



PALLIATIVE CARING

Information for people who are caring for a person with a life-limiting illness or condition



PalliativeCare
WESTERN AUSTRALIA

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DISCLAIMER

Every effort has been made to ensure this booklet contains information which is current and consistent with accepted standards of practice and available services.

Community diversity has been considered in the creation of this booklet. 

FEEDBACK

Palliative Care WA welcomes feedback on the content of this booklet. Please contact us with corrections or suggestions which will inform future editions.

 1300 551 704

 info@palliativecarewa.asn.au



We acknowledge the traditional owners of country throughout Western Australia and recognise their continuing connection to land, waters and community. We pay our respects to their elders, past, present and emerging.

INTRODUCTION

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

It is also a role that can be 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 this 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 for both the unwell person and your personal needs and circumstances. Rather than giving detailed medical or nursing information, it presents options to consider and references a range of approaches, services and supports that might be helpful.

Despite the 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. Your GP will play an important role not just for your loved one but also for you as you negotiate the myriad feelings, emotions and caring considerations.

Palliative Caring has been written for people who are caring for a person with a life-limiting illness or condition. It is a companion booklet to **My Palliative Care**, which has been written for people with a life-limiting illness or condition who are receiving palliative care. This booklet aims to provide you with information to help you understand the process of caring for someone who is dying and most importantly, provides resources to help you care for you.

“

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.

You matter.

”

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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**

CHAPTER 1

HOPE FOR THE BEST AND PLAN FOR THE REST

Receiving a serious illness diagnosis or a referral to palliative care can be overwhelming for both you and the loved one you are caring for. Perhaps neither of you know what the journey ahead will look like, and you both might be anxious and a bit fearful.

While the information in this booklet can't change the illness, it is hoped that it will help you understand how your loved one's illness might affect you both.

Following are seven keys that will allow you to be hopeful and prepared when facing the serious illness of your loved one.



ONE – Walk two roads

This approach encourages you to take two approaches at the same time – hope for the best and plan for the rest.

It is important to try to stay hopeful, but the type of hope might change over the course of the illness.

While you might hope for a cure in the early stages of your loved one's illness, this might change to hoping for the best outcome from treatments and the best quality of life for what time remains.

To plan for what may lie ahead, you need realistic information about your loved one's illness, but this can be tricky for a couple of reasons:

- you or they don't feel ready to ask the hard questions about the illness, treatment options or timeframes
- their medical team seems to focus on treatment plans only.

It can be hard to find the right words or the right time to raise questions or concerns. You might find that this type of conversation with your loved one's medical team is easier for your loved one if you help with this conversation. The most important thing is that you both get the right amount of information to help your loved one to plan for what matters most to them.

TWO – Zoom out

'Zooming out' is about enabling you and your loved one to access enough information to better understand their illness so that you both can plan ahead. This big picture view may enable you to both feel more grounded and in control rather than reactive and crisis-driven.

It is important to understand that while everyone's illness journey is slightly different, research and clinical experience has identified an average timeline for most diseases as an ability to identify an early, middle and late stage.

Having a road map for your loved one's journey is essential so that you can make informed choices, have a sense of control and realistic hope.

THREE – Know your style

All of us manage difficult things and difficult times in our own way. Think about problems that you have faced in the past – how did you manage them, who did you turn to for support? Recognising that you have supports and will need to share the load is about planning ahead. Make a plan to use your energy well – what tasks can you get someone else to do that would free up your time to spend with your loved one and other people who matter.



FOUR – Customise your order

To make sure that the care that is planned for your loved one is best suited to their needs, it is important for them to share information about who and what matters most to them, including:

1. Who are the important people in their lives – if they could not communicate for themselves, who do they think would be best to communicate on their behalf? Have they told them this?
2. Where do they want to spend their time?
3. If they become more unwell, where do they want to be cared for?
4. If they need to go to hospital, are there some treatments or procedures that they would not want?
5. Do they have cultural, spiritual and/or lifestyle needs that must be respected?

It is quite common for us to avoid these conversations with our loved one but without understanding what their values and preferences are, it's likely that the care they receive may not be what they would choose.

Time is precious, they are the most important person in this illness journey – they need to tell the people that they care about and their health care team what they would like their care plan to be.


FIVE – Anticipate ripple effects

The impact of your loved one's illness will not only be felt by your loved one but will also impact you and other important people in their life. This can be described as a 'ripple effect' and can result in lots of changes for all those concerned. The biggest change can be when your loved one may need help with the daily tasks of looking after themselves. This can take a lot of getting used to for your loved one and you and others helping with this care.



It is important to seek out professional support early to ensure that your loved one's care needs are supported as things change and that you as the carer don't become exhausted.

The Carer Gateway, managed by Carers WA, provides a wide range of services and supports for carers. For more information:

 **1800 422 737**
Monday to Friday
between 8am and 5pm

 **carerswa.asn.au**



SIX – Connect the dots

It is not unusual for you and your loved one to feel frustrated when you have to repeat information to different healthcare professionals. The reality is that information about their illness, treatment and current medications is not held in a central spot accessible to all health care staff. To make things easy for you and your loved one, it is a good idea to keep information about the following in one place and take it to every appointment with their GP or hospital doctor:

- list of medications being taken, including the dosage details
- dates of major medical events and the outcomes
- hospital admissions
- any changes in living arrangements
- any other events of significance.

