



# Preparing for the death of a loved one who has chosen voluntary assisted dying

# Purpose of this Guide

This Guide provides advice on what to do both before and after a friend or family member has died from accessing voluntary assisted dying in New South Wales.

The Guide is divided into three sections:

- Planning for death
- Administration of a voluntary assisted dying medication
- After death care.

Information about the voluntary assisted dying process is available on the NSW Health website and should be read in addition to reading this Guide. This can be found at <u>https://www.health.nsw.gov.au/voluntary-assisted-dying/Pages/carers.aspx</u> and includes links in different languages, information for Aboriginal people and an Easy Read Guide.

It can be a difficult and stressful time when someone you care for is at the end of their life or has died. This Guide is intended to give you information and options for further support as you need it.

If you need additional support and are unsure where to start, you can call the **NSW Voluntary Assisted Dying Care Navigator Service on 1300 802 133** (Monday to Friday 8:30am to 4:30pm excluding public holidays) or email <u>NSLHD-VADCareNavigator@health.nsw.gov.au</u>.

# Acknowledgments

NSW Health acknowledges that some of the content from this guide has been extracted or adapted, with permission, from:

- When someone dies: a practical guide for family and friends, from the Care at the End-of-Life Collaborative, Queensland Health
- *Preparing for a death,* from the Queensland Voluntary Assisted Dying Support and Pharmacy Service

# 1. Planning for death

Thinking and talking about the end of a loved one's life can be hard. For some people, it might also be difficult to hear that a loved one is choosing to access voluntary assisted dying.

Having early discussions about end-of-life and planning for death can help you and your loved one feel more prepared for managing this significant time, even if your loved one does not access voluntary assisted dying.

Your loved one will have a coordinating practitioner (doctor) to support them through the voluntary assisted dying process and in planning for their death. If your loved one agrees, the coordinating practitioner can also involve you, your family and friends in planning.

The coordinating practitioner is often supported by a care coordinator from their local voluntary assisted dying team, or the NSW Health Voluntary Assisted Dying Care Navigator Service who can also help if you have any questions or need support.

Contact information for your local voluntary assisted dying team:

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More information on supporting someone through the voluntary assisted dying process is available on the NSW Health website: <a href="http://www.health.nsw.gov.au/voluntary-assisted-dying/Pages/supporting-someone.aspx">www.health.nsw.gov.au/voluntary-assisted-dying/Pages/supporting-someone.aspx</a>.

# What decisions need to be made?

If your loved one has been found eligible to access voluntary assisted dying, they will need to make some important decisions with the help of their coordinating practitioner.

A coordinating practitioner will provide information to help your loved one to:

- make an **administration decision**. Your loved one must choose to either:
- take the voluntary assisted dying medication themselves (self-administration); or
- have a doctor or nurse practitioner give them the medication (practitioner administration).

identify a **contact person** (*only required if self-administration has been chosen*). The coordinating practitioner will talk to your loved one about things to consider when choosing a contact person. The contact person has legal responsibilities and will be given detailed instructions on what they need to do. This includes telling the coordinating practitioner when your loved one has died and returning any unused or remaining medication as soon as possible.

- identify a **witness to administration** (only required if practitioner administration has been chosen). The coordinating practitioner will talk through who this person can be, in many cases the health service will identify a person to fulfil this role.
  - plan the more personalised details of the day of administration of the voluntary assisted dying medication, such as:
    - where your loved one would like administration to take place. This might be at home, on

country, in hospital, in a palliative care unit or a hospice, or in a residential aged care facility.

- who they would like to be present when the medication is administered.
- **the environment during administration**: some people might like to have music, sounds, scents or objects (e.g. blankets, photos or jewellery) with them during their final moments.
- whether there is a **favourite outfit** they might like to wear.
- **any religious, spiritual or cultural practices** that are important to them at this time. If your loved one is in a facility, it is also helpful for facility staff to know of any end-of-life customs, such as preparations for burial or cremation, so arrangements can be made.

