



First request patient information guide

Voluntary assisted dying

health.nsw.gov.au/vad

First request patient information guide: Information if you have made a first request for voluntary assisted dying in NSW

This guide contains some legal and medical words. If you need help understanding these words, you can speak to your doctor or contact the **NSW Voluntary Assisted Dying Care Navigator Service on 1300 802 133**.

You can call the **Translating and Interpreting Service (TIS National) on 131 450** and ask for the NSW Voluntary Assisted Dying Care Navigator Service if you need language support.

Remember, you can pause or stop the voluntary assisted dying process at any time, even after you get the medication. You do not need to continue if you do not want to. You do not need to give a reason.



SHPN (OCHO) 230868 ISBN 978-1-76023-661-8 © NSW Ministry of Health 2023

Version control					
Version Date		Details			
1.0	17 November 2023	Approved by NSW Health Secretary			

Key information about voluntary assisted dying in NSW

28	Eligible people can choose to access voluntary assisted dying in NSW from 28 November 2023
	This 'First request patient information guide' outlines the background to voluntary assisted dying and the eligibility criteria. It has information about the voluntary assisted dying process for patients who have made a first request (a formal request to a doctor to access voluntary assisted dying).
	If you make a first request to access voluntary assisted dying to a medical practitioner (doctor), they must tell you whether or not they accept your first request (see ' <u>Step 1: First request</u> ' below for more information about making a first request).
	Only certain medical practitioners can accept your first request. These medical practitioners are called authorised voluntary assisted dying practitioners. A medical practitioner must complete special training to become an authorised practitioner.
	If a medical practitioner accepts your first request, they will provide you with clear information about the next step in the voluntary assisted dying process.
CY	If a medical practitioner does not accept your first request, it may be because they are not an authorised practitioner. In this case, you should speak with your general practitioner, treating clinical team or call the NSW Voluntary Assisted Dying Care Navigator Service on 1300 802 133, who can help you find an authorised practitioner.
	There are strict eligibility criteria to access voluntary assisted dying. You must meet all criteria and these are outlined below.
	It is important to know about options available to you at the end of your life. This includes palliative care and other treatment options. Even if you ask for voluntary assisted dying, you can still have access to high-quality palliative care and treatment.
	There is information about support available for you at the end of this guide.

Background

What is voluntary assisted dying?

Voluntary assisted dying means an eligible person can ask for medical help to end their life. The person must have an advanced and progressive disease, illness, or medical condition that is expected to cause their death within six months (or 12 months for neurodegenerative diseases such as motor neurone disease). They must also be experiencing suffering that can't be relieved in a way that is acceptable to them.

Who is eligible for voluntary assisted dying in NSW?

You can only access voluntary assisted dying in NSW if you meet all the eligibility criteria and follow the process outlined in the law, including getting approval from the NSW Voluntary Assisted Dying Board.

To be eligible to access voluntary assisted dying, you must:

- 1. Be an adult (18 years or over) who:
 - a. Is an Australian citizen, or
 - b. Is a permanent resident of Australia, or
 - c. Has been a resident in Australia for at least three continuous years when you make your first request.
- 2. Have been ordinarily resident in NSW for at least 12 months when you make your first request (*see below).
- 3. Have at least one disease, illness or medical condition that:
 - a. Is advanced and progressive,
 - b. Will, on the balance of probabilities, cause your death within six months (or within 12 months for neurodegenerative diseases such as motor neurone disease), and
 - c. Is causing you suffering that cannot be relieved in a way you consider tolerable.
- 4. Have decision-making capacity in relation to voluntary assisted dying.
- 5. Be acting voluntarily (your own choice) and not because of pressure or duress from another person.
- 6. Have an enduring request for voluntary assisted dying. This means the request is continuous, ongoing, and lasting.

If you do not meet all these criteria, you will not be eligible to request voluntary assisted dying.

^{*} You may still be eligible to access voluntary assisted dying in NSW if you have not been ordinarily resident in NSW for at least 12 months. You need to be granted an exemption for this to happen. You will need to apply for this through the NSW Voluntary Assisted Dying Board. Information about residency exemptions is available on the NSW Health website: www.health.nsw.gov.au/voluntary-assisted-dying/Pages/board.aspx

What does decision-making capacity for voluntary assisted dying mean?

