

Dying at Home

A guide to support people, families and carers plan for end of life at home.



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The information contained in this booklet is for general information and guidance only. It aims to provide a pathway to access further information and resources about palliative care. Whilst every effort has been made to ensure that the information provided in this booklet is correct and current Home Instead Senior Care cannot accept legal responsibility for any errors or omissions that may have been made. Publication date September 2015.



Introduction

Let's face it; talking about dying is difficult. Most people do not want to think of, let alone talk about dying. And when we try to raise the subject, we often don't know how to, or what to ask. You may not know where to go for information or what support is available or the choices you have for end of life care.

This booklet aims to empower, inform and encourage individuals, families and friends to talk about dying. If you are faced with a life-limiting illness, what do you need to plan for and how do you 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, 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

Many Australians, 70% in fact, wish to die at home, surrounded by their friends and families. Unfortunately, without advance planning, dying at home often does not become a reality with only 14% of people actually passing away in the comfort of 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 your wishes with your family and friends, your doctor and palliative care specialists so you have the opportunity to put all of the necessary plans in place to ensure your end of life happens as you wish.

What is palliative care?

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

It is much more than clinical 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 whilst also providing relief from pain and other symptoms and 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.

Planning ahead

Talking about dying, particularly with those close to us is never easy. However, discussing your end of life with loved ones will allow you and them to prepare and plan ahead. End of life is an emotional journey, and 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.

Initiating the conversation with your loved ones can be the biggest challenge. Maybe you're not one to share your personal thoughts and feelings, or you are afraid of upsetting them. It is almost certainly a conversation you don't want to have, but know you need to.



What do we need to talk about?

There is no right or wrong way to bring up the subject of dying. The key is to have these conversations before they are needed or overdue.

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 and don't you 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?</i>

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 them 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.
- 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 and, whilst this is hard, their choice needs to be respected.



Getting your affairs in order

Once you have talked about dying and shared your personal preferences with loved ones, it is important to set these plans in place.

1. Document your 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.
3. Power of Attorney (PoA), Enduring Power of Attorney (EPoA) or Enduring Guardian. This appoints someone you trust to manage your financial and/or medical health affairs when you ask them to or you are deemed to not have capacity to make your own decisions.
4. Develop an Advance Care Plan and/or Advance Health Directive.

Planning ahead empowers you to have a say in your end of life. It will ensure you have given appropriate consideration to your end of life choices and that your wishes are followed, even if you are no longer able to make decisions or have capacity to communicate.

Whether it be a family member or friend, it is important that you choose someone you trust and are confident they would make decisions based on your wishes.

Advance Care Planning and Advance Health Directives

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

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

Who do I trust to make health decisions on my behalf?

What medical treatment do and don't I want to receive?

Where do I want to spend my last months/days?

You don't need to consult a lawyer to complete an AHD, but it is important to talk to your doctor in order to fully understand your future health needs. They 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.

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

The legislation surrounding Advance Care Planning varies in every State and Territory. For more information in regards to Advance Health Care Planning visit www.advancecareplanning.org.au



Speech pathologist

Community support organisations

Palliative care nurses

Dietician

Medical specialists

Professional CAREGivers

Social workers

Allied health professionals

Physiotherapist

Chaplain

GP

Friends

Family carers

Counsellors

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 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 link you in 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, pain 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, but not all. Speak to your doctor about who you can contact if you cannot visit the surgery or 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. Professional CAREGivers can support you with a range of activities of daily living such as showering, dressing, bed baths, continence, meal preparation, light housekeeping and laundry. They can also provide companionship for those living alone and respite services for family carers.

You may not need to access all of the above 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 about the costs involved so you can prepare financially and know what you can or cannot afford.

Costs that you need to consider are:

General Practitioners. Ask your GP about their fees, especially in relation to home visits. Some GPs may bulk bill their services.

Palliative care specialists and services are generally funded by Medicare and/or government funded programs, although a contribution or co-payment may be required. Check with your local services as costs vary from State to State. Also check what health services and equipment your private health fund will cover.

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.

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 Government 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.