#### Verification and Certification of Death

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- identify **who will verify the death** (a required examination to confirm that a person has died, which needs to be completed before a person can be moved to a funeral home): Only doctors, registered nurses and certain other health professionals with specified qualifications are allowed to do this. The coordinating practitioner will help to determine who the best person to verify the death will be.
- identify **who will complete the Medical Certificate of Cause of Death**: a doctor must complete a Medical Certificate of Cause of Death within 48 hours of a person's death. The coordinating practitioner will help to determine which doctor will do this.

If your loved one has chosen self-administration, it is important that relevant family or friends are aware of who has been identified to verify the death and complete the Medical Certificate of Cause of Death, and how to contact them. This could be a number of people depending on your situation.

## Expected Home Death Forms for NSW Health

If your loved one is being cared for by NSW Health and expects to die at home, your local health district can organise death certification arrangements that allow a funeral home to remove the person from their home after the verification of death has occurred, and before the Medical Certificate of Cause of Death is completed. In this event, the Medical Certificate of Cause of Death must be completed within 48 hours.

Each local health district will have their own processes and forms to complete for an expected home death. If you have any questions about this, ask your coordinating practitioner or care coordinator from your local voluntary assisted dying team.

# Further considerations

When planning for death, it can be helpful for your loved one to tell you, or other friends or family about their wishes.

This includes providing details that will help you or others to make decisions on their behalf when they are unable to make or communicate decisions, or after they have died.

Depending on their wishes, you may be able to support them with some of these. This could include:

- writing a will
- cultural or spiritual practices that are important
- exploring funeral or memorial plans, which could include a living wake
- making a list of important documents, personal details and passwords
- documenting memories: some people decide to write letters, record videos, share recipes or stories, or put together photo albums or other keepsakes with their loved ones.

The NSW Government webpage (<u>www.nsw.gov.au/family-and-relationships/planning-for-end-of-life</u>) provides guidance on planning for end of life. This includes information on wills, funeral plans and documenting preferences for future care and medical treatment in an Advance Care Directive.

The NSW Trustee and Guardian (<u>www.nsw.gov.au/departments-and-agencies/trustee-guardian</u>) also provides information on making end of life wishes known.

An Advance Care Directive can help family and health professionals to make decisions for a person when they are unable to make or communicate decisions about the care and treatment they want. It is important to note that an Advance Care Directive cannot be used to request access to voluntary assisted dying because a person must have decision-making capacity in order to access voluntary assisted dying. However, it may still be used if a person chooses not to take the voluntary assisted dying medication or if they are unable to continue with the voluntary assisted dying process.

More information on advance care planning can be found at <u>www.health.nsw.gov.au/patients/acp/</u>.

Gathering personal information, identification, and essential documents, listed below, can help to simplify the process and responsibilities which follow someone dying.

Personal information to gather includes (as relevant):

- the person's full legal name (birth name or legal name at the time of death; avoid using nicknames)
- any names previously used, including maiden surname
- last residential address
- their Medicare number, Tax File Number and Centrelink Customer Reference Number
- the person's date and place of birth (town and state if born in Australia and country if born overseas)
- marriage and/or divorce certificates, or date of marriage/civil partnership if certificate not available
- name, occupation, and birth date of the surviving spouse
- financial information, including loan details, house title/lease documents, superannuation and insurance.



# 2. On the day of administration of a voluntary assisted dying medication

People prepare for the death of a loved one in different ways. This may be a challenging and emotional time, and it is important to take care of yourself and those around you as well.

It is important to talk to your loved one about their preferences.

Your loved one will have chosen to:

- take the voluntary assisted dying medication themselves (self-administration) or
- have the medication administered to them by a doctor or nurse practitioner.

Your loved one can pause or stop the process at any time. They can also decide not to take or be administered the medication.

It is normal to have questions about the administration of voluntary assisted dying medication and what to expect.

Ask your loved one's coordinating practitioner about any questions you or your loved one may have.

