baths, continence, meal preparation, light housekeeping and laundry. They can also provide companionship for those living alone, as well as respite services for family carers.

You may not need to access all available support services, and you won't need them all at once, but it is helpful to know what support services are available – should you need them in the future.

Cost of care

The cost of palliative care will vary depending on your needs and the services you require at home. Some services may be government-subsidised, but always ask service providers about the costs involved so you can prepare financially and know what you can or cannot afford.

Costs that you need to consider are:

- 1. General Practitioners.** Ask your GP about their fees, especially in relation to home visits. Some GPs may bulk bill their services.
- 2. Palliative care specialists** and services are generally funded by Medicare and/or government-funded community health programs, although a contribution or co-payment may be required. Check with your local services, as costs vary from state to state. If you have a private health fund, also check what health services and equipment your fund will cover.
- 3. Equipment** can be purchased, hired or loaned and costs may be covered in part or fully under a government program or by your local palliative care service.
- 4. Medications** and dressings generally have to be paid for by the person they are prescribed to, although some palliative care programs may be able to assist in circumstances of financial hardship. Prescription medicines listed on the Pharmaceuticals Benefits Scheme (PBS) are subsidised and if you have an Australian Health Care Card there is only a small fee to pay. Some prescribed medications may not be listed on the PBS and will be more expensive. In this instance, your private health fund may provide a rebate for some of these costs, depending on your level of cover.

5. Home care services such as respite care, personal care, home help or transport can be purchased privately, or you may be eligible for home care support through a wide variety of government-funded community health programs. The two key programs are the Home Care Package Program (HCP) and the Commonwealth Home Support Program (CHSP). For further information, contact your local Home Instead office, Aged Care Assessment Team or visit www.myagedcare.gov.au

6. Carer Allowance and Carer Payments are available through Centrelink. Carer Allowance is not income-tested and is available to anyone looking after a person with a medical condition. The Carer Payment is subject to income and asset-testing and can be paid in addition to the Carer Allowance. Centrelink can advise you about both payments.

Equipment at home

Equipment or modifications may be necessary to ensure your home environment is as practical and comfortable as possible, especially if your mobility declines and you need to spend longer periods of time in bed.

Walkers, wheelchairs, ramps, handrails, raised toilet seats, shower chairs, air mattresses, bed poles, bed tables, waterproof mattress and pillow protectors, bedpans and urinary bottles, hospital beds and lifting machines are all examples of equipment that can be useful when caring for someone with limited mobility.

An Occupational Therapist can review and help prepare your home for limited mobility. You may also consider making practical modifications in advance, such as installing handrails or moving your bed downstairs.

You can easily buy or hire the equipment you need to assist you to safely mobilise at home. Some services have equipment available for loan. Again, there are a range of government-funded programs that provide access to equipment for family caregivers.

Remember, an Occupational Therapist, your palliative care support team or your local Home Instead office can assist you to hire or purchase any equipment or aids that you need.



PAIN & SYMPTOM MANAGEMENT

Effective pain and symptom management is at the heart of quality palliative care. As people move towards the end of their life, they may experience a range of different symptoms and feelings.

Fear of Pain

Being fearful of death is common for people with a life-limiting illness, particularly the fear of pain. Pain can hurt and it wears you down. However, pain is not inevitable and not all people experience significant pain as their condition progresses.

It is very important to be honest about your pain. Most pain can be relieved or controlled, but many people hide their fear of pain because they worry that it cannot be controlled without awful side effects. This is not true.

Sometimes people report less pain than they experience because they want to appear stoic rather than weak. They think increasing pain may be a sign their condition is worsening. People also worry that if they start on strong painkillers now, there will be nothing strong enough later – but there are no limits to the pain relief you can access if needed.

Pain management is central to good palliative care. It often forms the core skill of your palliative care support team. Communicating with your palliative care team and developing an effective pain management plan will ensure that pain is kept under control, and you remain as pain free as possible.

A pain management plan focuses on preventing pain (rather than waiting for pain to occur before taking action), by planning medication doses in advance. Additional doses are available to manage periodic excess pain if needed.

Discuss pain medications with your doctor or the clinical staff in your palliative care support team to understand what is available, including the dose, frequency of use, and how and when it is to be taken.

Reducing your pain can help you live better in the time you have left; it can improve your psychological, emotional and spiritual wellbeing. Always be honest about your pain levels, so you can get the help you need.