SEVEN – Invite yourself

People accessing the health system are generally naturally respectful and wait for doctors and nurses to initiate conversations about important matters relating to the illness.

Progressive illnesses have lots of twists and turns so there should be lots of questions, discussions and decision-making for your loved one and you the carer.

People managing an illness journey often make comments like:

- I wish I didn't just go with the flow
- I wish I had asked more questions
- I wish that I had spoken up.

Key questions to start the conversation might include:

- How serious is this illness?
- Have you seen this type of illness before?
- What might this disease look like over time?
- Can care be provided at home or on country?

To get the best out of appointments with medical teams, encourage your loved one to be proactive by writing down questions and concerns and ask for more information if you or your loved one are unsure about what's been said. Your loved one should try to think about what matters most to them so they can make health choices based on this.

The above information is based on the seven keys to being hopeful and prepared when facing serious illness that have been developed by Hsien Seow PhD and Samantha Winemaker MD after many years of consultation with people who are ill, their carers and families, and informed by their research and medical experience.

Together they have written a book on this subject: Sammy Winemaker & Hsien Seow. *Hope for the Best, Plan for the Rest: 7 keys for navigating a life-changing diagnosis*. Page Two, 2023.

Should you wish to access their very informative and engaging podcasts, please listen to them here:

 waitingroomrevolution.com/season1



CHAPTER 2

MY ROLE AS A CARER

Sharing the end-of-life journey with someone who matters to you is both a privilege and a challenge. It offers the opportunity for closeness, intimacy and working together to achieve the very best outcome of healthcare, focussing on comfort and enabling the person who is unwell to set their life priorities.

The following quote from Carers Australia captures this well.

“

‘Caring for someone at the end of their life is not something all carers are able to do, but people who have say it is both the hardest and the most important thing they have done.

Whether you have been caring for someone for a long time or have only recently been told they have a life-limiting illness, realising they are not going to recover is a very emotional time. People sometimes think there is a right or wrong way to feel about dying, so the range of emotions experienced can be hard to cope with. Relationships can change significantly, and the caring role can become much more intense at this end of the caring journey, and into grief and bereavement.

Even if you have been caring for many years, awareness of approaching end-of-life can create new fears and uncertainties. There are things to think about and plan for. It is important that you take care of yourself during and after this time.’

”

For more information visit: www.carersaustralia.com.au/information-for-carers/palliative-care-and-end-of-life-care/



My changing role

Sometimes we do not identify ourselves as carers, even when we are fulfilling this role. Most of us first see ourselves in the context of our relationship, whether it is as a spouse, partner, parent, child, sibling, friend or neighbour. If you are providing help for someone you care about to carry out basic daily living activities, then you are a carer. If you are the person who is providing most of the support, then it is likely that you will be referred to as the 'primary or main carer'. This caring relationship can involve adjustment for every person involved – it can bring increased opportunities for closeness or, sadly, it might become a time of conflict. Taking time to talk to your loved one about what kind of care they might need as things change will help you understand whether there are aspects of this care that they do or don't want provided by you or family/friends.

Talking to your family and friends about what your role involves and what roles everyone else might have will go a long way to helping you understand how much care can be provided by others, where you might need professional help and what the limits of care might be. These conversations with your 'support system' will help reduce the risk of someone feeling unhappy or disconnected from the plan of care.



Allowing yourself to feel

Being a carer means that you will experience a range of feelings and emotions, some good and some not so good.

There are also times when you will see the funny side of things. It helps 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. It is important to recognise your physical and emotional limits.

It is okay if you stop being a carer. Even though you may have promised the person who is unwell that you will always look after them, it may not be possible due to unforeseen circumstances. 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 okay 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 different way. By handing over the physical care, you may be able to give the emotional support by providing an important sense of presence and full attention to the relationship. This can be a bonus.

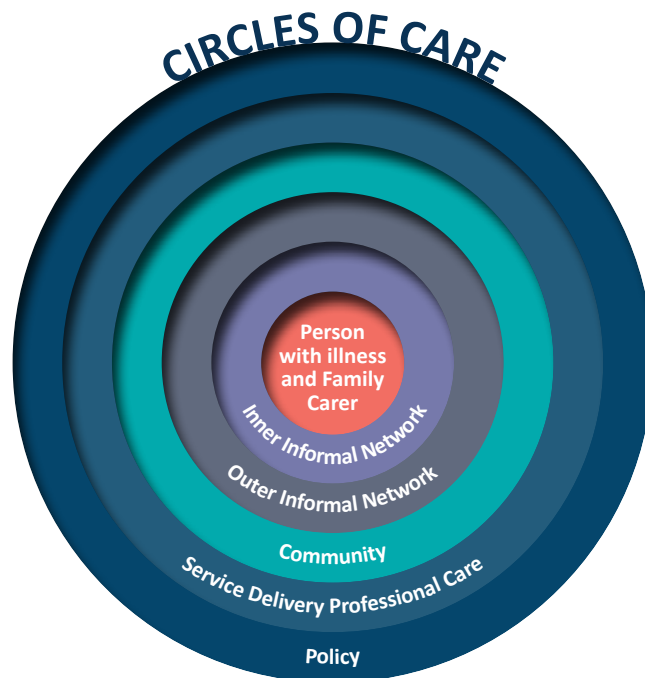
Asking for help and accepting it

Sometimes as a carer you may find it hard to acknowledge that you need help, fearing it is a sign of weakness or that you 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. Asking for help is important. Your wellbeing is vital to your role as a carer. By sharing the load, you will avoid becoming 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 cooking a meal, walking the dog, buying groceries and hanging out the washing can make a big difference. It helps to let others know what will be of greatest support. You could consider the following:

