

Living, dying & grieving well

A guide to palliative care



Appreciation

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Palliative Care
V I C T O R I A
Specialist health care and practical support



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Palliative Care Victoria Inc.
Suite 3C, Level 2
182 Victoria Parade
East Melbourne Victoria 3002

Tel +61 03 9662 9644
Fax +61 03 9662 9722
E info@pallcarevic.asn.au
W www.pallcarevic.asn.au and www.pcvlibrary.asn.au

Reg. Inc. No A0022429M
ABN 88 819 011 622



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Introduction

Palliative care helps people with a life-limiting illness to live, die, and grieve well.

This booklet helps you understand what palliative care is and how it can help improve your quality of life, at any stage of your illness.

You can read it in any order, at your own pace, and when you are ready.

Palliative Care Victoria was established as a charity in 1981. We work with government, palliative care services and other groups to enable people to receive high quality palliative care when and where they need it.

We want more people to know about palliative care, and to help the community deal with life-limiting illness, death, grief, and loss.

We hope you find this booklet helpful.

Palliative Care Victoria can help you find a palliative care service or give you more information. Our contact details can be found at the end of this book.



..quality of life..

about palliative care

“Palliative care is for the living. They helped us get our lives back on track.”

What is palliative care?

Palliative care is specialised care that helps you live well with a life-limiting illness.

The aims of palliative care are to make you comfortable, to improve your quality of life, and to support family and friends involved in your care.

Palliative care professionals are trained to help with difficult issues such as managing pain and other symptoms or needs you may have. They include palliative care doctors, nurses, physiotherapists, occupational and speech therapists, counsellors, social workers, other staff and trained volunteers.

Palliative care services work with you, your family, your GP and other health services to provide the best possible care. The type of support available to you will depend on your needs and the services in your local area.

Depending on your needs, palliative care services may help with a specific issue for a short time, or they may become more involved over a longer period of time.

Most importantly, palliative care supports you and your family to make important decisions about your care and quality of life.

Whole person care

Palliative care doesn't just treat your body. It also cares for your social, spiritual, emotional and cultural needs. Palliative care looks after you as a whole person.

Because palliative care focuses on your quality of life, it helps you to live as well as possible and, when the time comes, to die in comfort.

Your palliative care team can help you to plan ahead and share your wishes about your care and other arrangements. They can help you to get legal advice, financial assistance and other information.

Palliative care assists you to be at peace with yourself and those you love. It can be very helpful to talk about fears, feelings and any regrets, especially with those close to you.

Many people find this is a time when they think about the meaning of their life. Palliative care has counsellors and spiritual care workers you can talk to.

Support for family

Palliative care also gives practical and emotional support to family and friends involved in your care. This can include care advice, equipment, a break from providing care, carer support groups, and counselling.

Who can benefit?

Palliative care is for anyone with a life-limiting illness who needs specialist support. It can help people with a wide range of conditions, such as cancers, chronic diseases, dementia, and degenerative conditions.

People of all ages, cultures and beliefs can receive palliative care.

Does this mean I'm giving up hope?

Not everyone who receives palliative care is about to die. Some people live with their condition for a long time, others have periods of wellness, and some may recover. People can move in and out of palliative care as their needs change.

Hope continues to be important – what one hopes for, however, may change.



Hope continues to be important..

Who gives palliative care?

Palliative care is delivered by a team, including your GP and specialist doctors, as well as nurses, social workers, physiotherapists, occupational and speech therapists, spiritual carers, other staff and / or trained volunteers. Your family and friends can also play a big role.

Where can I get palliative care?

Most palliative care is provided in your home or where you live by a community palliative care service.

You can also receive palliative care in a hospital, a hospice (a special facility that provides palliative care), or other health or care facility.

Ask your GP or contact your local community palliative care service or Palliative Care Victoria.

Do I need to pay?

Most palliative care services are free, although private therapists, some hospitals and hospices may charge fees. If you are unsure, talk to your palliative care team.

How do I get palliative care?

Your GP, you or your family can contact a community palliative care service directly.

A referral from a doctor is needed for admission to a specialist palliative care facility (sometimes called a hospice) or hospital.

