
End of life and palliative care at home

Summary

- End of life care is provided by a wide range of providers in healthcare, community, social and local government agencies.
- Palliative care at home is provided by specialist community palliative care services.
- Your local doctor (GP) will be part of your care team at home and can provide further information.
- After-hours palliative care support is available by telephone in most areas.
- Other options for care are available as your needs change.
- You can decide your care preferences and have them documented in an advance care directive.
- You can make changes to your advance care directive at any time.
- Support is available for family or friends who are caring for you.

If you are living with a life-limiting illness, end of life and palliative care services can be provided to you at home. This may include visits from a range of service providers on an occasional or regular basis. Your needs determine what services you may require, not your diagnosis.

Home to you may mean the house or apartment you live in. Home may also mean a residential care facility or supported accommodation or on Country in a remote area. Many people living with a life-limiting illness prefer to remain at home because of the familiar environment, feeling of independence, privacy and close access to family, friends and the local community. Receiving care at home can also help people to maintain a daily routine and feel more secure.

However, not everyone chooses to remain at home for end of life or palliative care, and you should not be 'persuaded' to receive home-based care if this is not right for you, or you don't have adequate care and support at home. You may choose to make this decision together with your family or people you live with. If you live alone you may like to discuss this with your GP, a trusted health professional or close friend.

There may be different levels of end of life care services available, depending on where you live. **End of life care services at home** may include:

- support from a wide range of healthcare and community service providers such as district nurses
- allied health services such as physiotherapy, occupational therapy, podiatry and music or art therapy
- nursing support and review
- medical support from your GP
- practical support and assistance from volunteers formally trained in end of life supportive care
- emotional and spiritual support
- information and resources
- complementary therapies such as massage or aromatherapy
- support for family or those caring for you
- bereavement support.

Palliative care at home

Palliative care at home is provided by specialist community palliative care service providers. These programs are designed to be flexible to meet your needs and the needs of your carers and family. You may want to have specialist palliative care provided at home if your condition worsens or becomes complex, or you may choose

another option for care such as a residential care facility, hospital or inpatient service.

There may be different levels of services available, depending on where you live. Most specialist community palliative care services offer:

- specialist palliative care nursing
- specialist palliative care medical support
- medical support and liaison from your local doctor (GP)
- specialist palliative care allied health such as physiotherapy, occupational therapy, podiatry and music or art therapy
- practical support and assistance, including from formally trained palliative care volunteers
- emotional and spiritual support or specialist psychological counselling
- information and resources
- complementary therapies such as massage or aromatherapy
- support for family or those caring for you
- access to medical review and assessment in your home
- other medical specialist support if required.

Speak to your doctor about palliative care providers in your local community. Specialist palliative care providers have a range of services but you may not need all of them. Often one of these specialist professionals may be the coordinating person you mostly liaise with.

After hours palliative care support

Most specialist palliative care services in Victoria offer 24-hour telephone access for advice and support. In urgent situations, a nurse may be able to visit you at home after-hours. These services can differ from region to region, depending on where you live.

Changing care needs

While there are a lot of benefits from being cared for at home, staying at home may not always be possible. There may be times when you need more care than can be given at home, or those caring for you either need a break or can no longer cope with your increasing needs. If your condition worsens, you may need to consider another care option such as a residential care facility, hospital or inpatient service.

This may only be temporary, due to intermittent episodes of a condition or fluctuations in your needs. A hospital admission may be necessary to manage a difficult symptom. Often people return home after an episode that requires specialist treatment. Sometimes these episodes can be managed at home by the community specialist palliative care team.

Planning ahead – have the conversation

In Victoria your wishes and preferences for care and for where you want to die can be documented formally in an through advance care planning.

Advance care planning clarifies treatments you do or don't want, allows you to appoint a medical treatment decision maker and gives you and your family peace of mind. Talking with family and loved ones and letting them know about your wishes helps, particularly if you become unable to make your own decisions.

The type of care you receive at home, your ability to be independent, and the impact that your care has on your family may affect the decisions and preferences you choose.

Many people make a choice that they would prefer to die at home, where it is familiar and comforting. Home may also mean a residential care facility or on Country in an outback remote area. Many people also make the choice not to die at home. Both choices are equally valid, and this decision is yours to make. You may choose to make this decision together with your family and loved ones.

At a later time, you may also make changes to these choices. It may seem desirable to you to plan to die at home

when you're still feeling well, but your thoughts on this matter may change depending on changes to your health and your own life circumstances. It's okay to make these changes in your preferences.

It is a good idea to talk to your family or carer about how you are feeling and check in with them to make sure that they can cope.

There is more information on recording wishes for future care and related matters in the section on **advance care planning**.

Support and care from family members, friends or carers

How much support you get and the type of care you receive from your family or friends will depend on your immediate needs, your family's availability and what tasks you are all comfortable with. You may need to discuss with your family and other people close to you, how much support they are able to provide.

Some family carers offer emotional support or help out with meals and day-to-day chores, while others are involved with more intimate aspects of palliative care at home such as personal grooming or bathing. Your palliative care team can also provide these services.

Have an open and honest conversation with your family or carer about what you are both comfortable with so you can decide together on the best plan for your palliative care. End of life and palliative care staff can assist you with these conversations.

Where to get help

The palliative care team are there to support you as well as the person or people caring for you. Talk to them about what will make your life easier, and talk to your doctor about what emotional and financial support is available.

Information about further support services across Victoria is available from:

- **Palliative Care Victoria** Tel. (03) 9662 9644
- **Palliative Care Australia** Tel. (02) 6232 0700
- **CareSearch** – Palliative Care Knowledge Network Tel. (08) 7221 8233
- **Carers Australia Victoria** Tel. 1800 242

This page has been produced in consultation with and approved by:

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