- 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.
- Setting up a roster if more than one person is providing care

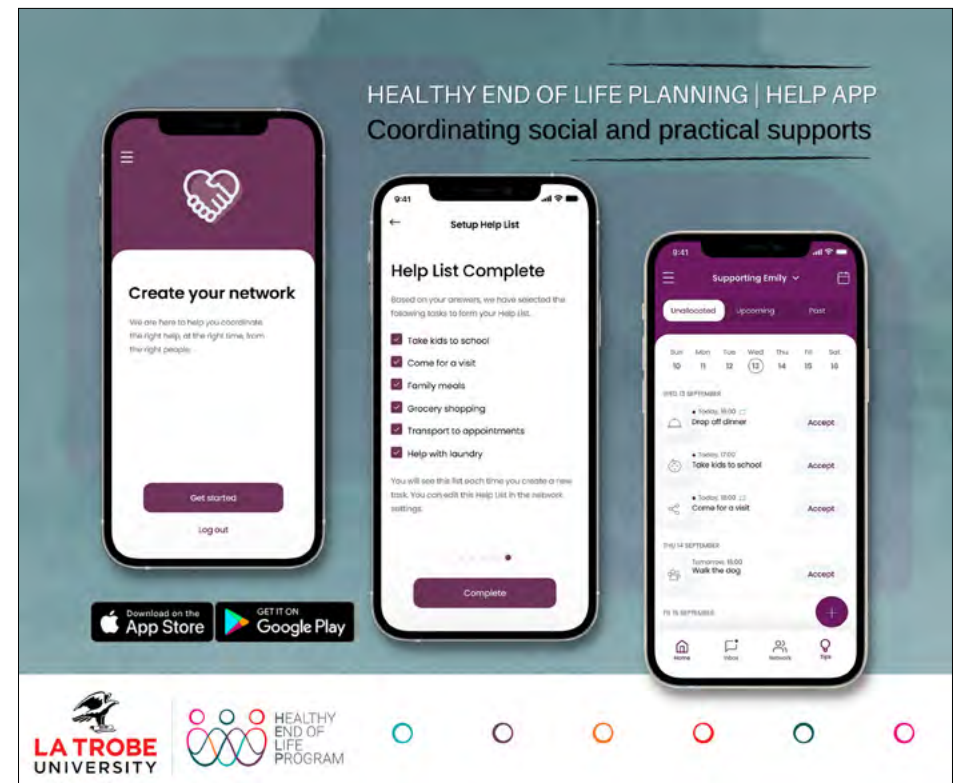


Mentioned by Abel et al (2013), and adapted by Aoun et al (2021) for the public health approach to palliative and end-of-life care.

- Asking a friend or family member to stay overnight, so you can get a good night's sleep.
- 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.

To help you coordinate social and practical care, consider using the HELP App created by La Trobe University's Public Health Palliative Care unit. HELP aims to help families by simplifying the act of asking for and accepting help with the goal of making a positive and meaningful difference to the wellbeing of everyone involved.

For more information visit www.healthyendoflifeprogram.org
Download the App via the App Store and on Google Play.



Respite care


Respite care provides you with an opportunity to have a break from the caring role. Respite can be provided by your friends and family, and you may choose to create a roster of people (see the HELP app p.15) who are willing and able to provide a few hours each week to be with your loved one while you take some time for yourself.

In-home respite can also be available through care organisations such as aged care providers – there may be a cost associated with this.

Out-of-home respite (residential respite) is usually provided in an aged care home. It is best suited to people who need carer support for most tasks and can be for a few days through to a few weeks at a time. There will be a cost related to this care.


Respite care is often planned in advance. For instance, if you are planning a trip or have an appointment to attend. However, it is also available in emergencies or for unexpected situations.

If you need emergency respite care, contact **Carer Gateway**:

 **1800 422 737**

 **carergateway.gov.au**

For tips on a successful home respite, see the resource below that was adapted by WA Primary Health Alliance and Albany Community Hospice from a resource by Murrumbidgee Primary Health Network – part of the Australian Government national PHN program:

 **albanyhospice.org.au/wp-content/uploads/2021/02/Planning-a-Successful-in-home-respite-visit-Small.pdf**



Ongoing communication

It is normal for our relationship with the person we are caring for to sometimes be easy and sometimes be difficult. 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. Our 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. This can be 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 if their questions are dismissed. Encourage them to ask questions and then provide reassurance. Expressing our emotions, including sadness, gives children permission to do the same.

It helps to give children choices about how to interact, whether that is face-to-face, drawing pictures, making cards or sending photos, messages or letters.

It also helps if we 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, you might suggest a reasonable period of time for their stay. As the time to leave approaches, you might remind them if necessary.

It also helps to 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.



CHAPTER 3 CARING FOR MYSELF

Caring for someone with a life-limiting illness can be both fulfilling and challenging. On top of that role, you may also 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, spiritual, and mental health is important, so be sure to make this a priority. There is no need to feel guilty about caring for yourself. Many people receiving care feel better if they know their carers have a life balance as well as opportunities to rest.