Speak to your doctor or palliative care team about your specific needs. Ask lots of questions and tell them what your needs, wishes and fears are. Writing these down can also be helpful.



..Ask lots of questions..

Debbie's^{story}

"My son Oliver was a healthy, cheeky boy until age 12, when he started to stumble and fall.

When the children's hospital found Oliver had a very rare and incurable illness, they introduced us to a community palliative care team.

Oliver received palliative care at home from time to time over three years. He was able to go to school sometimes.

The palliative care nurses visited regularly and were there whenever he needed additional support.

I had a counsellor to support me, and a volunteer came every week to sit with Oliver so I could go shopping or just have a little time out.

I could not have cared for my darling boy at home without the palliative care team – they showed me how to nurse him and walked with me through the most difficult time.

I knew I could always call them and I valued their support." - Debbie



personal comfort and wellbeing

"Palliative care is a blessing. They eased my pain so I could get on with living."

Physical comfort

Your personal comfort and wellbeing are very important. Your palliative care team will help you to be comfortable and free of pain so you can focus on what is important to you.



Pain

Many people fear pain and think that it can't be controlled. Palliative care doctors and nurses are specially trained to control pain so that it disappears or is lowered to a level that you are comfortable with.

If you are worried about pain, talk to your palliative care doctor or nurse. They will work out the best treatment to relieve your pain and discomfort.

Morphine and codeine are very effective medicines used in palliative care to relieve pain. These medicines are sometimes called 'opioids'.

There is a lot of misunderstanding about how these medicines are used in palliative care. Some people worry about becoming addicted to the medicine. Others worry that using morphine brings on death. Neither of these is true. Palliative care uses these medicines in safe ways. You will not become addicted and they will not give you a 'rush' or a 'craving'. Nor will they make death happen any sooner.

Your pain medication will make you as comfortable as possible. Don't wait until you are in pain to take your medication. Take them on time and as advised.

Some pain medications have side effects like nausea and constipation. These can be treated.

If the medicine does not seem to relieve your pain as expected, talk to your palliative care team or doctor so they can find the best solution for you.

Palliative care also uses other ways of relieving pain, such as physiotherapy, hot or cold packs, and meditation. Talk to your palliative care team about any pain or other symptoms and they will help to make you comfortable.

Nausea and lack of appetite

Nausea (feeling as though you may vomit) and lack of appetite are sometimes part of advanced illness. It helps to understand these symptoms and how to relieve them. Nausea and lack of appetite can be due to a range of factors, including:

- certain smells, tastes, sights or movements
- feelings such as sadness, depression or anxiety
- not drinking enough water
- constipation
- kidney or liver problems
- infection
- some medications.

If you feel sick or don't feel like eating, discuss this with your palliative care team. They will check for any causes that can be treated and help you with these symptoms. They may also refer you to a dietitian or speech therapist.

If you have nausea or loss of appetite, eating small meals regularly can help. Eat your favourite meals – it is more important to eat what you enjoy than to worry about a balanced diet.

Fatigue and exhaustion

Extreme tiredness may also affect you and your family carer. You may not be able to concentrate. You may feel fuzzy-headed, irritable or easily upset. Some treatments and medications can cause fatigue.

Taking naps during the day, doing small amounts of exercise, and making sure you don't do too many activities in a day, can help to reduce fatigue. Doing something you enjoy each day - like talking with a friend or watching a movie - can also help. Use your energy for what you like doing.

If you or your family carer are finding it hard to sleep, talk to your palliative care team for advice and help so that you get the rest you need.

The process of dying

All of us will die at some time. It can be very helpful and reassuring to understand how people die in palliative care.

Palliative care helps you to die in comfort, free from pain, and with dignity.

Generally, as a person gets closer to death, the body begins to gently wind down. There is less circulation of blood and a noticeable slowing of breathing and brain function. It is natural to sleep for longer periods and to refuse food and fluids. This is part of the gradual shutting down of the body in readiness for death.

Some people may become restless or agitated. Your palliative care team can help to relieve symptoms so there is no pain or suffering.

The presence of family and friends can be very comforting. Hearing the voices of loved ones and feeling their gentle touch can be soothing. Music and certain scents may also help.

Some people prefer to die at home. If this is your choice, the palliative care team will work with your family to achieve this goal, as long as your comfort and care can be maintained at home.

