

|  |
| --- |
| Voluntary assisted dying considerations in end-of-life care |
|  |

# About this guidance

This guidance has been developed for executives, managers and senior staff who are responsible for the systems and processes that govern person-centred care for voluntary assisted dying in health services.

Health services and health practitioners are responsible for ensuring the provision of end-of-life care is consistent with the guiding principles outlined in *Victoria’s end of life and palliative care framework.*1 The framework has a strong focus on patient-centred care, valuing and respecting people’s preferences and values for end-of-life care.

When a person requests information about voluntary assisted dying, it is critical that health practitioners are aware of the level of involvement their health service has in providing voluntary assisted dying and other end of life support services, including:

* support services available to assist with end-of-life care
* other services provided as part of a health service partnership.

These may include, but are not limited to:

* psychological support, social work and spiritual care
* specialist palliative care
* advance care planning
* organ, tissue and body donation for transplant, research or teaching
* care of the deceased
* bereavement services
* debriefing.

Existing policies, procedures and guidelines should be updated to ensure patients requesting voluntary assisted dying have access to these services as part of high-quality end-of-life care. This should also include updating policies, procedures and guidelines to include clinical handover, deactivation of implantable cardioverter defibrillators and mortality review for voluntary assisted dying.

# Psychological support, social work and spiritual care

Health practitioners should be aware of the range of local support services to assist with end-of-life care that is accessible to the person. The aim of reducing suffering, distress and anxiety and improving the person’s quality of life is paramount.1 Health practitioners should endeavour to have purposeful conversations to understand a person’s unique cultural needs, values and beliefs and ensure they are respected in their end-of-life care.1 Some end of life concepts can be confronting and confusing for some cultures, and understanding and exploring the preferences of the relevant culture or group may be helpful to understand required spiritual care and/or psychological supports.1 Referrals may be required for the person to access services for the provision of psychological support, social work and/or spiritual care.

# Palliative care and specialist palliative care

Palliative care is available throughout Victoria, with specialist palliative care services providing bed-based, home-based and consultancy services in regional and metropolitan areas.1

The purpose of palliative care services is to prevent and relieve suffering and potentially improve a person’s quality of life.

Provided by health practitioners who have advanced training and/or have specialist qualifications in palliative care, the role of specialist palliative care services includes:

* providing direct care to a person with complex end of life and palliative care needs
* providing consultation to support, advise and educate non-specialist clinicians who are also providing palliative care.1

People require varying levels of end of life and palliative care. Not every person who is at the end of their life requires specialist palliative care and some people may not want to be referred to a specialist service.

Referral to a specialist palliative care service may be considered for relief of suffering through symptom management and interventions to improve quality of life.

# Advance care planning

Advance care planning enables people to have conversations about what matters to them and to plan for this in advance.1 It allows a person to express their preferences to inform future medical treatment if they become unable to participate in decision-making.

A person who requests access to voluntary assisted dying is not required to complete an advance care directive, though they may wish to do so. This may provide the person with an opportunity to consider other medical treatment options and how their ongoing treatment will reflect their preferences and values.

A request for access to voluntary assisted dying may also indicate that a person’s existing advance care directive needs to be revised, in light of the person’s changed circumstances.

# Clinical handover

Clinical handover is the transfer of professional responsibility and accountability for some or all aspects of care of a person to another person or professional group on a temporary or permanent basis.3

Voluntary assisted dying can be a sensitive subject and health practitioners need to exercise due care and skill in relation to clinical handover to ensure high quality care. Questions to consider in relation to voluntary assisted dying as part of clinical handover may include (but are not limited to):

* Who is the patient’s coordinating medical practitioner and where can their contact details be found?
* At what point in the voluntary assisted dying process is the person?
* Which forms have been completed?
* Which permit, if any, has been issued?
* Is the person in possession of the voluntary assisted dying medication?
* Who is the contact person?
* Where does the person want end-of-life care to occur?
* Which carers, family members or friends know about the voluntary assisted dying request, and how much information do they have?
* Has the person specified a date on which they are planning to take the medication?
* What are the person’s plans in the lead up to taking the medication?
* Who does the person want present when they take the medication?
* Does the person have any specific requirements following administration of the voluntary assisted dying medication and for after-death care?
* What bereavement supports may be required post death for those involved?
* Is there any additional information staff of the health service may need to know – e.g. pre and post debriefing processes?