Pain Medication

Morphine and other forms of opioids are commonly used in palliative care. They help make a person comfortable and relieve pain. There is no need to worry about becoming 'addicted' to medically-prescribed opiates – many patients will remain on the same dose despite the progression of their condition. The correct dose is the one that stops your pain and makes you comfortable, but it may vary from person to person – this is normal.

Pain can also be managed by keeping a diary, where you record when you are in pain, the type of pain you are experiencing and where. You can record the level of pain (on a scale from 1-10), compared to previous periods of pain and what triggered the pain. This information can be useful for clinicians monitoring your pain management plan and prescribing medication.

Also try different body positions and test different supports for your body (such as pillows, chairs, bed etc), as these may help to reduce pressure and relieve the pain. There are also a range of physical aids including cold/warm packs, and other treatments that can help relieve pain such as physiotherapy, massage or meditation.

Your support team can help you develop personal pain relief strategies. Sometimes distraction can work, including music therapy, because any activity that diverts and holds your attention will help lessen your awareness of pain.

Know who to call if you need urgent help with pain at home – day, night, weekends and public holidays. Keep all contact information in a place where it is easy to find, such as on the fridge.

- Your GP
- Current medical specialists
- Palliative care support team members
- Local palliative care tele-health network (these vary from state to state)
- Home nursing service
- Home care provider
- Allied health professionals: occupational therapist, physiotherapist, speech pathologist, massage therapist etc.
- Social worker
- Counsellor
- Chaplain



PROVIDING PALLIATIVE CARE

Careful thought and extra attention should be given to the following factors when providing palliative care for a person with a terminal condition:

- Careful positioning to promote comfort.
- Mouth care, especially dry mouth conditions.
- Breathing difficulties.
- Skin care, especially dry skin.
- Bowel and bladder management.
- Mobilisation to avoid bed sores.
- Personal support and extra support for family members.

Palliative Care is person-centred and as such everyone's journey is different. Some of the signs a person's condition may be deteriorating include:

- Increased incidence of infections such as urinary tract infections or pneumonia.
- Impaired movement including difficulty walking or moving, causing the person to be bed-bound.
- Incontinence, leading to full dependence on others for toileting and hygiene.
- Loss of the ability to communicate through words.
- Difficulty swallowing and eating, leading to weight loss and pneumonia.

Palliative Care and Dementia

It's very important to discuss end-of-life wishes with your loved one who has been diagnosed with dementia, as early as possible, particularly given many of the signs listed above can occur sooner for a person living with dementia. It's also a good idea to have their wishes written down in legal documents as early as possible, before they lose capacity to make decisions. Regardless, palliative care will provide comfort in consultation with the person's family members.

Palliative care can best help a person with dementia die in comfort and with dignity. Sometimes people with dementia may experience more restlessness and even aggression as their condition deteriorates, and these symptoms can be controlled with medication where required. There is also strong evidence of under-recognition of pain in people with dementia, and this should be taken into account by the palliative care support team.

Terminal dementia occurs when dementia is effectively the cause of death. It means the disease has progressed to the point where a person's brain can no longer regulate the body's functions.



CARE MANAGEMENT & SERVICE COORDINATION

Navigating the health care system and finding out who to contact, what to ask and where to find the information you need, can be very challenging. Effective service coordination ensures that care is delivered in a logical, connected and timely manner, and the holistic needs of the person are met at all times.

A professional care manager can assist you and your family to coordinate the various services required for your end of life at home. Identifying and documenting personal goals, preferences for care, medical interventions or withdrawal of treatments will ensure your wishes are understood, respected and followed.

Home Instead can best assist you with care management and service coordination, including:

- Liaising with your support team including palliative care staff, GP, medical specialists and other health professionals regarding your care and the services required to support you at home.
- Identification, referral and coordination of local health and community services and equipment.
- Coordination of medical appointments and home visits.

Palliative care meets the unique needs and preferences of each individual. Respecting a person's values and decisions about how they wish to be cared for at the end of their life is paramount, so proper coordination of care is very important.

If you are a family carer, you are also a vital part of the palliative care support team. Sharing your observations, questions and concerns with the health professionals and service providers caring for your loved one will ensure the most appropriate resources are in place to deliver the best possible care for your loved one.

HOW TO SUPPORT A FRIEND OR FAMILY MEMBER

It's hard to know how to best support someone who is going through palliative care, and there are no hard and fast rules because everyone is different. What works to console and comfort one person might not be the most appropriate or appreciated action for another person. Compassion is key; and companionship – just 'being there'.