Every experience is unique, and your palliative care team can help you and your family understand what to expect.



..what to expect..

Peter's story

"I was diagnosed with pancreatic cancer at 62. I worked outdoors building all my life, so I thought the pain in my back and stomach was muscle strain, not cancer.

The pain made it difficult to sleep or do simple things, even reading the paper.

When my cancer specialist referred me to palliative care, it seemed too early. I'd read about people becoming addicted to prescription medication and I didn't want to put my family through that.

But the palliative care team explained the different ways to manage the pain and I started on morphine tablets. Almost overnight I felt much better. I started sleeping again, my appetite improved and my mood lifted.

Taking properly prescribed morphine doesn't mean you are going to become addicted. People like me use it safely every day. Living without pain has given me strength to get out and about and do what I want to do." - Peter

"Almost
overnight I felt
much better"

quality of life

"Dad was never interested in art, but he painted plates for all five of his children as a legacy. We now have them on display in our homes. It's like he's still with us."



Personal interests & goals

Making the most of life involves doing what is important and meaningful to you and gives you enjoyment. For example, spending time with people you love, enjoying nature, celebrating a special event or working.

Setting personal goals can help you maintain hope and enjoyment in life.

Health professionals such as physiotherapists, occupational, speech, music and art therapists can help you achieve your goals. So can your family, friends, counsellors and spiritual care workers.

Creativity and expression

Creative activities such as music and art can help you enjoy life, express your feelings and feel better in yourself.

You don't need to be musical or artistic to enjoy expressing your creativity or being part of a group.

Music and art therapy help relieve anxiety, depression and insomnia. They can also give you a chance to create gifts for your family, such as songs, poems or paintings.



Leaving a legacy

Sharing memories and creating legacy items are a great way to leave a message for those you love. You might like to write letters, make photo albums, create time capsules (for opening at a later time) or make a video of yourself.

Trained volunteers may be available to help with these activities, including recording your biography for your family.

Finding meaning

Living with a life-limiting illness can bring up a lot of questions about what matters to you and the meaning of your life. Palliative care gives you a chance to talk about your thoughts and ask questions if you want to.

Some people find meaning in their faith or religion, while others find it in close personal relationships, nature or reflecting on their contributions.

Whatever it is, your palliative care team can support you to focus on what is meaningful to you.

Spiritual and cultural care

Palliative care is available to all people, regardless of their cultural, spiritual or faith backgrounds.

Palliative care respects your personal spiritual, cultural and communication needs. Discuss these with your palliative care team.

Spiritual care workers (also called pastoral carers) are trained professionals who can support you to explore what is important to you. They are skilled in listening to people's worries and fears. If something is troubling you they can help you and your family.

If you wish, your palliative carers can also arrange for you to talk with spiritual leaders such as priests, rabbis, reverends and imams.

Your cultural needs are important and it helps to discuss these with your palliative care team. This might include special food requirements, how you want decisions about your care to be made, and particular rituals to be observed.

You can also ask for an interpreter.

Looking after your feelings

Looking after your feelings is important. There is no 'right' or 'wrong' way to feel. Simply understanding how you feel and being kind to yourself can help.

Coming to terms with a life-limiting illness takes time. It is natural for you and your family to have a range of feelings, such as loss, sadness, fear, anger, guilt, grief and shock.

Talking about your feelings, fears and wishes with family and friends can help you to support one another and feel less lonely or anxious. It's also helpful to ask for counselling support when you need it.



Sue's story

"I have Motor Neurone Disease, which means everything I do is getting harder - breathing, walking, talking and eating.

The palliative care team supports me in different ways. Doctors help with medication for my breathing and to control the pain.

Occupational and physiotherapists help me with exercises so I can do day-to-day activities without getting too tired or short of breath. I also use a walker and wheelchair so I can save my energy for what is important to me.

It's frustrating when I can't talk clearly to my friends and family. The speech pathologist helps me to speak as clearly as possible and has set up a program on my iPad that says what I type out loud.

I've also found it helpful to talk with the counsellor. There are lots of emotional and practical issues she has helped me to deal with.

