



Being prepared as a family decision-maker



**Palliative Care
Victoria**
Living, dying & grieving well



PCV acknowledges the Traditional Owners and Custodians of the land on which we live and work across Victoria and pays respects to elders, past, present and emerging.

Being prepared

As the substitute decision-maker for your family member in residential care, you will be asked to make decisions about their treatment and care. This is an important responsibility. If you take some steps to help prepare yourself practically and emotionally, you will be better equipped to make decisions on behalf of your family member when the time comes.



Practical preparation

Understanding your family member's wishes and preferences

A fundamental part of your role as decision-maker is to develop an understanding of what your family member wants for their future care.

A good place to start is to review any Advance care plan that your family member has previously completed. This will give you valuable information about what medical treatments they would want (or not want) now or in the future.

Where there is no Advance care plan, talking with other members of the family or people close to them, or their doctor (their general practitioner or GP), will help you learn about their preferences for ongoing care, and at end of life. It is important to record your family member's preferences for easy reference. The aged care home may have a preferred document for recording this information.

Some people will have completed an Advance care directive, which is a legally binding document, and this will be honoured in the aged care home or in a hospital.

When you know what your family member wants for future care, you will be better prepared to make decisions that reflect those that your family member would make if they were able to communicate their wishes.

The types of decisions you may need to make

There are lots of decisions – big and small – that you may be asked to make as decision-maker for your family member. Some decisions will be straightforward, such as letting the aged care home know your family member's food preferences, while others may be more challenging, such as making medical treatment decisions.

It can be helpful to talk with the nursing team or GP about the types of decisions you may need to make for your family member.

Emotional preparation

The role of decision-maker can require considerable strength and perseverance. Anticipating the road ahead and putting some supports in place will help you as you take on this important role for your family member.

In particular, identify a family member or close friend to help you with some of the tasks or to talk through certain decisions that you may need to make. It is also important to schedule time each week to do something replenishing for yourself, such as having coffee with a friend or taking a walk in the sunshine.

You will probably feel uncertain, stressed or experience other emotions at some point in your role as decision-maker. Acknowledging these emotions and taking steps to care for yourself will help you remain strong through the journey.

“Even though it was difficult to talk with my siblings about what kind of medical treatment Dad would want in the future, and we didn't always agree, I found it very reassuring to have had these conversations ahead of time. I also made sure to document these discussions. It made it so much easier when he started to decline.”

(Daughter and Medical treatment decision-maker of Barry)



Working together

When your family member moves into an aged care home, important new relationships are set in motion. Getting to know how the aged care home operates, building relationships with key staff, and understanding how the home provides good-quality care will support you in your role as decision-maker.



Key staff and clinical care support

The manager and the nurse in charge of clinical care are two key people in the aged care home whom it is good for you to know. It is a good idea to keep track of their names and contact details should you need to be in touch.

Getting to know other staff, including the nurses who provide direct clinical care, the personal care attendants and the lifestyle staff, will help you know whom to talk to about the different needs of your family member.

It is also important to know your family member's GP. The GP is responsible for assessing and directing medical care, prescribing medication and undertaking referrals to specialist services. (In some homes, a Nurse Practitioner has these duties.)

Allied health services are integral to quality care and your family member is likely to use one or more of these services, sometimes on a regular basis. These services span a range of specialty areas including physiotherapy, podiatry, speech pathology (which includes treatment for swallowing) and dental services.

Many aged care homes have access to specialist palliative care services. These services provide care to patients with complex palliative care needs or challenging medical symptoms related to a life-limiting condition. Some homes have access to community-based hospital specialists who can provide a range of hospital level care in the aged care home. You can ask the aged care home about what services they have access to.

Inclusive care

Aged care homes are required to provide inclusive care that recognises and supports each resident's individuality. As the decision-maker, you are likely to be the person advocating for your family member and this may include understanding how the aged care home provides appropriate cultural or spiritual care or, for example, what supports they have in place for people from different sexual orientations or who identify as gender diverse.

Understanding and monitoring good-quality care

Working together

An effective partnership between you as the decision-maker and the nursing and medical team is essential for good-quality care. Building trust between you and the aged care team – which will make open communication and shared decision-making easier – is key to this partnership.

“Learning how the aged care home was able to care for my wife helped me develop more realistic expectations about what the home can provide. The care is good, but it isn't the same as the care my wife received at home. Aged care homes have some limitations and I think it's helpful to know that.”

(Husband of Doris who is living with dementia in an aged care home)



Good-quality care

As the decision-maker, you will find it helpful to know what good-quality care looks like and how to keep track of the care your family member is receiving.