Decision-making capacity for voluntary assisted dying means you must have capacity to do the following at each step of the voluntary assisted dying process:

- understand information or advice given to you about voluntary assisted dying.
- remember the information or advice given to you so you can request voluntary assisted dying or decide to access voluntary assisted dying (a voluntary assisted dying decision).
- understand the process, steps and requirements involved in a voluntary assisted dying decision.
- understand what happens when you make a voluntary assisted dying decision. This includes understanding that taking the voluntary assisted dying medication will result in your death.
- weigh up the information above before making a decision to access voluntary assisted dying.
- be able to communicate a voluntary assisted dying decision by talking, using communication tools, or using sign language or gestures.

What does acting voluntarily mean?

Acting voluntarily means it must be your choice to access voluntary assisted dying.

No one can pressure you or force you to start or complete the voluntary assisted dying process. Pressure can include abuse, coercion, intimidation, threats, and undue influence.

It is against the law (illegal) for anyone to pressure you to choose voluntary assisted dying.

Using an interpreter during the voluntary assisted dying process

You can use an interpreter at every stage of the voluntary assisted dying process if you need support communicating. If you need an interpreter, your medical practitioner will organise one. Further information on who can interpret is available below under '<u>What information and supports are available to me</u>'.

Voluntary assisted dying process

There are 11 steps in the voluntary assisted dying process. The flow chart on the next page shows the main steps in the process. More steps may be required based on your individual situation.

Voluntary assisted dying in NSW

There are **11 steps** in the voluntary assisted dying process in NSW. You can pause or stop the process at any time.

STEP 1.	You make a first request for voluntary assisted dying to a doctor	
STEP 2.	A coordinating doctor completes a first assessment	
STEP 3.	Another doctor does a consulting assessment	
STEP 4.	You complete a written declaration	
STEP 5.	You make a final request for voluntary assisted dying	
STEP 6.	Your coordinating doctor completes a final review	
STEP 7.	You decide how to take the medication, with support from your doctor	
STEP 8.	Your doctor applies for a medication authorisation. The Voluntary Assisted Dying Board grants approval	
STEP 9.	Your doctor prescribes the medication	
STEP 10.	You take or are given the medication if and when you choose	
STEP 11.	A death certificate is issued	Y

The NSW Voluntary Assisted Dying Care Navigator Service

is a phone line to answer questions about voluntary assisted dying.

The Service will support everyone including patients and families.

Call **1300 802 133** Monday to Friday 8:30am to 4:30pm.

This is a summary of the key steps of the voluntary assisted dying process under the Voluntary Assisted Dying Act 2022. This summary is indicative only and does not cover all the scenarios that might arise during a patient's individual voluntary assisted dying process.

Voluntary assisted dying (11 steps)

Step 1: First request (you make a first request for voluntary assisted dying to a doctor)

To start the voluntary assisted dying process, you need to make a formal request to a doctor who is eligible to help you. This is called a 'first request.'

The doctor could be your general practitioner (GP) or a specialist, for example. You need to make this request during a medical appointment. This may be a face-to-face appointment or in a videoconference appointment where the doctor can see and hear you.

- Your request must be clear and not ambiguous. This means the doctor must be able to understand that you are
 asking for voluntary assisted dying. To make it clear you could say "voluntary assisted dying". You can also use
 a communication tool or gestures if you need help to communicate your request. The doctor may need to check
 with you to make sure they understand what you are asking.
- If you are making general enquiries or asking for information, this is not a first request.
- Only you can make a first request. No one else can make a first request on your behalf.

The doctor will tell you if they can accept or refuse your first request. This means they say yes or no to being able to help you through the process.

Not all doctors provide voluntary assisted dying services. If your doctor says no to you because they do not support voluntary assisted dying, it is called a 'conscientious objection.' If this happens, the doctor must tell you straight away that they refuse your first request and cannot help you access voluntary assisted dying.

A doctor may also say no to you because they are not eligible or able to accept the request. This may be because they:

- have not been a doctor long enough or hold the right qualifications
- have not completed the mandatory training, or
- have another reason (such as not being available).