I really enjoy the time I spend with a palliative care volunteer who is recording my life story. We have had lots of laughs as I share my past life. When the biography is ready for my family, I will feel a great sense of achievement." - Sue

your choices and decisions

“Palliative care made me comfortable and gave me a chance to think about my care choices.”

Your values and wishes

Palliative care aims to support your dignity at all times. This involves understanding and respecting your values, wishes and decisions about your care.

It is very important to think ahead about your care choices and goals, and discuss this with your family, GP, and palliative care team.

This is the best way to make sure that your wishes will be met.



Advance care plans

Writing down your wishes about your care and treatment options helps to make sure your wishes are respected if you are no longer able to speak for yourself. This is called an Advance Care Plan.

It helps to make a list of the things that you want to happen and talk to your family, GP, appointed decision maker and palliative care team about them.

You can consider and discuss questions like:

- Who will I trust to carry out my wishes?
- Who do I want to make decisions for me if I can't?
- What level of health care and quality of life do I want?
- What medical treatments do I NOT want?
- Where do I want to spend my last days?
- Who do I want to be with me when I die?

If you find it difficult to talk about death or dying, or if your cultural practice is for your family to make these decisions, let your palliative care team know.

Appointing decision makers

Choosing someone to make decisions for you, if you are no longer able to do so, is a good way to make sure your wishes will be met. It can also help to avoid conflict between family members and health professionals.

You can appoint three main types of decision makers to make decisions for you if you can't:

- Enduring Guardian
- Enduring Power of Attorney (Medical)
- Enduring Power of Attorney (Financial).

Enduring Guardian

An Enduring Guardian is someone you trust to make health and lifestyle decisions for you. They can decide where and with whom you should live and what kind of care you receive.

An Enduring Guardian cannot refuse medical treatment for you. This can only be done by your Enduring Power of Attorney (Medical).

Enduring Power of Attorney (Medical)

A Medical Power of Attorney is someone you choose to make medical decisions for you. Sometimes they are called your 'medical agent'.

Your medical agent can only make decisions about your medical care if you are unable to understand or communicate.

Your medical agent can agree to - or can refuse - medical treatment based on their understanding of your needs and wishes.

Your medical agent cannot refuse reasonable medical treatments to relieve pain, suffering and discomfort or food and water given to you by mouth.

If you are on life-support, your medical agent can request that it be turned off.

Enduring Power of Attorney (Financial)

When you appoint an Enduring Power of Attorney (Financial), you are giving a trusted friend, relative or professional adviser the power to make legal and financial decisions for you.

This person can only make decisions about your financial and legal affairs if you can't.

This can give you peace of mind that your financial affairs will be looked after well.



Refusal of medical treatment

Every competent adult in Australia has the legal right under common law, and in Victorian law, to accept or refuse any health care or treatment, even life-saving treatment.

There may be a time in your illness when you want to refuse treatment. If that time comes, it's important to know your rights.



..you can choose..

What can I refuse?

You can refuse most forms of medical treatment. This includes surgery, drug therapy, blood transfusion and radiotherapy.

You can choose to accept some medical treatments and refuse others.

You can also refuse treatments such as resuscitation, breathing machines and being fed through a tube.

What can't I refuse?

In Victoria, you can't refuse reasonable medical treatments to relieve pain, suffering and discomfort.

Food and drink to be taken by mouth can be offered to you, but you don't have to accept it.

How do I refuse treatment?

A person who is competent to make decisions can refuse medical treatment. This refusal must be given freely and be specific. It should be recorded in writing, signed and witnessed.

In Victoria, this can be done using a Refusal of Medical Treatment Certificate. A copy should be given to your GP and other healthcare providers.

A written refusal of treatment is limited to the person's current medical condition and may not apply if the person's condition changes significantly in the future. For this reason, it is helpful to appoint an Enduring Power of Attorney (Medical) who can refuse treatment on your behalf if your situation changes and you are unable to make a decision.

Getting the forms

The Office of the Public Advocate has the forms you need to appoint someone to make decisions for you. You can also ask a member of the palliative care team or call Palliative Care Victoria on the number listed in the back of this booklet.

You don't need a lawyer to fill out these forms. To be valid they need to be filled out correctly and witnessed by a person authorised to sign a statutory declaration – such as a GP, chemist, or accountant.