Assessments and care planning are the building blocks of good quality care. Your family member will be assessed when they are admitted to the aged care home, when changes occur (such as a fall, loss of weight, return from hospital or changes in behaviour), and at regular review times. Assessments record a person's physical, cognitive, social, psychological and cultural needs.

These assessments are used to construct or update the Care Plan, which the aged care home will use to guide the care requirements of your family member.

Care Plans are reviewed on a regular basis, and as the decision-maker you will represent your family member in this process. The review is a good time to check your family member's overall wellbeing, note any changes in their needs and preferences, and have conversations about how to manage any changes in your family member's health. You can request a copy of the Care Plan.

Family Case Conferences are another important part of good-quality care and often include the GP and other professionals if required. These meetings can be initiated by you or the aged care home. These meetings support effective communication and monitoring of care.

Each aged care home will have its own process of assessment and care plan review. As the decision-maker for your family member, it is important to understand how the aged care home assesses, documents and reviews care and how you can contribute to this process.

Making decisions



Your role as decision-maker

The crux of your role is to represent your family member's preferences for care. If your family member has not made their own wishes known, you can talk with other family members and close friends of your family member to support your own knowledge; this informal knowledge will also support any formal advance care planning information if those documents do exist. The nursing and medical team will be looking to you for guidance about what your loved one would want when treatment and care decisions need to be made.

Another aspect of your role is to keep track of your family member's health so you are aware of any changes that may be relevant to decisions that need to be made. Communicating regularly with the nursing team will assist you with this.

Often, you will be responsible for communicating and updating family members on the wellbeing of your family member.

Goals of care

Sometimes treatment and care decisions are required with little warning. This can be the case for ongoing care decisions such as actively treating a reoccurring infection as well as decisions that may be required after a decline in your family members health. Some of these decisions can be complex and emotionally taxing, particularly during the dying phase or when a significant debilitating incident has occurred.

Medical treatment decisions

Some medical treatment decisions will be straightforward; others require more thought, preparation, or discussion.

Making decisions in these situations will be easier when you have considered the kinds of medical interventions your family member would want (or not want) given their current abilities and health. Decisions may include whether your family member would want to be resuscitated, be treated for recurrent infections, or focus on comfort and relief of symptoms. These discussions and decisions are best made in consultation with the nursing team or the GP or both.

Some aged care homes will refer to this process as establishing your family member's current goals of care, while others may use a less formal process such as a case conference or Care Plan review meeting to discuss medical treatment decisions.

When reviewing your family member's current goals of care with the nursing team or GP, it is important to consider what medical treatments are appropriate given their current state of health along with any previously stated values and preferences for medical treatments.

This goals of care process provides up-to-date guidance for the nursing team at the aged care home and the GP about what medical treatment interventions your family member would want to receive in the event of an emergency or if their health suddenly declined.

Goals of care are about current treatment goals and should be reviewed regularly.

Hospital treatment

In some situations, your family member will need to go to hospital to manage a complex issue such as a fracture or uncontrollable pain. For less urgent concerns, such as an infection or management of a wound, the nursing team may be able to support your family member more comfortably within the aged care home.

Hospital transfers can be distressing, due to the unfamiliar environment and staff, for older people, particularly those with dementia. While certain medical interventions can be provided within

the hospital, it is important to understand if these medical interventions are what your family member requires.

You can discuss decisions to transfer your family member to hospital with the nursing team and GP. Your family member has the right to access hospital care if they prefer and if this is the case, their wishes should be respected. The overall aim is to improve the care and comfort of your family member where this cannot be achieved within the aged care home.

"After many trips to the emergency department with mum due to infections and ongoing swallowing problems, I sat down with her GP and the clinical care manager at the home to talk about where to from here. Mum had dementia and never coped well in the hospital setting, and it always took her several weeks to get back to her old self (or close to her old self) once she returned to the home. We talked about options for keeping mum at the home when these problems came up again. The GP ordered certain medications and the staff were advised of the new plan. Soon after, mum developed another chest infection but this time she received oral antibiotics in the home along with other care and it went much better. It was such a relief to have this new plan in place and avoid those hospital admissions unless absolutely necessary."

(Daughter and Medical treatment decision-maker of Lylie living in the aged care home)

End-of-life care



Palliative care

Palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting condition. The focus is on treating distressing or painful symptoms of the condition and supporting the person's emotional, psychological, cultural and spiritual wellbeing.

Within aged care homes, some residents receive palliative care from arrival, while others do so when their health significantly declines.