A doctor who does not have a conscientious objection must:

- tell you if they accept or refuse your first request
 - immediately, if they are not eligible to accept the request, or
 - within two business days of your request otherwise.
- give you this 'First Request Patient Information Guide'. You must be given this guide regardless of whether they accept or refuse your first request.

If the doctor refuses your first request, you can make a request to another doctor. The NSW Voluntary Assisted Dying Care Navigator Service can help you find another doctor who can accept the request (see 'What information and supports are available to you?' on the next page).

Step 2: First assessment (a doctor completes a first assessment)

Once a doctor accepts your first request, they become your **coordinating practitioner**.

This means they will:

- begin and coordinate (manage) the voluntary assisted dying process for you.
- assess whether you are eligible to access voluntary assisted dying. This is called the 'first assessment'. The first assessment happens in a face-to-face appointment.

Your coordinating practitioner needs to make sure that you meet all the eligibility criteria for voluntary assisted dying (see '*Who is eligible for voluntary assisted dying in NSW*' above). This may include:

- asking for proof of your age
- asking for proof of Australian citizenship, permanent residency or NSW residency
- asking questions about your medical history, medical condition and your request to access voluntary assisted dying.

Documents that might help the coordinating practitioner include your NSW driver licence, Australian passport, bank statements and utility bills that show your residential address.

If you **are not eligible**, your coordinating practitioner will explain why and what they can do to support you.

If you **are eligible**, your coordinating practitioner will provide you with some additional information about the voluntary assisted dying process, and check you know about your palliative care and treatment options. You may also move to the next step.

Step 3: Consulting assessment (another doctor does a consulting assessment)

The coordinating practitioner will ask another eligible doctor (independent to them) to provide a second opinion on your eligibility to access voluntary assisted dying. You do not need to find this doctor – the coordinating practitioner will do it for you.

This doctor is an authorised practitioner called a 'consulting practitioner'. The consulting practitioner will do the 'consulting assessment.' The consulting assessment includes the same steps as the first assessment.

The reason you need another assessment is because two doctors need to check you are eligible to access voluntary assisted dying. This makes sure that voluntary assisted dying is an appropriate and legal option for you. The consulting assessment is a face-to-face assessment.

One or both of your assessing doctors can ask another healthcare worker or expert (such as a psychiatrist or psychologist) for their advice on whether you meet certain eligibility criteria. This may happen if your assessing doctors need more information to decide if you are eligible for voluntary assisted dying.

Step 4: Written declaration (you complete a written declaration)

If the coordinating and consulting practitioner both find that you are eligible for voluntary assisted dying, and you want to continue the process, you need to make a written declaration. This means completing a form in writing that says you want to access voluntary assisted dying.

Either the coordinating or consulting practitioner will give you the declaration form to complete. For most people this will be a physical piece of paper you need to sign.

The written declaration does not need to be signed in front of your coordinating practitioner or consulting practitioner. You can sign it at home or another location of your choice. If you lose the form, you can call the NSW Voluntary Assisted Dying Care Navigator Service for another one (see 'What information and supports are available to you?').

You need to complete and sign this form in front of two people (called 'witnesses').

The witnesses cannot:

- be a child (17 years and under)
- be a family member (this includes extended family such as step sibling, step parents or step children)
- know or believe that they are a beneficiary in your will
- know or believe that they may benefit financially or in any other material way from your death
- be your coordinating practitioner or consulting practitioner
- be a family member or employee of your coordinating practitioner or consulting practitioner.

You can talk to your coordinating practitioner about who you can ask to be a witness.

If you are unable to sign the document, you can ask another adult to sign on your behalf. To do this, you and your two witnesses must be with you when the person signs for you. The person signing on your behalf cannot be one of your witnesses, your coordinating practitioner or your consulting practitioner.

You may also be able to sign electronically if you can't physically sign the declaration and this is something you usually do.

If you want to move to the next step in the voluntary assisted dying process, you must give the completed written declaration form to your coordinating practitioner.

Step 5: Final request (you make a final request for voluntary assisted dying)

If you complete the written declaration and want to continue with the process, you need to make a 'final request'. This request must be made to your coordinating practitioner. You need to be clear that you wish to access voluntary assisted dying in this step.

When you can make a final request

There are rules about when you can make your final request. This is to give you time to think about your decision and check you have not changed your mind.