Consider visiting your GP if you are struggling emotionally or physically. They can recommend counselling services and options, such as a mental health plan through Medicare, as well as other support services if appropriate.

Get some exercise. Doing something physical will help you maintain fitness, wellbeing 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. 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 have difficulty on a regular basis, see your GP. Most 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. Make sure to take up any offers of meals provided by family or friends.

Be social. Try to maintain social contact with friends, other family members and usual social groups. There are various online support forums available but most importantly keep up your usual activities as much as possible.

Practice your own spirituality or religion. Whether it be meditation, yoga, mindfulness, prayer or conversations with a spiritual care worker, maintaining religious or spiritual practice will assist you in staying well.

Do something for yourself every day. Consider activities to help clear your mind including walking, gardening, and meditation or listening to music. Take a break. List the things you enjoy that would give you a short break and renew your energy. Participating in something enjoyable each day can revitalise your wellbeing.



CHAPTER 4

WHAT IS PALLIATIVE CARE?

The main aim of palliative care is to help your loved one to have the best quality of life possible, and to live with dignity and respect until they die. Palliative care also supports the people who matter to the person who is dying in dealing with loss, grief and healing.

Who is palliative care for?

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 and other neurological conditions, or end-stage kidney, heart or lung disease.

For some people, palliative care may be helpful from the time of diagnosis of a serious life-limiting illness.

Palliative care can be provided alongside other treatments.

Where is palliative care provided?

Palliative care is provided where the person and their family want it to be provided, where possible. This may include:

- at home
- in hospital
- in a hospice
- in a residential aged care facility.

Who is in the palliative care team?

Palliative care may be provided by a wide range of people, including your loved one's GP, aged care worker, cardiologist, and any other health care provider, as well as family and other carers. They are supported by specialist palliative care services if symptoms become difficult to manage.

What is specialist palliative care?

Specialist palliative care is provided by a team of health professionals who have undertaken extra training to provide specialist care for people with a progressive life-limiting illness who are experiencing difficult problems that are not being resolved by the current approach to care.

Specialist palliative care teams work in collaboration with your loved one's GP. If they do not currently have a GP, it is very important to find one who will support them.

How does your loved one get palliative care?

For help and information, your loved one should ask their:

- doctor
- Aboriginal health worker
- hospital liaison officer
- nurse.

Diverse communities

Each person's uniqueness influences how they express themselves and how they interact with the world. It can shape a person's response to pain and illness, and their willingness to accept palliative care.

Palliative care does not try to define who a person is based on the population group or groups that they belong to. It is a speciality that is person-focused, understands that people often identify with a number of population groups, and is accepting of diversity.

Diverse populations can include people who are:

- Aboriginal and Torres Strait Islander
- culturally and linguistically diverse
- people with a disability
- homeless
- LGBTQIA+
- care leavers
- prisoners.

It can be difficult for healthcare professionals to understand exactly what is important to your loved one, even if they are aware of a group they identify with. There are sometimes barriers in place for people from diverse communities. This is why it is so important that wishes are communicated and that your loved one documents what is important to them in an Advance Care Plan.

Diversity brings a richness to who people are and by communicating their needs, beliefs and values, those working in palliative care can look to not only provide person-centred care but also to assist your loved one with accessing services that may be most beneficial and appropriate to them.

Complementary and alternative therapies

Many people receiving palliative care explore therapies outside conventional medicine and may find them beneficial. It is wise to discuss these options with health professionals managing your loved one's care so that any potential side-effects or undesirable interactions with prescribed medication are understood. Be careful not to presume that because something is deemed natural, it won't cause harm.

Bush medicines and complementary therapies aim to enhance quality of life and improve wellbeing. They are generally used in addition to conventional medical treatment. Some palliative care staff and trained volunteers may offer complementary practices such as 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 may be used in addition to planned care. They can include various diets, herbal and homeopathic therapies. There are varying levels of evidence for these therapies, and some have been found to be harmful.

It is important that your loved one informs their healthcare team about any additional therapies they are using to make sure any risk of interactions with prescribed medicines can be avoided.


Where can I find more information?


Your loved one can contact their GP or hospital team, or the Palliative Care WA Helpline 1800 573 299 or Palliative Care WA's office on 1300 551 704.


Multilingual Palliative care factsheets are available on the following website:

 palliativecare.org.au/resource/multilingual-resources/

You may wish to access an interpreter. For more information contact the Australian Government's Translating and Interpreting Service or telephone 1800 131 450.

LGBTQ+ Toolkit for Palliative Care and end of Life Decisions is an informative resource ( acon.org.au/what-we-are-here-for/palliative-care-support/).

Talking End of Life ( caresearch.com.au/tel/tabid/5100/Default.aspx) is a great source of information for how to teach people with intellectual disability about end of life. Learn more about advance care planning and disability.

 advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-in-specific-health-areas/advance-care-planning-and-disability



CHAPTER 5

PLANNING AND DECISION-MAKING

Advance Care Planning

Advance Care Planning (ACP) provides a way for someone to have a say in what happens in the last part of their life. It involves making plans that cover future care, lifestyle, health and financial arrangements.

Everyone is encouraged to have an ACP in place – your loved one and also you as an individual and carer. Being prepared makes things easier and clearer for everyone concerned, including family, friends, carers and health professionals.

“It is important for individuals to convey their preferences while they still have the legal capacity to make decisions.”

