End of life and palliative care explained

Summary

- End of life and palliative care helps improve the quality of life for someone who has a life-limiting illness, by offering services, advice, information, referral and support.
- End of life and palliative care offers emotional and practical support to families, friends and carers.
- Palliative care is not just for people nearing the end of their lives.
- You can receive palliative care at the same time as other treatment for particular conditions.
- End of life and palliative care in Victoria is based on person-centred care, which means you and your family are treated in the way you want to be treated.
- Palliative care can help you plan your care including using an advance care plan.
- Any person can make a referral for themselves or someone else to palliative care.

What is end of life and palliative care?
End of life and palliative care aims to help you if you have a life-limiting or life-threatening illness. The focus of this type of care is managing symptoms and providing comfort and assistance. This includes help with emotional and mental health, spiritual and social needs. End of life and palliative care provides practical help with daily tasks as well. The goal is to improve your quality of life and that of your family, friends and carers. End of life and palliative care is based on what your needs are, not your diagnosis. If you have an illness that cannot be cured and will lead to the end of your life, end of life and palliative care will be suggested.

Who is end of life and palliative care for?
Anyone with a life-limiting or life-threatening illness is eligible for end of life and palliative care from a health service in Victoria. Chronic life-limiting illnesses for which you can receive end of life and palliative care include, but are not limited to:

- cancer
- heart and lung diseases
- motor neurone disease and multiple sclerosis
- Alzheimer’s disease and dementia
- renal disease
- stroke and other neurological conditions
- other life-limiting illnesses.

However, end of life and palliative care is not just for people nearing the end of their lives. If you have a life-limiting or chronic ongoing illness you can receive end of life and palliative care, regardless of your age, culture, background or beliefs.

End of life and palliative care is not just for people with cancer. It is available to you if you need treatment to manage symptoms such as pain or breathlessness no matter what your illness is. End of life and palliative care is also available if you need support dealing with difficult emotions related to your condition. Sometimes this is referred to as ‘supportive care.’

One or more carers or family members may be providing care in varying ways for your end of life needs. Family members or friends who are providing care for you can also access support from end of life and palliative care services. You can find more information on Better Health Channel’s End of life and palliative care services page, under the ‘Support for family and carers’ tab.

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Who delivers end of life and palliative care?

End of life care is delivered by a wide range of providers. Many people who work in health, human services or community agencies can help provide end of life care, such as:

- staff at your local community health centre
- staff at your GP clinic
- staff at your local rural clinic
- local government agencies
- cultural and religious service providers
- residential care facilities
- disability services
- hospitals
- medical specialists.

The end of life care provided may include listening and talking with you after news about the possibility of the end of your life, being empathetic to your concerns and needs, and referring you to more specialised support or care if required.

A range of people and services may be involved in your care and, as your condition progresses, the people who care for you may change to suit your needs.

Palliative care is delivered by specialist palliative care staff who are trained with specific skills and knowledge to help you, your family and carers. Palliative care staff have specialist expertise in symptom management, emotional, spiritual, practical and cultural care. Palliative care staff include specialist doctors, nurses, allied health professionals and spiritual care workers.

Palliative care may be delivered by these staff at the end of life care venues listed above as visiting specialists. Palliative care is also provided by these specialists at:

- community palliative care
- inpatient palliative care units (hospices)
- hospitals
- outpatient clinics
- day hospices.

Palliative care staff also provide advice and support to the people that are providing end of life care to you. If your condition becomes complex, specialist palliative care staff provide care directly to you.

How end of life and palliative care can help you

End of life and palliative care focuses on improving your quality of life – helping you manage symptoms and providing emotional, spiritual and practical support as you need it. (For more information see the page culture, background or beliefs)

Some people may have a condition causing them to be very ill and may need palliative care for only a few weeks. Others may need end of life and palliative care at intervals over a period of months or years.

End of life and palliative care is best commenced early in the disease process to help you maintain the best quality of life, according to your wishes, for as long as possible.

You can receive palliative care in your home, at a specialist inpatient palliative care unit, or in a local hospital. There is more information on these services under Palliative care at home and Palliative care in a hospital or community residential home.

End of life and palliative care extends to providing support for families, carers and others after death has occurred.
Palliative care and other treatments

Palliative care is not the end of active treatment. You can receive palliative care at the same time as other treatment for particular conditions. For example, if you are receiving treatment for cancer, you can receive palliative care at the same time. You don’t need to stop active treatment for particular conditions while you are having palliative care, but you may choose to if you wish.

Person-centred palliative care

‘Person-centred care’ means that:

- you are at the centre of planning and decision-making around your end of life and palliative care
- your individual, cultural and religious needs are considered when care is planned
- you are treated in the way you want to be treated
- your preferences and values are recognised and respected
- you are treated with respect and dignity whatever your age, cultural background, religion or sexual orientation.

By responding to your needs and those of your family in this way, your palliative care team can help you make the most of each day.

There is a focus in Victoria to ensure people from culturally and linguistically diverse backgrounds and other groups receive the care that is right for them. More information is available on Better Health Channel’s End of life and palliative care services page under the ‘Palliative care for all communities’ tab.

Planning ahead with end of life and palliative care

End of life and palliative care staff can help you decide what care you need, if you are likely to be entering the last year of your life.

Identifying this time is important as you may have rapid changes and fluctuations in your condition during this period. You may also have contact with a wide range of health or community services over this time.

A focus on approximately one year allows for the best planning of care. You can discuss your preferences for care and what matters to you most with your loved ones and doctor or other health professionals. The aim is to meet your needs according to your wishes in the last year, months, weeks and days of your life.

More information on making an advance care plan, can be found on the Better Health Channel’s Advance care plans page.

Cost of palliative care

Palliative care is generally free but you may have to pay for the hire of some specialised equipment, medications, dressings and treatments.

There will be extra fees if you access palliative care in a private hospital, so always check with your health insurance company to find out more about your options and the potential costs.

Getting a referral for palliative care

You can contact palliative care services directly or you can be referred by your doctor, nurse or local health provider, your carer or a family member.

Where to get help

- Your local palliative care service

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