It's often helpful to let your friend or family member know that you will be there for them, whenever they need you. Ask them how you can support them, no matter what happens. They might not always know what support they'll need, but it will provide solace to know that you are there to help.

Managing Emotions

The end of life is a very emotional time. The grieving process often starts at the diagnosis of a person's life-limiting condition. They may be grieving their own life, just as their friends and family begin grieving their impending loss. Be prepared to talk and listen to your loved one in palliative care. They may need to express feelings such as sadness, anger, disbelief, fear and loneliness. Having someone listen to them helps give them dignity and some relief that they can air their worries. Talking about fears and concerns always helps, especially in palliative care.

You will also likely experience a huge range of emotions as you offer your support. It can be very sad to see changes in someone you know well. It's important to treat the person who is ill in the same ways as you always have – with warmth, love and concern. This will help you too, as well as the person in palliative care.

Just be yourself. It is a sad time, but it can also be fulfilling when you know that your support is making a difference to your loved one, at the end of their life.

Mental Health

Dealing with all the emotions you are feeling as you deal with the impending end of a loved one's life can lead to a deep sense of uncertainty. This can impact negatively on your mental health.

It is very important that you take the time to think about your feelings and value the relationship you have with your loved one. Take the time to grieve

and let your emotions out when you can. Crying is both a physical and emotional release and helps eliminate stress hormones, rather than bottling it all up.

Remember, your kindness and compassion during this time helps others and enriches your life as well.

Self-Care for Carers

Caring and just being there for someone at the end of their life can be physically and emotionally exhausting. Although taking time for yourself is often easier said than done, pushing yourself too far can leave you burnt out. If you put your own health at risk, you might not be able to care for your loved one as you have planned, or even be able to be with them if you are unwell.

As a CAREGiver, it is important you take care and TREAT yourself right!

T	Talk. You may experience a range of feelings such as fear, anger, denial or resentment about your loved one's life-limiting illness and the demands of caring for them. Talking to a trusted friend, counsellor, social worker or chaplain can help.
R	Rest. Take a break, see a movie, take a walk, meet up with friends, or simply rest. Make sure you are getting adequate sleep, some physical activity, and have times where you are able to do something you enjoy. You may only feel confident to take a break if someone is present with your loved one. Family members, friends, volunteers or professional CAREGivers can help provide respite care.
E	Eat. Prepare regular meals and maintain a healthy diet. It is easy to let the basics slip when you are under pressure. But a healthy diet is critical to your overall wellbeing. It will also help you think clearly and improve your energy levels.
A	Accept. Accept help from others. You are not alone. Accepting support from others is not a sign that you cannot cope. Friends and family members may offer their support – as much to help you as they need to feel they are helping. Whether they cook meals, run errands or provide you with respite, let others help you with your palliative care journey.
T	Time. Dedicate time to plan ahead, be prepared and have support strategies in place to look after you and your loved one at each stage of their end-of-life journey. This will ensure you make the most of the time you have left and ensure your loved one's final days are as positive, supportive and comfortable as possible.

LEAVING A LEGACY

The end of life is a time for reflection on one's achievements, as well as an opportunity to create a lasting legacy for the future. It's difficult not to be sad or angry about the imminent end of life, but it can be helpful to remember that many people do not have an opportunity to plan for the end of their life. Some people find it beneficial to focus on legacy-related activities before it is too late. It is your choice.

Memory Books

Family photos can be reproduced and printed in wonderful memory books. These can be especially treasured by younger generations who might grow up and like to know more about you and your life. It's a good idea to make multiple copies for different family members. If you're unsure of the technology, your Home Instead CAREGivers can help source extra support and advice.

Messages of Hope

Sometimes you might want to impart a special message to your children or grandchildren. These can be in letter form or even videos. Your messages of hope can be drawn upon during the difficult times of grieving, but also later in life when guidance may be sought. They can be a powerful legacy.

Massage Therapy

Massage therapy can be very beneficial in relieving pain and other symptoms, especially in palliative care. There is new research showing that massage can also improve the emotional wellbeing of palliative care patients, helping reduce anxiety, fatigue, nausea and depression.

Massage therapy in palliative care does not replace conventional medicine or painkillers, but it is thought to promote a greater sense of connection between the mind and body during what is clearly an emotional time.

There are particular massage therapy techniques that specifically relate to palliative care, including manual lymphatic drainage (MLD), which can be effective in addressing swelling conditions such as oedema and lymphoedema. Oncology massage can also be helpful.