Advance Care Planning can be explained in four easy-to-understand steps – Think, Talk, Write and Share. The diagram below shows what is involved in each of those steps.



Palliative Care WA offers free advance care planning community workshops in-person or online. Some are *Safe Space* online workshops which are **only open** to people with a chronic condition or terminal illness, as well as their carer. Comprehensive resource packs are provided upon registering.

📞 1300 551 704

🌐 palliativecarewa.asn.au/advance-care-planning

Palliative Care WA also offers a free in-person support service that provides personalised and practical help with advance care planning in your home, at our office or elsewhere in a community setting.

📞 1300 551 704

🌐 palliativecarewa.asn.au/carers-and-families/advance-care-planning/advance-care-planning-support-service/



The written components of Advance Care Planning

Values and preferences

A values and preferences form is a record of what someone values and what they want in the last stage of their life. It can include where they want to live and what living well means to them including special preferences, requests or important messages.

This form guides health professionals, enduring guardians, family and carers, and is particularly useful if at some time in the future the unwell person is unable to communicate their own wishes.

It is a non-statutory document as it is not recognised under specific legislation. In some cases, a values and preferences form may be acknowledged as a Common Law Directive.

 healthywa.wa.gov.au/ACPvaluesandpreferencesform


Making a will


A will is a written, legal document setting out how a person wants their assets and belongings distributed upon their death. If a person dies without leaving a valid will, an administrator will be appointed to distribute property and other assets in accordance with the law. This can take many months. A new will should be made when financial or personal circumstances change, for example, divorce, separation, new partner, new children, new stepchildren or new grandchildren. A person must be of sound mind when they make a will and appoint one or more executors to administer it after they die.

It is important to note that there are some assets that are not covered by a will. People with superannuation funds or insurance policies should nominate a beneficiary. Jointly held assets (property and bank accounts) will pass to the other owner. Property trusts are not covered.


Legal advice is recommended before making a will. For more information, contact:


Public Trustee

 1300 746 116

 publictrustee.wa.gov.au


Citizens Advice Bureau


 9221 5711

 cabwa.com.au


or a lawyer of your choice

Aboriginal Legal Service

 1800 019 900 Free call

 als.org.au

Elders Rights WA

 1300 650 579 Free call

 EldersRightsWA@legalaids.wa.gov.au

Enduring Power of Attorney

In WA, an enduring attorney is the person legally appointed to make property and financial decisions on behalf of someone who is no longer able to make or communicate their decisions. A Power of Attorney or Enduring Power of Attorney only relates to decisions about money and property and does not include a person's medical treatment and care. The Enduring Power of Attorney ends when the person who has made it dies.

The person you are caring for can appoint one or two people as their Enduring Attorney. It should be someone they trust to make decisions in their best interest and who will follow their instructions.

Enduring Power of Guardianship

In WA, an enduring guardian is the person legally appointed to make personal, lifestyle and treatment decisions on behalf of someone who can no longer make or communicate decisions for themselves. The person you are caring for can give their enduring guardian the capacity to make all personal, lifestyle and treatment decisions on their behalf or they can limit authority to specific areas.

When making treatment decisions, the enduring guardian should take into account the person's expressed preferences along with their clinical situation, the risks, as well as the burdens and advantages of proposed treatments. An enduring guardian should be chosen carefully, briefed thoroughly and regularly to ensure the person's preferences are clearly understood.

An enduring guardian cannot overturn treatment decisions made in an Advance Health Directive.

Advance Health Directive

An Advance Health Directive is used to document preferred future medical treatments and procedures.

This may include whether the person you are caring for wishes to receive palliative care, and consent to life-sustaining measures such as assisted ventilation and cardiopulmonary resuscitation.

An Advance Health Directive can also be used to refuse treatment, including food and fluid, under specific circumstances.

Treatment decisions outlined in an Advance Health Directive will come into effect only when the person you are caring for is unable to make or communicate decisions. An Advance Health Directive is a legally binding document and must be completed by the person you are caring for when they have legal capacity to make decisions. Seeking advice from a health care professional is recommended when completing an Advance Health Directive. It must be written in English.


 healthywa.wa.gov.au/AdvanceHealthDirectives

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.

Office of the Public Advocate

 1300 858 455

 justice.wa.gov.au/epa

For more information regarding
My Health Record:

 1800 723 471

 myhealthrecord.gov.au



Other considerations

Choice of 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 you are caring for who is dying to discuss their views and preferences with you, family and friends. It is also important to note that plans are not always able to be met as they are open to change depending on individual circumstances. While it is important to support the choice of your loved one, not all carers will be comfortable with having their loved one die in their home/bedroom. A conversation is needed so that you and your loved one's wishes are considered.

A discussion with your GP and other services involved in supporting care at home will provide a clear picture of what can be provided. 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 home, a palliative care unit, a hospice or your local hospital.

Funeral planning

Talking about funeral arrangements may cause a lot of emotion and for some people, this may be something that is never discussed while the dying person is still alive. You will know what the right approach within your family is and/or your community.

If possible, start with the person you are caring for regarding their preferred funeral arrangements. Next, talk to key members of your family and important friends. If plans are not clearly articulated, then there is a risk that people will have different opinions that may cause conflict.

If there are important burial traditions that need to be respected after the death of your loved one, then you must make your loved one's health care team aware of these requirements.