End-of-life care

When a person is still in good health, a palliative approach to care will focus on helping them to continue living as independently as possible. This may include supporting decisions for treatment that slow the progression of a life-limiting condition and managing other health concerns like an infection.

As a person's health declines, they may experience new symptoms that cannot be cured or relieved easily. This often marks the transition to end-of-life care and may evolve slowly over several months or occur more suddenly after a significant deterioration in their health. Key signs of declining health include subtle changes such as increasing frailty, eating less, becoming less active or choosing to sleep more. More significant changes can include repeated infections, increasing difficulty swallowing or where the person shows more confusion than before.

When someone is receiving end-of-life care, it is expected that they will die within 12 months or sooner; priority is then given to treatments that can maintain physical comfort and minimise distress.

The final days

The final hours or days of a person's life is known as the terminal phase of end of life care. During this phase, the person may experience symptoms they have not had before, particularly if they have multiple health conditions.

- **Pain and agitation:** Pain is a common symptom as the body shuts down. The person can also become restless, agitated or confused. Nursing staff use a combination of medication and non-medication-based care to maintain comfort.
- **Difficulty eating and drinking:** During the final days, a person may be unable or not want to eat or drink. These changes are a natural part of the dying process. The care team will soothe the person's mouth with moist mouth swabs.
- **Increased personal care needs:** Many people become bed bound in their final days. When this occurs, personal care staff will provide washes in bed and assist with regular repositioning.
- **Changes in breathing:** A person's breathing patterns can change during this time. Some people may breathe faster or slower than usual with extended pauses followed by large breaths. For some, breathing can become louder as saliva collects at the back of their throat.

Most of these symptoms can be managed within the aged care home. If a person has complex symptoms because of their condition, a specialised palliative care service may be contacted.

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

(Dame Cicely Saunders – founder of the palliative care movement)



The decision-maker's role in the final days

The time a person takes to die varies for everyone. Some people may take days while others may die suddenly or unexpectedly.

When your family member moves into the terminal phase of palliative care, the nursing staff will contact you immediately if you are not already aware.

As the decision-maker, your role is to ensure that this last phase of your family member's life is as close as it can be to what they would choose for themselves. When you can be with your family member, you can observe their level of comfort and stay in close communication with the aged care staff. If your family member seems to be mostly asleep, familiar scents, gentle touches, familiar voices or preferred music can still be comforting for them.

You may also be managing visits from family and friends who have come to say goodbye. It can be a deeply emotional time; remember to take time to eat, rest and replenish yourself.

After your family member has died, the nurse or a doctor will let you know and ask about any special requests, such as religious rituals, or if you would like some time at the bedside to grieve privately. The nurse will then contact your chosen funeral provider to arrange a suitable time to transfer your family member to their care.



Remaining strong



Being trusted to make treatment and care decisions for another person can be difficult at times. Finding ways to de-stress, share the load or replenish yourself can be important to maintaining your overall wellbeing and to help you to manage the demands of the role.

The tips outlined below include a range of suggestions to help you remain strong and supported as decision-maker for your family member.

Everyone is different and what works for one person may not work for another, and anything you decide to do will need to fit in with your lifestyle and day-to-day commitments.

Healthy habits

- **Eat well:** Keeping a balanced diet can be difficult when you have limited time or energy to prepare meals. Consider what you can do to make this easier, such as using a meal delivery service or pre planning your menu for the week.
- **Move more:** Making time for physical activity will benefit your physical health and reduce stress. Even just 15 minutes a day can help!
- **Sleep tight:** Most adults require 7–9 hours of sleep a night. A good night's rest has been shown to have a number of health benefits.
- **De-stress:** Practicing some relaxation or mindfulness techniques, keeping a diary or talking with a close friend can help reduce stress and anxiety.
- **Seek professional support if needed:** Getting professional support from your GP or a psychologist can help you work through challenging situations.

Coping with change

When your family member moves into an aged care home, the changes to your day-to-day life may bring new challenges. You may have taken on a new role overseeing the care your family member receives at the aged care home and be developing new relationships with key staff. Your world outside the aged care home may also have been disrupted with changes to your daily routines or activities.

Whatever the changes, it can be helpful to acknowledge them and know that you are likely to adjust given some time. It can also be helpful to

build in some positive activities such as scheduling time to go to the cinema or meet up with a friend for a coffee. If this isn't easy to arrange, you might plan something closer to home such as spending time in the garden or watching a TV show you enjoy.

If you find yourself faced with a challenging situation, consider asking for support from someone or write down any questions you want to ask those involved. If you are struggling with feelings of loneliness or sadness and would like to talk to someone, speak with your GP about options for support.