# If your loved one has chosen to take the voluntary assisted dying medication themselves (self-administration)

If your loved one has chosen self-administration and has received the medication from the pharmacy, they can take the medication whenever they choose. They can choose to be alone, or to have their loved ones with them when they do this.

### How do I know my loved one has died?

There are some physical signs that can help you identify when a person has died. They will:

- stop breathing.
- not have a heartbeat or pulse.
- have fixed pupils (not moving) that do not react to changes in light. You might notice that they are staring straight ahead. Their eyelids may not be closed.

Do not worry if you are not sure, as this can be confirmed when the formal verification of death is completed.

#### What should I do immediately after my loved one dies?

After your loved one has died, it can feel like there are a lot of things that need to happen all at once. It is important to remember to give yourself time, as there is usually no need to rush.

If you are with your loved one when they die:

- you may wish to lie them down to a flat position. Keep the room cool (if possible). Using an air conditioner or a fan can help with this.
- consider spending some time with them. There is no need to contact anyone straight away. However, you may wish to telephone a relative or friend if you want them to be with you.

When you are ready, you will need to:

call the person who was identified to verify the death

call the doctor who was identified to complete the Medical Certificate of Cause of Death.

After verification is complete and the Medical Certificate of Cause of Death has been completed, you can contact the funeral home within the timeframe you have agreed with them. As explained above, if your local health district team has made arrangements for an expected home death, you can contact the funeral home after verification is complete.

You do not need to contact police about an expected home death, except if your loved one's doctor has advised you to do so.

If your loved one expressed wishes for people to visit after their death:

- you can arrange for an amount of time to let friends and relatives visit and say goodbye. The timing of this might differ if your loved one is at home, or in a health, residential or care facility. If at home, you may be able to access support for cooling the person from your funeral home or palliative care team.
- families or carers can attend to cultural, religious, or other practices, such as bathing the person. It is best to prepare for this beforehand.

If you are the contact person, tell the coordinating practitioner that your loved one has died, and make a plan for returning any substance to the Pharmacy Service. If you are not the contact person, you will need to tell the contact person that your loved one has died so they can fulfil their responsibilities.

# If your loved one has chosen to be given the voluntary assisted dying medication by an administering practitioner (practitioner administration)

The doctor or nurse practitioner who gives your loved one the voluntary assisted dying medication is called the administering practitioner. Often the doctor who is the coordinating practitioner is also the administering practitioner.

On the day of administration, the administering practitioner will come to the agreed place at the agreed time. They will talk to your loved one to check that they have decision-making capacity, are acting voluntarily, and still wish to go ahead with administration.

They will be able to talk to any friends and family present and answer questions.

When your loved one is ready, the practitioner will administer the voluntary assisted dying medication. The administering practitioner may stay until your loved one dies or may leave and be available by phone.

#### What should I do after my loved one dies?

The administering practitioner will be able to verify the death and organise for completion of the Medical Certificate of Cause of Death.

Family and friends can then carry out the plan put in place with the loved one before their death. This might include:

- spending some time with your loved one who has died.
- having friends and relatives visit and say goodbye. The timing of this might differ if your loved one is in a health, residential or care facility.
- attending to cultural, religious, or other practices, such as bathing the person.

# 3. After death

# Managing affairs after a death

After your loved one dies, it can be overwhelming to think about who needs to be notified and what else needs to happen.

The New South Wales and Australian Government has some information on next steps after a death:

- After a Death (NSW Government), provides information on funerals, wills and death certificates: <a href="https://www.nsw.gov.au/family-and-relationships/deaths/after-a-death">www.nsw.gov.au/family-and-relationships/deaths/after-a-death</a>
- Who to tell when someone dies (Services Australia), provides information on who to notify when someone has died and what information is needed: <a href="http://www.servicesaustralia.gov.au/who-to-tell-when-someone-dies">www.servicesaustralia.gov.au/who-to-tell-when-someone-dies</a>? Note: this is in addition to the responsibilities a person has if they are the identified contact person (for self-administration only).
- Death and bereavement (Service NSW) provides information on how to notify government organisations and others and complete the tasks required after someone has died: <a href="https://www.service.nsw.gov.au/guide/death-and-bereavement">www.service.nsw.gov.au/guide/death-and-bereavement</a>
- Revenue NSW and moneysmart.gov.au provide information on accessing death benefit entitlements in superannuation funds and life insurance policies: <u>https://moneysmart.gov.au/find-unclaimed-money</u> and <u>www.revenue.nsw.gov.au/unclaimed-</u> money