Important considerations include:

- the type and style of funeral service: family led, direct/unattended, private committal, church, cemetery chapel, graveside, memorial, or other
- burial, cremation or entombment
- coffin or casket
- death notices, mourning vehicles and flowers
- poetry, music, readings, photo presentations or memorabilia
- preferences of deceased, family and friends
- minister, celebrant or friend to officiate
- ashes placement
- cost implications.


A pre-paid funeral may provide peace of mind and remove the stress of arranging a funeral during a period of considerable grief. A funeral director can guide you through the planning process and explain your options.

Organ and tissue donation

To be considered as an organ donor, a person usually must die in an intensive care unit and be on life support. However, if they die in a general ward or out of hospital, they may still be able to donate some of their tissues.

It is important that you and others closest to the person you are caring for know if they want to be an organ and tissue donor. Relatives will be asked to give their consent before the donation can occur. Please note that family can overturn the decision of a registered donor.

Donate Life WA

 **1800 950 155**

 **donatelifewa.gov.au**

Body donation

The University of Western Australia (UWA) is licensed to practice anatomy and to accept body donations from members of the WA community.

These bodies are used for anatomical teaching, medical and scientific research, and specialist training at many teaching and research institutions. Bodies may be kept for up to five years before being cremated and with the ashes either returned to the family or interred in a memorial garden at Karrakatta Cemetery.

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

For more information or to register contact the **UWA's Body Bequest Program**:


 **uwa.edu.au/science/resources/body-donation-program**

Alternative care arrangements

Along with an Advance Care Plan for yourself and the person you are caring for, it is important that you both consider substitute care arrangements should you no longer be able to continue in your caring role. Consideration should be made for short-term and potential long-term care needs should you experience an unexpected event that causes you to be unable to continue in your caring role.

There may be other people within the current care network, such as family or friends who may be willing to provide care on a short-term basis while you are unable to. It is important to have discussions within the care network regarding an alternative caring plan before the need arises.

For more information or support contact **Carers WA**:

 **1300 227 377**

 **carerswa.asn.au**

Culturally and Linguistically Diverse Communities

Advance care planning information is available in 20 community languages, including Italian, Vietnamese, Greek, Croatian and Arabic from:

 **healthywa.wa.gov.au/Articles/A_E/Advance-care-planning**

Aboriginal Communities

An advance care planning information brochure for the Aboriginal communities of WA is available on the WA Department of Health website:

 **healthywa.wa.gov.au/~media/Files/HealthyWA/New/Advance-Care-Planning/Aboriginal-Advance-care-planning.pdf**



CHAPTER 6

CARING AT HOME

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 mean having additional care support come into the home or for care to be given in a different environment, such as a care facility or hospice. 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 a number of service providers offering in-home support that also provide specialist palliative care. In addition to providing nursing care, a visiting palliative care nurse can provide guidance and advice to you and the person you are caring for as well as help coordinate care from other services, health and allied professionals. Your GP or your loved one's GP can help connect you with the right services for you both.

Preparing the home

Caring for someone at home may require changes to rooms, additional fittings and equipment or even some structural changes. Changing the home can be disruptive to other family members, so first having a discussion to consider everyone's needs is important. The arrangements you make may need to change as the person's condition changes.

Physiotherapists and occupational therapists are well-placed to review the physical needs of the person you are caring for and suggest what will make the home safe for everyone. Occupational therapists have expertise in changing the way you do important daily activities and manage fatigue, pain, breathlessness or memory changes by providing information, 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 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.

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

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 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 handrails 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 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 daybed in the living room, ideally with a garden view.

If they find it difficult to get into or out of bed, seek advice on what specialised equipment might make it safer and easier. Reduce trip hazards and make getting around easier by removing unnecessary furniture and take 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, 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 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 alarm, which you can hear from any part of the house or garden, might bring you both peace of mind.





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. It is important to promote and support the independence of the person you are caring for while also planning care to reduce the risk of falls.

It is likely their personal care needs will increase over time which may in turn change your role in providing that care. 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.

It is not necessary for the person you are caring for to have a shower or bath each day. As the person that you care about and care for becomes more tired, the routines around hygiene need to be adapted.

Repositioning 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 mouths, 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 soft foam or cotton heads on the end of a stick, can be purchased untreated or impregnated with a flavoured paste.

If the person is 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. Lip balms can relieve 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 your loved one's 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 as needed. 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.

Clothing

It is important for clothes to be comfortable and practical as you need to be able to dress and undress your loved one 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.



Some helpful tips include:

- 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 food 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 consume 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.

CHAPTER 7

RURAL AND REMOTE CONSIDERATIONS

Palliative care for country patients

Palliative care in country WA is provided by doctors, nurses and allied health staff who are based in the local area. They are supported by specialist palliative care teams from WA Country Health Service who can provide palliative care within the home, hospital, hospice or palliative care unit, residential care facility and on country.


The specialist palliative care teams include Aboriginal health liaison workers, general practitioners, nurses, palliative care specialists and allied health professionals. They work from bases throughout regional WA and can travel to see people in their own communities. Their aim is to offer a choice to patients to receive the best palliative care in the location they wish.

WA Country Health Service uses innovative solutions to be able to provide palliative care across the vast distances of WA which include:

- supporting patients and carers in the home by providing nursing and medical support via personal devices such as iPads and smart phones
- partnering with community care providers to deliver packages for home care support and carer respite
- using purpose-designed resources to teach carers to manage symptoms and safely use injections.