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 Commonwealth or State Government Programs. The two key programs are the Home Care Package (HCP) Program and the Commonwealth Home Support Program (CHSP). For further information contact your local Home Instead Senior Care office, Aged Care Assessment Team or myagedcare.gov.au

Carer Allowance/Payments are available through Centrelink. Carer Allowance is not income tested and 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 Care 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, air mattresses, bed poles, bed tables, waterproof mattress protectors, bedpans and urinary bottles, hospital beds or 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, i.e. installing handrails or moving 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 and there are a range of government funded programs that provide access to equipment for family caregivers. An occupational therapist, your palliative care nurse or your local Home Instead Senior Care office can assist you to hire/purchase any equipment or aids you need.

Care management and service coordination

Palliative care endeavours to uphold 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.

Identifying and documenting personal goals, preferences for care, medical interventions and/or withdrawal of treatment/s will ensure your wishes are understood, respected and followed.

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

A professional care manager can assist you and your family coordinate the various services required for your end of life at home, including:

- Liaising with your support team including your 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/home visits.

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.

Your local palliative care service or Home Instead Senior Care office can assist you with care management and service coordination.



Pain and 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.



Being fearful of death is common for people with a life-limiting illness, particularly the fear of pain. However, pain is not inevitable and not all people experience significant pain as their disease progresses.

Pain management is central to good palliative care. Communicating with your palliative care support 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, planning medication doses in advance. Additional doses are available to manage periodic break through pain if needed.

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

Morphine and other forms of opioids are commonly used in palliative care. They will make a person comfortable and relieve pain.

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 (i.e. on a scale from 1-10) compared to previous periods of pain and what triggered the pain. This information is useful for clinicians monitoring your pain management plan and prescribing medication.



Also try different positions and test different supports for your body (e.g. 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 relieve pain such as physiotherapy, massage or meditation. Your support team can help you develop personal pain relief strategies.

Know who to call if you need urgent help at home – day, night, weekends and public holidays. Keep all contact information in a place where it is easy to find, e.g. 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

Self-care

Caring 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. Moreover, it can put your own health at risk, leaving you unable to care for them as you have planned or even 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 like 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. Ensure you are getting adequate sleep, some physical activity, and have times where you are able to do something that 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 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 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.

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 – and 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 as 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.

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 coping strategies to manage your grief.



Death at home

The end stage of a terminal illness is usually gradual and generally does not require any special clinical treatment, hospitalisation or assistance from a doctor or specialist.

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 service can guide you on how best to support your loved one at this end stage.

You will know someone has died when their breathing has stopped, there is no pulse and their muscles will 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 their 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 take your loved one and assist you in making funeral arrangements.

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 you can come together as a group to remember and honour the life of your 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. 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 one.
- 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?
 - There is a commonly held belief that a funeral must take place within a few days of death. This is not 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 of their family and friends. Most importantly, it should honour any specific requests of the deceased and reflect their values, personality, life experience and hopes for the future.

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

QUEENSLAND

Karuna Care www.karuna.org.au

Palliative Care Queensland
www.palliativecareqld.org.au

Queensland Health www.qld.gov.au/health/support/palliative-care

PalAssist 24hr Palliative Care Support & Advice 1800 772 273

AUSTRALIAN CAPITAL TERRITORY

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

Palliative Care ACT
www.pallcareact.org.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

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

Palliative Care South Australia
www.pallcare.asn.au

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

Eastern Palliative Care
www.eastpallcare.asn.au

South East Palliative Care
www.sepc.org.au

Palliative Care Victoria
www.pallcarevic.asn.au

Living, Dying & Grieving Well
www.pallcarevic.asn.au/families-patients/information/living-dying-and-grieving-well-a-guide/

WESTERN AUSTRALIA

Palliative Care WA
www.palliativecarewa.asn.au

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



Home Instead Senior Care is a specialist, national provider of high quality in-home care for older people.

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, as well as specialist dementia care and supporting end of life care at home. 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.

Appreciation and acknowledgement

Home Instead Senior Care wishes to thank everyone who has contributed to the development of this guide. In particular, our clients, their families and the CAREGivers who have supported them through their end of life at home. Special thanks to the following organisations for their contribution to this project and ongoing support of Home Instead senior care services:

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Research

Home Instead Senior Care developed this guide with support, advice and feedback from consumers, carers, palliative care specialists, health and aged care professionals. A series of focus groups with families who were currently receiving in-home palliative care and the bereaved carers of people who had received in-home palliative care services as well as a national survey of over 750 participants guided the content and information development.



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