Give copies of the witnessed forms to your decision makers, family and health care providers. Ask your GP about signing up to the electronic health record. Keep the originals in a safe place and let your family know where they are.

Suggestions and complaints

You can make a suggestion or complain about your care. It is a good idea to raise it with the person or service first. Sometimes just speaking openly about an issue or misunderstanding can resolve it. Most health services, including palliative care, have staff to assist with suggestions and complaints.

If you or your family need help to resolve your concern, there are services available to assist. You can ask your palliative care service or the Office of the Health Services Commissioner.

Funerals

You may want to think about the kind of funeral you would like, and talk to family or friends about your wishes.

If you find this too hard to discuss with the people closest to you, your palliative care team can help.

Even if you don't want to plan it in detail, it is a good idea to write down some basic information.

You may wish to consider things like:

- Would you rather be buried or cremated?
- Where would you like your remains or ashes placed?
- Who would you like to be invited?
- Is there a special memory or legacy you want to share?

If you do want to plan your funeral, there are two main options; pre-arranged funerals and pre-paid funerals.



Pre-arranged funerals

A pre-arranged funeral lets you talk about what you want with a funeral director. This service is often free of charge and he or she will probably give you a copy of their notes, which you can pass on to your loved ones.

A pre-arranged funeral is not a formal agreement. When the time comes, your family, or the person with this responsibility, will still need to arrange and pay for your funeral.

Pre-paid funerals

A pre-paid funeral lets you organise and pay for your funeral in advance. You can pay for it in full or make a deposit and pay instalments over a fixed period. Only some plans offer a refund if you cancel, so check this before committing.

Options like funeral insurance and funeral bonds can be very expensive, so look into these carefully.

Your Will

Having an up-to-date Will means your affairs can be managed according to your wishes. It also lets you make plans for any family members, and leave money for people or charities that would otherwise miss out.

If you die without a Will, an administrator (usually a relative) will be appointed. Your assets will be sold and the money will be distributed according to a formula set by law.

Make sure you keep your Will in a safe place, such as with your solicitor or trustee, in a fire-proof safe at home, at the probate office or at your bank.

To assist you in preparing your Will, you can approach a trustee company, a local community legal centre, or find a suitable local lawyer.

Joanna's story

"I had been cancer-free for five years when I found out it was back and they told me I had about three months to live.

I sat down with the palliative care family support worker and we talked about all the things that were important to me.

I want to die at home if I can, so that's my goal. She helped me to plan and also to talk to my family about my wishes.

My son has Power of Attorney, and we've talked about my Advance Care Plan so he knows exactly what care I want if I am no longer able to make decisions." – Joanna



Cory's story

"I've got a disease that makes me weaker all the time. It's painful and I basically live in hospital now.

When they told me it couldn't be cured I was angry and a bit frightened - I'm only 17.

My palliative care team is really good. I talk to them about controlling pain, about how I'm feeling, and what I want to do with my life.

I can't go home, but I keep in touch with my friends and school. I talk to the carers about my treatment and getting into a hospice closer to home.

I know what treatments I want and what I don't want, and they helped me write all that down so it's clear for everyone and they help my family as well." - Cory



caring for your family

“We’ve had some of the best conversations as a family while I’ve been receiving palliative care.”

Caring for your loved ones

Palliative care often brings families closer together. Many say that it has brought them many moments of love, joy and laughter. However, it can also bring about difficult emotions.

You might find that your family are unsure about what to say. Being open with them about what is happening for you might help them to talk about their feelings and concerns.

If it is helpful, you could write down the name of each person that you love. Next to their names you could write what you want them to know and what you think they might like to hear from you. This can make the talking part a lot easier.

It can be hard to have an honest discussion about what you are facing and feeling, especially when you need to talk to children.

If you need support, your palliative care team can help you find a way to talk about dying with your family and friends.

A good first step can be talking to social workers, grief counsellors or spiritual carers who have helped many families deal with serious illness. There is support available for people of all cultures, religions and beliefs.



..‘I love you’..

Saying the things that matter

Facing a life-limiting illness can highlight what is most important in life. Many people in this situation say that it is their personal relationships with family and friends that matter most.