The final request cannot be made until after the '**designated period**' has ended. The Voluntary Assisted Dying Act 2022 defines the 'designated period' to mean, in relation to a patient's final request, the period:

- starting on the day on which the patient made the first request, and
- ending on the day that is 5 days after that day.

What this means for you is:

 you will have to wait at least 6 days from the day you made your first request before you can make your final request

AND

• you cannot make your final request on the same day that your consulting assessment is completed. You have to wait at least one day after your consulting assessment is completed. You can then make the final request from the next day onwards.

Example of the designated period (timeframe)

This example is used for illustrative purposes only, noting that you can take as much time as you want to move through the process.

Day	Day	Day	Day	Day	Day	Day
1 July	2 July	3 July	4 July	5 July	6 July	7 July
First request made					Consulting assessment must occur at least one day before the final request is made	Final request can be made from this date onwards

Key: Pink shading indicates the duration of the designated period in this example.

If a coordinating practitioner and consulting practitioner agree that a patient may die or lose decision-making capacity before the designated period ends, the patient may make a final request before the designated period ends. If this occurs in your case, your coordinating practitioner will discuss it with you.

After the final request is made, the coordinating practitioner will then start the 'final review' process.

Step 6: Final review (your doctor completes a final review)

The coordinating practitioner will do a final review after you make the final request. You do not need to do anything for this step, unless your coordinating practitioner contacts you with any questions.

The coordinating practitioner will need to make sure:

- all the paperwork and processes are complete and legally correct
- you still have decision-making capacity in relation to voluntary assisted dying
- this is your decision, and no one is pressuring you
- you still want access to voluntary assisted dying, and you understand this will result in your death.

Step 7: Administration decision (you decide how to take the medication)

After the final review is complete, if you want to continue you need to think about how you want to take the medication that will end your life.

This step is called the 'administration decision'. It must happen in a face-to-face appointment with your coordinating practitioner. It cannot be discussed or decided in a videoconference appointment or on the phone. This is because you will talk about how to take the medication. The law says that discussion must happen face-to-face.

You will need to decide with your coordinating practitioner if you will:

- take the medication yourself (self-administration), or
- have a doctor or nurse practitioner give you the medication (practitioner administration).

You can revoke (change your mind about) this decision at any time. If you decide to change how the medication will be administered, you should consult with your coordinating practitioner.

You must make an administration decision before your coordinating practitioner can move to the next step in the process.

If you choose self-administration

You will need to take the medication yourself. To take the medication yourself, you must be able to swallow it without help from anyone else. If you have a PEG (percutaneous endoscopic gastrostomy) or NG tube (nasogastric tube), you can also take the medication through this. You must be able to do this yourself. You can talk to your coordinating practitioner about what is right for you.

If you choose self-administration, you must nominate a contact person who agrees to act in this role. This contact person can be any adult (18 years and older) including:

- a family member or friend
- your coordinating practitioner
- your consulting practitioner
- another registered health practitioner.

Your contact person can:

- receive the voluntary assisted dying medication from the authorised supplier in certain circumstances
- hold and store the voluntary assisted dying medication for you in order to help prepare it or supply it to you.

Your contact person must:

- return any unused or remaining medication to a person called an 'authorised disposer' at a particular hospital pharmacy after:
 - you die, or
 - revoke your decision to self-administer the medication by telling your coordinating practitioner that you have changed your mind
- tell your coordinating practitioner if you die. They need to do this if you die from taking the voluntary assisted dying medication or if you die without taking the medication.

Your contact person will receive information from the NSW Voluntary Assisted Dying Board about their responsibilities as a contact person (more information below).

Your coordinating practitioner will give you a form to complete and you will choose your contact person. This is called the **Contact Person Appointment Form**.

For most people, this form is a physical piece of paper. You and the contact person both need to fill out and sign this form. Some people can sign the form electronically. Your coordinating practitioner will tell you if you can do this. If you cannot complete and sign this form, you can ask someone else to sign on your behalf. They need to sign this in front of you.

Once complete, you or your contact person must give the form back to your coordinating practitioner. They will give a copy of the form to the NSW Voluntary Assisted Dying Board. This must happen before your coordinating practitioner can move to the next step in the process.