Any palliative care massage technique should only be performed by a massage therapist specifically trained in palliative care massage.



Bucket Lists

Sometimes a legacy is about you, rather than those around you. If there are things left undone or goals still to be achieved, make a bucket list of what you want to complete before you die. Your list might be serious, or it might be frivolous – but if it's important to you – make a bucket list and do it.

Social Media Accounts

If you're an active social media user, you might want to control what happens to your accounts, and your data. You can sort this out yourself, or you can leave clear instructions so it can be managed by your loved ones after you've gone.

Every social media platform has different rules about deleting, deactivation and memorialisation of accounts, but you might not be aware that some will allow you to download and keep your data – so your much-loved family photographs and memories can be treasured by your loved ones.

For more information and detailed instructions, refer to Palliative Care Australia's 'Guide to a Social Media Afterlife'.

Your Will as a Legacy

Many Australians leave their money and possessions to family members, or to a favourite charity, or both. There are numerous different ways to support charities, including perpetual trusts that distribute the profits from your invested funds between a variety of charities for many years to come.

When you make or update your Will, ask your solicitor to explain the options for you to consider. Putting some thought into your Will can ensure you leave a lasting legacy.



DEATH AT HOME

It is normal to be afraid of what will happen during the dying process, especially if you have never seen anyone die. In the following section, we look at what commonly occurs as a person dies, so you and your loved ones can be informed of what to expect.

The Dying Process

The end stage of a life-limiting illness is often gradual and generally does not require any special clinical treatment, hospitalisation or assistance from a doctor or specialist. The time before death is usually peaceful, and there is a gentle 'winding down' of the body that can take several days. The body starts to 'let go' of life.

Common signs that death is approaching include drowsiness, constant sleeping, lack of interest, refusal to eat or drink, confusion, restlessness, incontinence, changes in breathing, or loss of vision or hearing. Some people move into unconsciousness, whilst others remain awake and alert almost until the end. Your palliative care support team can guide you on how best to support your loved one at this end stage. Please ask for help at any time.

There is little to do. In fact, the best way you can help your loved one is to simply sit with them, holding their hand and speaking in a calm and reassuring manner. Hearing is thought to be the last sense to leave a person. Talk to your loved one even if they appear to be unconscious or restless.

You will know your loved one has died when their breathing has stopped, there is no pulse, and their muscles relax. There is no urgency to do anything immediately and there is no need to call the police or ambulance service. It is OK to spend time with your deceased loved one, especially if they die during the night.

KEY STEPS:

- Within a few hours you need to call your palliative care service, nurse or doctor to visit and confirm the death.
- You may also wish to call someone to come and support you at this time. Think about who this will be in advance.
- Later you will need to advise family and friends. Some may wish to visit before your loved one is removed from the home.
- Contact a funeral home to collect your loved one and assist you in making funeral arrangements.

Loss, Grief and Bereavement Care

Grief is a natural response to the death of someone you love, and everyone experiences grief differently. The important thing is to allow yourself to grieve as much and for as long as you need to.

When someone has a life-limiting illness, there are many losses to grieve long before they die – this goes for the person who is dying, as well as their family and friends. You may grieve periods of continuous pain, loss of mobility or independence, impaired abilities or your limited future together.

Family and friends may also feel various emotions as they try to adjust and come to terms with the impending loss of someone they love – such as sorrow, anxiety, anger, fear, depression, denial and/or acceptance.

Not everyone will experience grief prior to death, but all of these feelings are normal for those who do. Grief is our response to loss. It is a normal, natural and inevitable response to the loss of a loved one.

Grief can affect every part of our life. Sharing our feelings and emotions with people we trust can reduce the sense of isolation that comes with grief.

- Ask for and accept help. Don't be embarrassed, you will be able to help someone else at another time. It is your turn now.
- Talk to family and friends; sharing memories, stories, thoughts and feelings can be comforting and strengthen your relationships.
- Consider joining a support group to share with others who have had or are having similar experiences to you.
- Draw on traditions that are meaningful to you and take the opportunity to be a part of a larger supportive group such as religious, community or volunteer groups.
- Talk to a counsellor, social worker or religious minister about your situation to seek advice and guidance on ways to manage your grief, especially when your life or your grief feels overwhelming.

Never forget that you are not alone. Seeking help from family, friends or professionals is not a sign of weakness or failure; it is often the start of healing and can help you develop invaluable coping strategies to manage your grief and help you move forward.