# Organ, tissue or body donation for transplant, research or teaching

Most health services have established policies and pathways with regards to organ, tissue or body donations. There are several facilities that provide for organ, tissue or body donation. Below is a summary of the position of specific services in relation to donations from people who have died following administration of the voluntary assisted dying medication. Each case will be explored on an individual basis.

|  |  |  |
| --- | --- | --- |
| **Type of donation** | **Responsible organisation** | **Details** |
| Body donation for research | Department of Anatomy and Neuroscience at the University of Melbourne | For a person to donate their body for the purpose of teaching, study, examination and investigation of human anatomy,4 the person should notify the Department well in advance of the person taking voluntary assisted dying medication by calling (03) 8344 5809. Each case will be considered on an individual basis.  <https://biomedicalsciences.unimelb.edu.au/departments/anatomy-and-neuroscience/engage/body-donor-program> |
| Cornea and sclera donation for transplant and/or research | Lions Eye Donation Service at the Centre for Eye Research Australia | If the person has made arrangements for cornea and/or sclera donation, the health practitioner will need to contact the Lions Eye Donation service. The tissue will be assessed to see if it is suitable for transplant, for medical research or for teaching.  The cornea and the sclera are the main tissues that are transplantable. The corneal tissue helps restore the vision of people who have corneal disease. The scleral tissue can be used for eye patch grafts and surgical reconstruction.  Donation does not delay funeral arrangements as the tissue retrieval is performed within hours of death. The notification of a person’s death must occur promptly.  The Lions Eye Donation service can be contacted on (03) 9929 8666.  <https://www.cera.org.au/community/lions-eye-donation-service/> |
| Brain donation for research | Victorian Brain Bank | For the person to donate their brain to support neuroscience research into different brain disorders including Alzheimer’s disease, Parkinson’s disease, Multiple Sclerosis, Huntington’s disease, Motor Neurone Disease, bipolar mood disorder, depression and schizophrenia, they should notify the Victorian Brain Bank well in advance of taking voluntary assisted dying medication by calling (03) 8344 1900. Each case will be considered on an individual basis.  When the person has died, either a family member or the health practitioner will need to contact the Victorian Brain Bank on the specified number given to the person.  <https://www.florey.edu.au/> |

# Deactivation of implantable cardioverter defibrillators

When a person requests access to voluntary assisted dying, the health practitioner must ask if the person has an implantable cardioverter defibrillator (ICD) device. If so, the coordinating medical practitioner should explain the procedure and implications fully to the patient. Every person who has an ICD insitu has been provided with (and should have) the device details on a card.

The coordinating medical practitioner must ensure the person is aware:

* of the overall risks versus benefits of deactivating the ICD
* that deactivating the ICD will not cause death7
* that deactivating the defibrillator (shocking) function of the ICD does not deactivate the pacemaker function of the ICD
* that an ICD can be reactivated if the person changes their mind about accessing voluntary assisted dying
* that leaving the ICD active may result in the delivery of defibrillation shocks near the end of life (these shocks are likely to be ineffective, but may be painful for the person and distressing for others to watch)
* of the process and timeframe to organise deactivation of the device.

Depending on the person’s decision, it is important to secure consent:

* to deactivate the ICD and document necessary details to avoid inappropriate cardiopulmonary resuscitation
* to having a cardiac technician available to deactivate the ICD at their preferred date, time and location of death.

The coordinating medical practitioner is responsible for coordinating any care requirements that may arise.

The details of these conversations with the person and any subsequent arrangements must be documented clearly in the person’s medical record.

# Mortality case review

It is recommended that when a person dies as a direct result of taking the voluntary assisted dying medication, that their case be submitted to the mortality case review meeting. The discussion should cover evaluation of the processes of care surrounding the person’s experience and identification of any unforeseen or undesirable outcomes, which may provide opportunities to improve care provision for the future.