Within five business days of receiving the **Contact Person Appointment Form**, the NSW Voluntary Assisted Dying Board will send information to your contact person. It will explain:

- that in some situations, they must return unused or remaining medication to a person called an 'authorised disposer' at a particular hospital or pharmacy
- penalties if the contact person does not follow the law
- support services available to help the contact person.

You must tell your coordinating practitioner if you decide you want to change your contact person. You must also tell your coordinating practitioner if your contact person refuses to continue to perform this role. You will need to choose a new contact person as soon as possible.

If you choose practitioner administration

If you choose this option, the person that will give you the medication is called an 'administering practitioner.'

In most cases, your administering practitioner will be your coordinating practitioner. It could also be another doctor or a nurse practitioner who are an authorised practitioner. You can discuss who it will be with your coordinating practitioner.

Your administering practitioner will give you the medication through an intravenous route. Intravenous means a needle (cannula) will be inserted into a vein in your body. The administering practitioner may also decide that using an existing intravenous line, or a PEG (percutaneous endoscopic gastrostomy) or NG tube (nasogastric tube) if you have one, is a better choice. You can talk to your administering practitioner about which option is best for you.

Step 8: Applying for a voluntary assisted dying substance authorisation (your doctor applies for a voluntary assisted dying substance authorisation)

After you make an administration decision, your coordinating practitioner will apply for a voluntary assisted dying substance authorisation (called a "medication authorisation" in this guide).

This application goes to the NSW Voluntary Assisted Dying Board. The NSW Voluntary Assisted Dying Board is a group of independent people.

The NSW Voluntary Assisted Dying Board reviews all applications for voluntary assisted dying. They check that all the documents have been received and all the legal requirements have been met.

If everything is correct, they will grant a medication authorisation. The coordinating practitioner can then write a prescription for the medication to end your life.

You do not need to do anything for this step.

Step 9: Prescription of the voluntary assisted dying medication (your doctor prescribes the medication)

The prescription for the voluntary assisted dying medication can only be supplied by people called 'authorised suppliers' who work at the NSW Voluntary Assisted Dying Pharmacy Service.

The coordinating practitioner will send the prescription directly to the authorised supplier.

You do not need to do anything for this step.

Step 10: Supply and use of the voluntary assisted dying medication (you take or are given the medication if and when you choose)

The authorised supplier cannot give you the medication without a prescription. Once they receive the prescription, the pharmacist checks the prescription. They do this to make sure it is legal and authentic (real).

The authorised supplier will not give you the medication until you decide you want it.

For self-administration:

- You will need to contact the NSW Voluntary Assisted Dying Pharmacy Service when you are ready to get the medication.
- The authorised supplier will deliver the medication directly to you. They will give you a lot of support, including written information about how to store, prepare and take the medication.

For practitioner administration:

- You will need to call your administering practitioner to organise a time for them to give you the medication.
- The authorised supplier will deliver the medication directly to the administering practitioner.

Step 11: Notification of death (a death certificate is issued)

After your death, a doctor completes a Medical Certificate of Cause of Death form. The Medical Certificate of Cause of Death is not the final death certificate. It is a document that says how you died. If you die after taking or having a voluntary assisted dying medication administered, your Medical Certificate of Cause of Death will say this. It needs to say this under the law. The certificate will also name the disease, illness or medical condition that made you eligible for voluntary assisted dying.

The final death certificate from the NSW Registry of Births Death and Marriages will not include anything about voluntary assisted dying.

What information and supports are available to me?

There are services available to support you. You are not alone during this process. Your coordinating practitioner is the best person to answer your questions. You can also contact your healthcare treating team or the NSW Voluntary Assisted Dying Care Navigator Service.

The **NSW Voluntary Assisted Dying Care Navigator Service** is available to support everyone including patients and families. The people you will speak to are called 'care navigators.' They can:

- provide general information about voluntary assisted dying in NSW
- help you find voluntary assisted dying practitioners who are eligible and available to help you through the process
- help you access other helpful resources.

To contact the Care Navigator Service:

- Call: 1300 802 133 Monday to Friday, 8:30am to 4:30pm (excluding public holidays)
- Email: <u>NSLHD-VADCareNavigator@health.nsw.gov.au</u>

You can call the **Translating and Interpreting Service (TIS National) on 131 450** and ask for the NSW Voluntary Assisted Dying Care Navigator Service if you need language support.