PALLIATIVE CARE RESOURCES

NATIONAL RESOURCES

Advance Care Planning Australia
www.advancecareplanning.org.au

Carers Australia
www.carersaustralia.com.au

My Aged Care
www.myagedcare.gov.au

Palliative Care Australia
www.palliativecare.org.au

Care Search Palliative Care Knowledge Network
www.caresearch.com.au

CarerHelp
www.carerhelp.com.au (08) 7221 8233

Caring@Home
caringathomeproject.com.au 1300 600 007

Palliative care initiatives and programs
www.health.gov.au/health-topics/palliative-care/palliative-care-initiatives-and-programs

End of Life Directions for Aged Care (ELDAC)
www.eldac.com.au

QUEENSLAND

Palliative Care Queensland
www.palliativecareqld.org.au

Karuna Care
www.karuna.org.au

Queensland Health
www.qld.gov.au/health/support/palliative-care
PalAssist 24hr Palliative Care Support & Advice
1800 772 273

AUSTRALIAN CAPITAL TERRITORY

Palliative Care ACT
www.pallcareact.org.au

Clare Holland House Palliative Care Services
www.clarehollandhouse.com.au

NEW SOUTH WALES

Palliative Care NSW
www.palliativecarenewsw.org.au

The Palliative Care Bridge
www.palliativecarebridge.com.au

HammondCare
www.hammond.com.au

NORTHERN TERRITORY

NT Palliative Care
www.health.nt.gov.au/palliative_care

SOUTH AUSTRALIA

Palliative Care South Australia
www.pallcare.asn.au

Mary Potter Hospice including in-home support services
www.calvarynorthadelaide.org.au/palliative-care-mary-potter-hospice.html

SA Health Palliative Care Services
www.sahealth.sa.gov.au

TASMANIA

Palliative Care Tasmania
www.tas.palliativecare.org.au

Tasmanian Department of Health and Human Services Palliative Care Unit
www.dhhs.tas.gov.au/palliative_care

VICTORIA

Palliative Care Victoria
www.pallcarevic.asn.au

Eastern Palliative Care
www.eastpallcare.asn.au

South East Palliative Care
www.sepc.org.au

Living, Dying & Grieving Well
<https://w6p3u3w8.stackpathcdn.com/wp-content/uploads/2015/11/LDGW-2018-Edition-web.pdf>

WESTERN AUSTRALIA

Palliative Care WA
www.palliativecarewa.asn.au

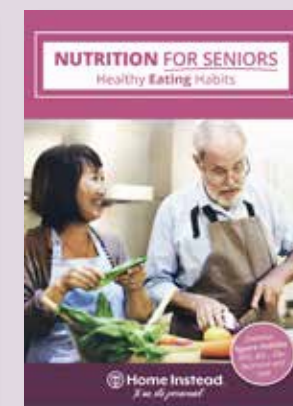
WA Health Cancer and Palliative Care Network
www.healthnetworks.health.wa.gov.au

Home Instead Resources

Information, tools, tips and other guides.

As a community care organisation, we are committed to educating and empowering individuals, families, carers and communities with an understanding of the various home care services and support available to them.

Home Instead strives to help you navigate ageing with a variety of senior care resources. From help with understanding the aged care system, negotiating family relationships and difficult conversations to resources on home safety, end-of-life planning and managing conditions such as dementia; helping you find answers is important to us.



Our website is another great resource for senior focused information along with our monthly newsletter and Facebook pages.

Find out more today at HomeInstead.com.au

I would **recommend** Home Instead services to anyone looking for **personalised, kind, and respectful** care for their loved ones

Maureen



To us, it's personal.

Home Instead is **YOUR** specialist, national provider of high quality in-home care for ageing adults.

We help with a range of personal and lifestyle needs while providing welcome companionship. Our services include assistance with personal care, light household duties, meal preparation, medication reminders, transport to appointments, shopping and social outings. We take personal responsibility for providing the best in-home care and support to meet our clients' needs and are committed to addressing the individual and national challenges of Australia's ageing population. Established in 1994, Home Instead now provides senior care across a network of over 1000 offices around the world.

In Australia, Home Instead's national network of independently owned and operated offices are committed to changing the face of ageing by enhancing the lives of seniors and their families.

We understand that to you, it's about finding trustworthy care for your ageing loved one.

To us, it's personal.

Contact your local Home Instead office for a free no-obligation care consultation where we can discuss your needs and provide you with information, advice, care and support to help you and your family find the right home care solution for you.

 **Home Instead.**
To us, it's personal

HomeInstead.com.au | 1300 008 018

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