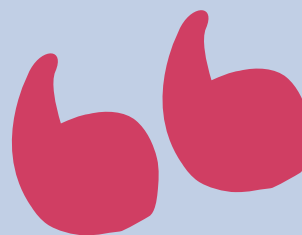
Staying connected

Caring for a family member living in an aged care home can feel isolating or burdensome at times and some people find it helpful to reach out to friends and family for support. Others prefer to become part of a support group within the local community, over the phone or online. These groups provide people with an opportunity to share their experiences and receive reassurance or advice from one another. The aged care home or your GP may be able to suggest who you can connect with a local support group.

Managing grief

Grief and sadness are natural emotional responses to loss and can occur before, during and after a person dies. If you are experiencing grief, it can be helpful to acknowledge what you are feeling. Everyone experiences grief in their own way, and it can give rise to different types of feelings. It is okay to reach out for support from family, friends or trained professionals.

Nola's story

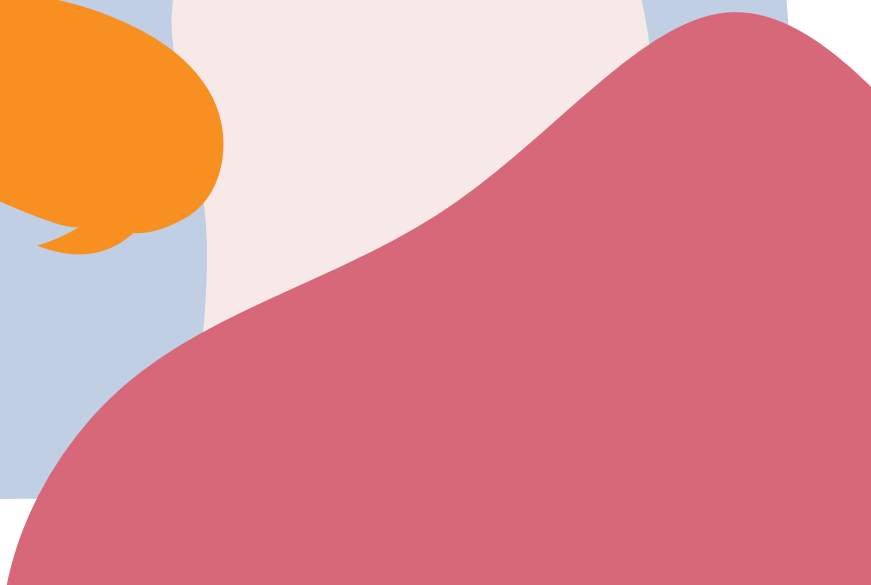
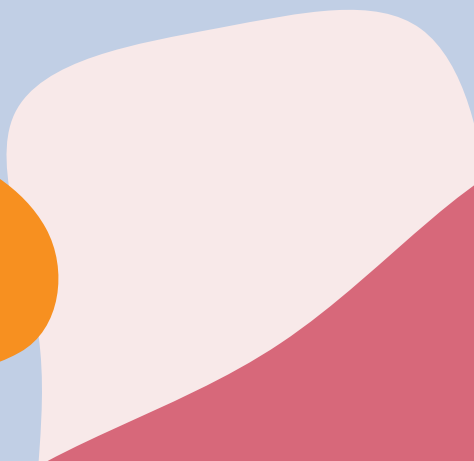
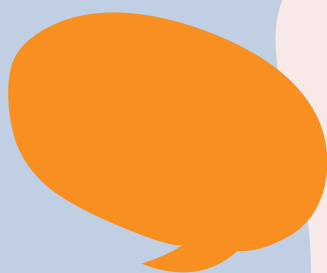


"When my husband was living with dementia, I made lots of decisions on his behalf, but three big decisions stand out.

My husband was a GP and he used to come home from his work in aged care and say, "That is not the way I'm going to finish." So, when I couldn't look after him anymore at home, it made the load for me even harder when I had to make that big decision to put him into the nursing home. It was so hard.

I used to come home from visiting Henry and cry. Then one day, a friend suggested I try grief counselling even though my husband was still alive. I decided to give it a go and what I found most interesting was that all my life I had been a wife and mother and the grief counsellor wanted to know about me... and it took about three times before I knew what to say about me. It was a wonderful thing to happen and helped me a lot when Henry was alive and when he passed away.

When Henry was in the advanced stages of dementia, the doctor told me he had stomach cancer and talked with me about different treatment options. Henry had let me know many times that life for him wasn't about quantity but QUALITY! Thinking about Henry's wishes and talking with my family, I made the difficult decision to not actively treat the stomach cancer and commence palliative care symptom relief instead. Henry was pain free and comfortable right up until the end which gives me great solace."