In country WA, any health professional can make a referral to the specific regional palliative care service.

For those who need to travel over distance for treatment, support is available through the **Patient Assisted Travel Scheme (PATS)**. This scheme provides a subsidy towards the cost of travel and accommodation for eligible permanent residents who are required to travel long distances to access specialist services including Telehealth. For more information visit:

 wacountry.health.wa.gov.au



Carer education

A free online education opportunity is available for anyone in WA through the Carer Education Program provided by Busselton Hospice Care. This program provides education and training in the practical elements of caring for a very unwell/dying person at home and develop the skills and confidence of participants to care for a person at end of life.

The program consists of three online webinar training sessions:

- Session One – Symptom and Pain Management – 90 mins.
- Session Two – Dealing with Medications and Health Professionals – 90 mins.
- Session Three – Practicalities of Providing Care – 90 mins.

Participants are supported with presentation handouts and resource material available online via an email link. Participants can self-refer to the program, which is delivered on a flexible 'as needs' basis and is offered free-of-charge.

Please contact Busselton Hospice Care on (08) 9751 1642 for details about the program schedule and video conference (webinar) arrangements.



CHAPTER 8

LAST DAYS OF LIFE

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, personal view of the world or a connection to something bigger than us that helps 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 spiritual care worker. People with no faith or religion may wish to explore this.

Intimacy

It is important to recognise that when someone is dying, they may 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. Equally, some people may not seek physical contact.

Intimacy may include physical contact 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, but this is an individual choice.

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 delivering 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. Their desire or need for food and fluid may reduce or stop altogether. This usually does not cause any discomfort and is a normal part of the body's preparation for death.

Becoming vague, confused or restless

Sometimes people become quite restless in the 24-48 hours before they die. This can often settle easily with reassurance or with prescribed medication. If the restlessness is not settling with simple measures or is becoming more distressing, it is important to have your loved one assessed by a health care professional. The restlessness is not necessarily the result of pain, particularly if they have not experienced any prior pain. 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 else comes in to indicate their presence.

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. Hearing may be affected and though they may not be responsive to conversation, they may find familiar voices calming. Encourage family, friends and other visitors to talk with them, and between themselves, so the person is aware they have company.

Incontinence

Loss of bladder and bowel control may occur when the person is very near death. Use incontinence pads to maintain comfort and hygiene and additional linen to protect the bed.

Breathing

When someone is approaching death their breathing pattern changes. You may notice gaps in breathing of several seconds or several minutes. This is part of the natural process of dying 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 putting them onto 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.



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.

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 but also possibly 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 which reflects the strain they are under. It is a very understandable reaction, so it is important to talk about these feelings so you do not feel guilty about them.

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

Preparing your loved ones

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 may encourage sharing, for example, 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 as 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 if they cry.

GPs have a critical role in end-of-life care for patients who wish to die at home. Your GP may go through a checklist or plan with you to make sure that you feel prepared and have important information about what supports are available in the last days of caring for your loved one and what to do after your loved one has died. This checklist can be found here:

 caresearch.com.au/Portals/20/Documents/Health-Professionals/GPChecklistForAHomeDeath.pdf



CHAPTER 9

DEATH AND BEREAVEMENT

Signs the person has died and what to do next

The main signs that tell us someone has died are their breathing ceases and they have no heartbeat.

Contact your doctor or registered nurse and let them know that your loved has passed away. The doctor or nurse will need to come to the house to confirm the death and organise a death certificate.

After this, your chosen funeral director will provide advice on what to do next, including attending to the body and beginning funeral arrangements.

DO NOT CALL THE POLICE or AMBULANCE, unless this is the usual process in your community.

Your loved one's body can remain at home for a period of time to allow family and friends to say goodbye – it is important that this area/room is kept cool.

Caring for yourself

It can be a time of great sadness 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 thoughts, behaviour, beliefs, emotions, physical health and relationships with others.

You may have mixed reactions, including shock, 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 or length of time for those who do.

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 the death of your loved one.

Grief is the healing process for loss. Over time, the strength of your sadness and pain lessens as you adjust to life without your loved one. As difficult as it is, grief is related to the degree of attachment we feel towards the person who has died. As time goes on, there may still be things that trigger your pain and sadness, months or even years later and these emotions are all part of the healing.

Suggested approaches for bereavement self-care include:

- delaying major decisions if possible
- finding a creative way to express 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 alcohol and caffeine intake, particularly before sleep
- sharing memories and stories with others
- asking for help and accepting support from others.

Caring for our 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 family members know 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. You need to be conscious of your own needs to grieve and so 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 it can be surprising how much they work out for themselves.

One approach to discussing a loved one's death is to ask them what they know and invite any questions. Questions should be answered honestly and consistently. They may have an increased curiosity about death, experience 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 to their questions many times.

Some children will experience a loss of concentration and have dreams and nightmares. As with adults, children's responses will vary. They very often express their emotions through their behaviour, rather than in words. It might be helpful to let the child or teenager's school know what is happening in their family.

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. Children may benefit from creating memories of their loved one, by sharing stories, visiting their grave and creating a memory box.

Where possible, you can 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. You could pose a number of scenarios so they can choose the options they feel most comfortable with.

There are a number of organisations that provide support to children and teenagers who are grieving. Please see the resources and contacts section of this booklet.