# Care of the deceased

Care of the deceased should not alter from the processes that health services already have in place, with dignity and respect of the person being maintained at all times.

# Notification following death

There are specific requirements for notification of deaths of people who were the subject of a voluntary assisted dying permit. These requirements should be incorporated into health service processes.

The medical practitioner responsible for completing the Medical Certificate Cause of Death must identify that the person was the subject a voluntary assisted dying permit and whether a voluntary assisted dying medication was administered. Medical Certificate Cause of Death forms will be updated to ask for this information.

The medical practitioner must also notify the Coroner of the person’s death. Notification will be via telephone. This will not be a ‘reportable death’ and will only be investigated by the Coroner if there is a reason to investigate.

# Bereavement care

Bereavement care is paramount for those close to and supporting a person at the end of their life.

The significance of bereavement will differ for each person. Some may have mechanisms and supports in place to support their bereavement, while others may not.

Many health services will already have bereavement services available. It is recommended that health services consider the individual’s bereavement risk and assist the bereaved individual to access bereavement services – either within the health service or by referral.

Health practitioners may need to refer the bereaved individual to their GP for a mental health plan which will see a subsidised cost through Medicare for counselling or psychological care provision.

The Australian Centre for Grief and Bereavement Counselling and Support Service provides a statewide specialist bereavement service for individuals who need assistance following the death of someone close to them.

Health services may also find the bereavement support standards for specialist palliative care services helpful.9

# Debriefing

Staff involved in the delivery of voluntary assisted dying may want to participate in debriefing within health services after death.

As staff become more familiar and comfortable with the processes that health services have in place, debriefing may only need to occur on a case-by-case basis.

All staff should be aware of their health service’s employee assistance program and be encouraged to use this service. It is recommended that health services advertise this widely during implementation of the voluntary assisted dying legislation.

In addition, health services may elect to allocate a voluntary assisted dying liaison role within their organisation to support staff caring for people who have requested access to voluntary assisted dying. This may be allocated within an existing role or may form the basis of a new role.

References

1. Department of Health and Human Services, 2016, *Victoria’s end of life and palliative care framework*, retrieved December 2018   
   <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/palliative-care/end-of-life-and-palliative-care-framework>
2. Australian Commission on Safety and Quality in Health Care, 2015, *National Consensus Statement: Essential elements for safe and high quality end of life care*, Sydney, retrieved December 2018

<https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential->elements-for-safe-high-quality-end-of-life-care/ 

1. Australian Commission on Safety and Quality in Health Care, 2012, *Standard 6 Clinical Handover Safety and Quality Improvement Guide*, Sydney, retrieved December 2018   
   <https://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard6_Oct_2012_WEB.pdf>
2. University of Melbourne, N.D, *Body Donor Program*, retrieved December 2018   
   <https://biomedicalsciences.unimelb.edu.au/departments/anatomy-and-neuroscience/engage/body-donor-program>
3. Centre for Eye Research Australia, 2016, *Lions Eye Donation Service*, retrieved December 2018   
   https://www.cera.org.au/community/lions-eye-donation-service/
4. Florey Institute of Neuroscience and Mental Health, N.D, *Victorian Brain Bank*, retrieved December 2018   
   <https://www.florey.edu.au/science-research/scientific-services-facilities/victorian-brain-bank>
5. NSW Agency for Clinical Innovation, 2014, NSW *Guidelines for Deactivation of Implantable Cardioverter Defibrillators at the End of Life*, retrieved December 2018   
   <https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0008/179990/ACI-Deactivate-ICDs.pdf>
6. Island Health, 2019, *Bereavement group for MAiD*, Canada, retrieved December 2018   
   <https://www.islandhealth.ca/learn-about-health/medical-assistance-dying-maid/medical-assistance-dying-maid/bereavement-group-maid>
7. Hall C, Hudson P, Boughey A, 2012, *Bereavement support standards for specialist palliative care services*, Department of Health, State Government of Victoria, Melbourne, retrieved December 2018   
   <https://www2.health.vic.gov.au/about/publications/researchandreports/Bereavement-support-standards-for-palliative-care-services>