# Counselling and grief support

Grief is a normal and natural response to loss. It can affect every part of a person's life. Coping with grief is not about 'getting over' the person's death but about finding ways to live with the loss.

After a death, it can feel confusing and overwhelming. You may experience a range of intense feelings such as sadness, anger, or even relief. There is no right or wrong way to grieve and grief can be present and emerge at any time, sometimes seemingly out of nowhere.

Accepting another person's choice to access voluntary assisted dying will be easy for some people and difficult for others. Even if you are supportive of your loved one's choice, it is normal to be affected by the loss and the grief that follows a voluntary assisted death.

It can be easy to overlook your own needs when you are grieving. Take time to do the things you enjoy and be kind to yourself on the days that feel harder than others.

Often people can find that it is helpful to talk about emotions with the important people in their lives and sometimes people feel that it is easier to talk to people who were less involved in the process of their loved one's death.

## Talking to children about death and dying

Each child will react to loss in their own way. A child's response can be influenced by their age, development, environment, culture, and previous experiences with death and dying.

It is important to remember that a loss, at any age, is significant for a child. This may be the case, even when the child doesn't seem to show that they are sad.

Children often process grief in parts. Sometimes this can look like children addressing the loss for a few moments, before returning to play and their usual routine.

Allowing and normalising the child's experience as they move between their sadness and other emotions is important. It is not always necessary to 'fix' or 'solve' their grief experience.

Letting children know that it is natural to express sadness in various ways, just as they express other emotions, can be helpful. Take the time to talk and listen to children before and after someone has died. Answer their questions about death in an honest and consistent way.

For more information, visit the Australian Centre for Grief and Bereavement (<u>www.grief.org.au</u>).

#### Further information on grief support

If you are finding it difficult to manage on a day-to-day basis, it may be helpful to see a counsellor or another health professional. There are many organisations that can help you. You can also to talk to your GP (doctor).

#### **Grief Line**

griefline.org.au | 1300 845 745

Provides free bereavement counselling to people in NSW. A 7-day telephone support service and access to online forums, support groups and fact sheets are also available for people experiencing grief and loss.

#### **Grief Australia**

#### grief.org.au | 1800 642 066

Information for adults and children experiencing grief, including the MyGrief app.

#### **13YARN**

13yarn.org.au | 13 92 76

24-hour, 7 day a week crisis support provided by Aboriginal and Torres Strait Islander crisis supporters.

#### Lifeline

lifeline.org.au | 13 11 14

24-hour telephone and online counselling service.

#### **Mental Health Line**

https://www.health.nsw.gov.au/mentalhealth/Pages/mental-health-line.aspx | 1800 011 511

The 1800 011 511 Mental Health Line is NSW Health's 24/7 statewide phone service which links people with NSW Health mental health services.

worldwellnessgroup.org.au | 1300 079 020

Support and information to find aid, assistance and mental health services in your language.

#### Your GP

To find a GP in NSW go to https://www.healthdirect.gov.au/australian-health-services.

# More information

If you have further questions about information in this book or voluntary assisted dying, you can speak with your loved one's coordinating practitioner or care coordinator in the local voluntary assisted dying team.

You can also find more information, advice and support about voluntary assisted dying in NSW from the NSW Voluntary Assisted Dying Care Navigator Service (available Monday-Friday, 8.30am-4:30pm, excluding public holidays) using their details below:

- Phone: 1300 802 133
- Email: <u>NSLHD-VADCareNavigator@health.nsw.gov.au</u>
- Website: https://www.health.nsw.gov.au/voluntary-assisted-dying





# Notes

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