Who to advise of the death

As well as family and friends, it is advisable to let your loved one's GP and hospital specialists know when they have died. There are also a number of government departments, agencies, businesses and organisations that should be contacted when a loved one dies.


The Australian Death Notification Service is an Australian Government service that is supported by each of the states and territories in Australia. It is a free government initiative to help people get in touch with multiple organisations using a single online notification. To find out more, visit:

 deathnotification.gov.au

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

 servicesaustralia.gov.au/death-loved-one

To find out more on what to do with a loved one's digital profile, visit:

 esafety.gov.au/key-issues/how-to/digital-legacy

CHAPTER 10 RESOURCES

My Community Directory

My Community Directory is the one place people go to find community services and events so they can understand what's happening in their local community. The online directory includes hundreds of local health, social and community services across WA that the WA Primary Health Alliance has partnered with and invested in to address inequity and access.

These services provide high-quality treatment and support for both physical and mental health, improving access to primary healthcare, and helping Western Australians stay well and out of hospital.

 mycommunitydirectory.com.au

Indigo (formerly the Independent Living Centre)

Indigo provides a wide range of services, including community allied health and home modification services, carer support and respite, assistive technology and equipment, occupational therapy driver assessment, as well as equipment grants and other subsidies.

 indigosolutions.org.au




 (08) 9381 0600

CHAPTER 11

CONTACTS

Lasting Words

The Lasting Words project allows people who are approaching the end of their life to have their stories, thoughts and special memories captured. 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.

-  palliativecarewa.asn.au/volunteering/the-lasting-words-project/
-  1300 551 704
-  lastingwords@palliativecarewa.asn.au

Lion Heart Camp for Kids

Lion Heart Camp for Kids is a WA not-for-profit organisation that empowers bereaved children and families to navigate their grief journey through education, peer support, strength building and resilience.

To find out more visit:


-  lionheartcampforkids.com.au

Feel the Magic



Feel the Magic is an Australian charity providing early intervention grief education programs for children aged 7 to 18 years, who are experiencing pain and isolation due to the death of a parent, guardian, or sibling.

-  feelthemagic.org.au
-  feelthemagic.org.au/activities-for-grieving-children-and-teenagers/



Advocare

-  1800 655 566
- WA Elder Abuse Helpline**
-  1300 724 679
-  advocare.org.au



Alzheimer's WA

-  1300 667 788
-  alzheimerswa.org.au



Breast Cancer Care WA

-  (08) 9324 3703
-  breastcancer.org.au



Cancer Council WA

-  13 11 20
-  cancerwa.asn.au



Carer Gateway

-  1800 422 737
-  carergateway.gov.au


Caresearch

-  (08) 7221 8233
-  caresearch.com.au



Centrelink

-  13 27 17
-  servicesaustralia.gov.au



Citizens Advice Bureau

-  (08) 9221 5711
-  cabwa.com.au



Continence Foundation of Australia

-  1800 330 066
-  continence.org.au



COTA WA

-  (08) 9472 0104
-  cotawa.org.au



Dementia Australia WA

- National Dementia Helpline**
-  1800 100 500
-  dementia.org.au



GriefLine

-  1300 845 745
-  griefline.org.au

Huntington's Western Australia

-  (08) 6457 7599
-  huntingtonswa.org.au

Indigo

-  (08) 9381 0600
-  indigosolutions.org.au

Ishar Multicultural Women's Health Centre

☎ (08) 9345 5335
🌐 ishar.org.au

Lasting Words

☎ 1300 551 704
🌐 palliativecarewa.asn.au
✉ lastingwords@palliativecarewa.asn.au

Leukaemia Foundation

☎ (08) 6241 1000 (WA)
1800 620 420
🌐 leukaemia.org.au

Lifeline WA

☎ 13 11 14
🌐 lifeline.org.au
wa.lifeline.org.au

Motor Neurone Disease Association of WA

☎ (08) 6186 4133
🌐 mndawa.asn.au

MSWA

☎ (08) 6454 3222
1300 097 989
🌐 mswa.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

Neurological Council of WA

☎ 1800 645 771
🌐 ncwa.com.au

Office of the Public Advocate

☎ 1300 858 455
(08) 9278 7300
🌐 publicadvocate.wa.gov.au

Palliative Care Helpline

☎ 1800 573 299

Pancare Foundation

☎ 1300 881 698
🌐 pancare.org.au

Parkinson's Western Australia

☎ (08) 6457 7373
🌐 parkinsonswa.org.au

Public Trustee

☎ 1300 746 116
🌐 publictrustee.wa.gov.au

Relationships Australia

☎ 1300 364 277
🌐 relationships.org.au

Services Australia

Contact Information
🌐 servicesaustralia.gov.au

Silverchain

☎ 1300 650 803
🌐 silverchain.org.au

Solaris Cancer Care

Sir Charles Gairdner Hospital
☎ (08) 6383 3475

St John of God Subiaco

☎ (08) 9388 9788
🌐 solariscancercare.org.au

The Department of Veteran's Affairs

General Enquiries
☎ 1800 838 372

Counselling Service

☎ 1800 011 046
🌐 dva.gov.au

The Grief Centre of WA

☎ 0404 658 052
🌐 griefcentrewa.org.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

This book is available for download as a PDF file from the Palliative Care WA website:

🌐 palliativecarewa.asn.au

To have a free booklet posted to you, please contact Palliative Care WA:

☎ **1300 551 704**

✉ info@palliativecarewa.asn.au

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