Saying simple things like ‘thank you’, ‘I love you’, ‘forgive me’ and ‘I forgive you’, can bring great comfort and a sense of peace.

Having open, honest conversations with the people who matter most to you can be deeply healing and rewarding.

If there is conflict or unresolved issues in your family or between your friends, you can get help. Pastoral care workers, social workers, counsellors or spiritual leaders can assist.

Looking after children

Few children understand the idea of a life-limiting illness. When it does become part of their family life, they need help and support.

Children can often feel that something is wrong. If they don't understand a situation, they can sometimes blame themselves. Children can feel isolated and upset if no one talks to them about what is happening.

Children as young as four will have a basic idea about death. Talking to them openly and giving the illness a name will help them cope with the facts.

Try to avoid saying things like 'going to sleep' or 'going away', as children may take these literally. Respect their questions, even if they've already asked them a few times.

To cope well, children need:

- clear, easy to understand information
- comfort that their life will go on
- ongoing love and attention
- the support of their friends
- a chance to be part of your care.



Most children will want to be told that they are OK and that they will still do normal things like go to school, see friends and play sport. It's healthy for them to express their feelings. This can be by talking, drawing, or through play.

If your child is in primary school, you should tell their teacher about the illness. This will help the teacher to support your child. Older children may not want to tell their teachers. Try to respect their wishes and encourage a teenager to talk about their feelings with friends or with adults outside the family.

Counsellors can advise and help family members caring for children.

Getting financial help

Living with a life-limiting illness will affect the financial position of your family. It's a very good idea to seek independent advice early and before you make any decisions.

Financial advice

Getting the right advice from a certified financial planner can stop you making costly mistakes. Issues like superannuation, insurance and early retirement need to be dealt with carefully. It's best to sort these out with a professional so that you don't accidentally miss out on benefits or other forms of assistance.

Seek advice from suitable trained advisers about things such as:

- Insurance – health, life and income protection
- Superannuation
- Tax rebates
- Medical costs
- Loss of income
- Medicare safety net thresholds.

Early release of superannuation

Depending on your situation, you may be able to access your superannuation early. This is called an Early Release of Superannuation on Compassionate Grounds. It usually applies to people living with life-limiting illnesses and those in palliative care.

Life insurance

Financial help may also come from your life insurance policy. If you are unsure what you are able to claim, talk to your insurer or financial adviser.



Centrelink

You should also speak to your local Centrelink office about your situation and find out what help may be available to your family.

Other financial help

Electricity, gas, phone and water companies have hardship programs. Speak to them about time payments and any concessions.

Talk to your palliative care team so they can look at other ways help may be available.



story Mehmet's

"My mother Beren was 67 years old when her specialist said that her kidneys were failing and we should consider palliative care.

Mum didn't speak English very well and she didn't want to be in hospital, so we decided to care for her at home.

Our palliative care nurse, Diana, organised all the medication and equipment and carefully explained how to use it. She arranged for a special bed for mum to make her more comfortable.

Diana called and dropped by regularly to make sure we were all okay. We could also call palliative care for help at any time - day or night.

Mum died peacefully at home with her family around her - just as she wished." - Mehmet



Emilia's story

"We cared for my husband, Paolo, with the support of community palliative care. After Paolo's death, I was very sad and upset. I didn't feel like being with anyone or doing anything. Nothing mattered any more.

My family and friends tried to comfort me - but I was stuck in this deep feeling of sadness and loss. The palliative care bereavement counsellor called me and we met regularly for several months. She helped me to express my feelings and to understand the grieving process.

After a while, I joined a support group for bereaved carers – it was helpful being with people who are going through similar experiences. Recently, I've joined an exercise class and I feel ready to spend more time with my friends.

Paolo will always be important to me. I am learning to live with my sorrow and get on with my life." - Emilia



Finding a palliative service or more information

Palliative Care Victoria can help you find a palliative care service and provide information about palliative care to assist you and your family.

We can also link you to other helpful information, organisations and services.

If you would like to speak in another language, let us know and we will arrange for a telephone interpreter.

Free call: 1800 660 055

Phone: (03) 9662 9644

E-mail: info@pallcarevic.asn.au

Websites: www.pallcarevic.asn.au and www.pcvlibrary.asn.au



