End of life and palliative care for people living with a disability

Summary

- There are options for end of life and palliative care for Victorians living with a disability.
- End of life and palliative care for Victorians living with a disability can be provided at home, in specialist disability accommodation, in residential aged care or in an inpatient facility at a hospital.
- If you are younger than 65 years of age, be sure to consider all options for care before considering residential aged care.
- Planning ahead is a good idea for you or your guardian so that your views and preferences will be respected.
- You can record your preferences for care in an advance care plan.
- Advance care directives became legally binding from 12 March 2018.

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 of end of life and palliative care 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. For more information, visit **end of life and palliative care explained**.

End of life and palliative care options for people living with a disability

If you have been diagnosed with a life-limiting illness, you or your guardian can consider the various options for end of life and palliative care. You may like to talk about these options with your doctor, family or group home staff.

You can receive palliative care in your home, at a specialist inpatient palliative care unit (sometimes called a 'hospice'), or in a local hospital. Depending where you live, an outpatient clinic or 'day hospice' may be available.

Deciding whether to stay at home or move into an inpatient palliative care unit or hospital is not always easy. It is a good idea to talk through the different possibilities.

If your condition gets worse, or your family or friends or group home staff are no longer able to care for you, you may need to consider options for inpatient care.

End of life and palliative care at home

If you are living with a life-limiting illness as well as a disability, 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.

However, not everyone chooses to remain at home for end of life or palliative care. You should not be 'persuaded' to receive home-based care if it is not right for you, or you don't have adequate care and support at home.

You may make this decision together with your guardian or 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 and palliative care services at home** may include:

- support from a wide range of healthcare and community service providers such as district nurses
- support from specialist community palliative care for complex needs
- 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 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.

There is support available in Victoria if you choose to receive palliative care at home. However, there may be times when you need more care than can be given at home, and you may decide to move into residential care or inpatient care.

If your condition fluctuates, gets worse or becomes complex, you may need care in a hospital or an inpatient specialist palliative care unit. Depending on where you live, the closest palliative care unit may be in a local hospital. Often you can return home after a period of inpatient care.

For more information visit **End of life and palliative care at home**.

End of life and palliative care in specialist disability accommodation

If you live in a group home or specialist disability accommodation the support staff may be able to provide for some or all of your end of life care needs.

You can also have end of life and palliative care services (listed above) provided in your home. This may include visits from a range of service providers on an occasional or regular basis. Your needs determine what services you require, not your diagnosis.

Choosing to remain in specialist disability accommodation can be a good option if you have thought about issues such as:

- staying in a familiar setting among residents and staff who know you
- whether your care needs can be met by the staff
- allowing good-byes to occur in your own time
- whether other residents are comfortable with what is happening around them
- what to do if your condition gets worse or you are close to dying.

It is important that speak to your support provider and staff about your care needs when making this decision.

If your condition worsens or becomes more complex you may need to think about moving to an aged care residential unit, or inpatient palliative care unit.

If your support staff find it difficult managing your symptoms and cannot keep you comfortable, you or your guardian may choose to move to an inpatient palliative care unit.

It's okay to change your mind about what care you or your guardian think is best for you. It's a good idea for you or your guardian to talk with your doctor, family members, friends or trusted health professional or support staff.

End of life and palliative care in a residential aged care facility

If you decide to move into a residential care home such as an aged care facility you will receive the longer-term care you need as well as managing your end of life care needs. The facility can also involve the community palliative care service in your area to provide specialist care or advice.

For residential aged care you will need to be assessed by the Aged Care Assessment Service. For more information see the **Residential aged care homes** fact sheet.

There is more information on these services under **Palliative care in a hospital or community residential home**.

Younger people and residential aged care

If you are a person under the age of 65 years living with a disability and you need end of life and palliative care, you may be at risk of entering a residential aged care facility. Moving to this type of care should only occur if all

other care options have been fully explored and are not suitable.

If residential aged care is the only option, an individualised approach for you will be used with regular review of your support needs and options for care. The **Aged Care Assessment** Service uses a specific assessment for younger people living with a disability.

Palliative care in a hospital or inpatient specialist palliative care unit

If your condition fluctuates, worsens or becomes complex, you may need care in a hospital or an inpatient specialist palliative care unit. Depending on where you live, the closest palliative care unit may be based in a local hospital. Often you can return home after a period of inpatient care.

You may need care at an inpatient palliative care unit or hospital for one or more of the following reasons: symptom management, complex needs, respite or care as the end of life approaches.

Inpatient palliative care units (sometimes called 'hospices') are often part of a hospital but are designed to be as 'homely' as possible. You are always free to bring in items from home to make your stay more comfortable. Most palliative care units offer single rooms, but this is not guaranteed, so talk to the staff about available options.

For more information visit the page **Palliative care in a hospital or community residential home**.

Planning ahead

Planning ahead will help you and your family or friends to take advantage of the services that exist to help you prepare for the end of your life. It is a good time to reflect on the things that are important to you, and to make arrangements that suit you.

Depending on your illness you may need the help of your **Guardian** or **medical treatment decision maker** (previously known as a Medical Power of Attorney) to make your views known when decisions need to be made and you are not able to.

Read more about setting up guardianship or a medical treatment decision maker at **Planning for future needs**. There is more information on the website for the **Office of the Public Advocate**.

Planning ahead means your views and preferences will be respected and followed. It's a good idea for your family, friends or those important to you to be included in these discussions. One way to record your preferences is to write an advance care plan.

Make an advance care plan

Advance care planning is the process of making your care and medical treatment preferences known in the event that you cannot make these decisions yourself.

An advance care plan will help your guardian, family, friends or those important to you to know in advance about the level of healthcare and quality of life you would want if, because of your illness or disability, you are unable to have these discussions and make the decisions for yourself.

You and your guardian can talk with those close to you, your family, your doctor and treating team to make sure they are aware of what is important to you. For more information on starting a discussion with your family or friends visit '**Dying to talk**'.

An advance care plan should be respected by your family, medical team and support staff. Advance care plans can be overridden by a medical treatment decision maker, but from 12 March 2018 an advance care directive is legally binding.

For more information see the **Advance care planning** pages.

Advance care directives

The Medical Treatment Planning and Decisions Act 2016 came into effect on 12 March 2018. The Act is a single law for medical treatment decision-making for people without decision-making capacity. This will ensure that the person receives medical treatment that is consistent with their preferences and values.

In Victoria, since March 2018, you are able to create a legally binding advance care directive that will allow you to:

- make an instructional directive (providing specific directives about treatment you consent to or refuse)
- make a values directive (which will describe your views and values). A medical treatment decision maker and health practitioners will be required to give effect to a values directive
- appoint a medical treatment decision maker (who will make decisions on your behalf if you no longer have decision making capacity)
- appoint a support person (who will help you to make decisions for yourself).

If you have a Refusal of Treatment Certificate that was created before March 2018, this will still be recognised after March 2018 (but the certificate retains its original limitation to current conditions only). This means that there is no need to remake existing legal documents unless you choose to do so for a new condition.

If you already had an enduring power of attorney (medical treatment) before March 2018, this automatically becomes a valid appointment under the new Act. However, this person will be known as a 'medical treatment decision-maker' under the new Act. There is no need to remake existing legal documents.

For more information visit **Medical Treatment Planning and Decisions Act 2016** – frequently asked questions.

Where to get help

- Better Health Channel – use the 'Find a service' search option.
- **Palliative Care Victoria** search directory.
- **National Palliative Care Service** online directory.
- **CareSearch** – including information for specific groups.

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

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