More information about voluntary assisted dying including resources in your language is on the NSW Health website: www.health.nsw.gov.au/vad-info

Using an interpreter during the voluntary assisted dying process

You can use an interpreter at every stage of the voluntary assisted dying process if you need support communicating. If you need an interpreter, your authorised practitioner will organise one.

The interpreter must be accredited by NSW Health Care Interpreting Services (HCIS) or National Accreditation Authority for Translators and Interpreters (NAATI). The interpreter must not:

- Be your family member
- Know or believe they are a beneficiary in your will
- Know or believe they will benefit financially or in any other material way from your death (other than receiving reasonable fees for their interpreting services)
- Be an owner or manager of a health facility where you live or receive health care
- Be a person who provides you with health services or care services.

End of life support

People approaching the end of their life require different levels of care and support. Needs during these times will change. The NSW Health website provides a list of end of life and palliative care resources in NSW: www.health.nsw.gov.au/palliativecare

Advance care planning involves talking about your values, wishes and needs. It also may describe the type of health care you would want to receive if you became seriously ill or injured and could not speak for yourself. An advance care directive cannot replace the process described in this guide to access voluntary assisted dying.

More information is on the NSW Health website: www.health.nsw.gov.au/patients/acp

Mental health support

Talking about death and voluntary assisted dying may be hard and sad.

Call these free services if you need support:

- Lifeline on 13 11 14 open 24 hours for crisis telephone support. Also online: <u>www.lifeline.org.au</u>
- Beyond Blue on 1300 22 4636 open 24 hours for crisis telephone support. Also online: www.beyondblue.org.au
- Transcultural Mental Health Line on 1800 648 911 open Monday to Friday between 9am and 4.30pm. Speak to clinicians who understand your culture and can communicate in your language
- 13YARN on 13 92 76 open 24 hours for crisis telephone support. Yarn with an Aboriginal or Torres Strait Islander Crisis Supporter
- Mental Health Line on 1800 011 511 open 24 hours to connect you with NSW Health mental health services

Support for patients living in regional and rural NSW

The Isolated Patients Travel and Accommodation Assistance Scheme provides financial assistance from the NSW Government towards your travel and accommodation costs.

You may be eligible for the Scheme for voluntary assisted dying related appointments if you meet eligibility requirements.

Visit the Isolated Patients Travel and Accommodation Assistance Scheme website or call 1800 478 227 for more information: www.iptaas.health.nsw.gov.au/for-patients/voluntary-assisted-dying

What happens to my personal information?

The NSW Voluntary Assisted Dying Board is committed to protecting your privacy if you request or access voluntary assisted dying in NSW.

For more information, see the privacy statement on the NSW Health website: Privacy Statement.

Who do I need to tell about my request for voluntary assisted dying?

You decide who you tell about your choice to access voluntary assisted dying. You should think about any help you may need from other people during this process.

You are encouraged to tell your usual doctor about your request for voluntary assisted dying. You should do this even if they are not involved in the process. If you live or are staying in a residential facility, you should also tell the facility manager.

Providing feedback on the voluntary assisted dying process

Anyone involved in the voluntary assisted dying process (you, your family, friends or carers, and practitioners) may wish to share their personal experience or feedback about the process.

You can provide this information by completing the feedback form on the NSW Health website: www.health.nsw.gov.au/patientconcerns/Pages/feedback.aspx

Complaint information

If you are concerned or have a complaint about your experience with the voluntary assisted dying process you should first talk to your coordinating practitioner if you have one.

It is against the *Voluntary Assisted Dying Act 2022* for a doctor to stop the care you would normally get because you have asked for medical help to die. You can make a complaint about individuals or organisations in NSW to the Health Care Complaints Commission (HCCC). Further information can be found on the HCCC website: <u>www.hccc.nsw.gov.au</u>

You can raise concerns about the conduct or performance of a registered health practitioner with the Australian Health Practitioner Regulation Agency (Ahpra). Further information can be found on the Ahpra website: www.ahpra.gov.au

Acknowledgement

The information in this guide is based on the resources of the end of life care program (WA Department of Health). It has been used with permission.