Guiding checklist



Being prepared

- Build a good understanding of your family member's wishes and preferences for future care.
- Check if your family member has previously documented these preferences in an Advance care plan or an Advance care directive, and that the aged care home has this document on file.
- Learn about any health conditions your family member has. This can include how they may progress, the effect it may have on their lifestyle, and any specific symptoms that need to be managed.
- Recognise that you may encounter challenges that can be both practically and emotionally difficult. Prepare by becoming familiar with the types of decisions you may need to make. Consider where to reach out for support and how to take time out for yourself.



Working together

- Get to know the staff in the aged care home and find out to whom you should talk to about the care your family member is receiving.
- Confirm that your contact details are with the aged care home and that you (or someone you have delegated to) can be contacted in the event of a sudden change in your family member.
- Learn about the nursing team's assessment and Care Plan review processes with your family member and how you as decision-maker can be involved.
- If you would prefer support when talking with the staff at the aged care home, reach out and ask another family member or close friend to join you, or contact an advocacy service for support.



Making decisions

- Talk with the nursing team or your family member's GP about what types of medical treatment decisions you may need to consider now and in the future.
- Organise a meeting with the nursing team at the aged care home to talk about what treatments your family member would choose for their ongoing care and if they were approaching death.
- Ask the nursing team about different options for receiving medical care in the aged care home. Discuss when it would be necessary for someone to go to hospital for further treatment and what you would need to do in these situations as their decision-maker.
- Record what your family member would choose for their current goals of care. Documenting these preferences with the aged care team makes it easier for you and the staff to make decisions about medical treatment in an emergency.
- Review and update your family member's current goals of care regularly, particularly when changes in their health are identified or after a significant medical episode such as a fall or a transfer to hospital.



End-of-life care

- Ask your family member's aged care home what palliative care support they offer and if they are connected with a specialist palliative care service.
- Plan how you will share important news with extended family or close friends.
- Consider making initial contact with a funeral provider before your family member requires end-of-life care. This can lessen the stress later.
- Learn about the physical and behavioural changes that can occur when a person is transitioning to end-of-life care or is actively dying.
- Don't forget or ignore your own needs. Organise some supports to help you through what can be a rewarding but also emotionally and physically taxing time.

Glossary of terms

Advance care directive

A legally binding document a person completes with their GP that details what medical treatment they want or don't want should they lose the capacity to decide for themselves.

Advance care plan

A document that provides information about a person's values and preferences for healthcare treatment should they become seriously unwell or be unable to make their own decisions.

Care plan

A document developed by health professionals outlining a person's individual care needs.

Decision-maker / Substitute decision-maker

A person who makes decisions for someone else who can no longer make decisions for themselves. In Victoria, a person who can make decisions about another person's medical care is called a Medical Treatment Decision Maker.

Dementia

A term used for a number of progressive brain disorders that cause confusion or memory loss as well as difficulty with language, problem solving and day-to-day tasks. All types of dementia are considered a life limiting condition.

End-of-life care

Specific care provided to people when their health has irreversibly declined, and they are expected to die within the next 12 months or sooner.

Family

Families take many forms, shapes and sizes and can refer to one's biological family, chosen family, a significant friendship group or as defined by you as your family.

Goals of care

These are the decisions that should be reviewed regularly about what medical treatments a person would want to receive currently and includes preferences for resuscitation (CPR), being transferred to hospital, or choices about curative treatments versus comfort care.

Life-limiting condition

A large number of progressive illnesses that lead to physical decline in health and shorten a person's life expectancy.

Palliative care

Care that helps people live their life as fully and as comfortably as possible when living with a life-limiting condition or terminal illness by treating distressing or painful symptoms of the condition and supporting their emotional, psychological, cultural and spiritual wellbeing.

Terminal phase

This is the final hours or days before death when a person may require specific medications or care to treat symptoms that can occur when actively dying.



To find out more about being prepared as a decision-maker for your family member, visit the Dignified and Respectful Decisions website:
www.pallcarevic.asn.au/dard

or scan the QR code below



**Palliative Care
Victoria**

Living, dying & grieving well

Palliative Care Victoria can be contacted 9am to 5pm,
Monday to Friday, excluding public holidays.

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Let us know if you would like to speak in another
language, so we can arrange a telephone interpreter.

**DIGNIFIED
& RESPECTFUL
DECISIONS**



Australian Government
Department of Health and Aged Care

