



# Assisted Dying Service 555

# The assisted dying process

November 2021

Information for a person who is terminally ill and wants to request assisted dying

Assisted dying is a sensitive topic and may be difficult for some people. If reading this information raises some distressing feelings for you, support is available. You can call or text **1737** for free to speak to a trained counsellor at any time.

This document contains general information about assisted dying. It does not replace the advice of your health care team. If you would like to know about assisted dying, speak to your doctor or health care team about the options available. This document will be reviewed and updated from time to time; please make sure you have the latest version. (Last updated – November 2021)

# **Summary**

- You must meet strict criteria to be eligible for assisted dying. You must go through an assessment process set out in law to find out if you meet these criteria.
- Only you can choose to access assisted dying. You can stop the process at any time, for any reason.
- You will need to make a formal request for assisted dying, and then be assessed by two doctors. Some people may also need a third assessment by a psychiatrist.
- You can involve your whānau in the assisted dying process if you want to. They can come with you to appointments and talk to you about your choices.
- A doctor, known as an attending medical practitioner, and a clinical advisor at the Ministry of Health will support you through the process and answer your questions.

- If you are not eligible for assisted dying, your attending medical practitioner will explain why. They will help connect you to appropriate care.
- If you are eligible for assisted dying, your attending medical practitioner will help you start making plans for your assisted death if you want this.

# The assisted dying process is set out in law

The process for accessing assisted dying is set out in the End of Life Choice Act 2019 (the Act).

Each step in the process may be made up of more than one appointment. The health professional involved at each step can visit you if needed. Appointments by phone or video call may be possible for some of these steps.

A doctor will support you through the assisted dying process. This doctor is known as your attending medical practitioner.

The steps involved include:

- · you making a formal request for assisted dying to your attending medical practitioner
- your attending medical practitioner assessing whether you are eligible
- a second, independent doctor assessing whether you are eligible
- if required, a psychiatrist assessing whether you are competent to make an informed decision
- planning for the assisted death (including choosing a date, time and the method for administering the medication, as well as social, cultural or spiritual considerations)
- your attending medical practitioner or a nurse practitioner administering the medication.

Your attending medical practitioner will explain this process in more detail when you make a request for assisted dying. They will support you and answer any questions you and your whānau might have.

A clinical advisor from the Ministry of Health will also offer support and information to you and your whānau throughout the process.

# Requesting assisted dying

## You need an attending medical practitioner

Your attending medical practitioner might be a doctor who is already involved in your care, such as your general practitioner or specialist.

Some doctors do not provide assisted dying. They may not have the experience or skills needed, or they may choose not to due to their personal beliefs.

If you raise assisted dying with your doctor, and they don't provide this service, they need to:

- explain why they do not provide assisted dying services
- connect you with a doctor who can be your attending medical practitioner, or tell you how to find one.

The Support and Consultation for End of Life in New Zealand (SCENZ) Group holds a list of doctors who provide assisted dying services. To get in touch with them about finding an attending medical practitioner, contact the Ministry of Health by phone on 0800 223 852 or by email at **AssistedDying@health.govt.nz**.

You will be given a clinical advisor to help you, and they will work with the SCENZ Group to find you an attending medical practitioner.

You can read more about raising assisted dying and getting an attending medical practitioner in the *Considering assisted dying* information sheet.

#### Making a formal request to your attending medical practitioner

Once you have confirmed your attending medical practitioner, you will meet with them to discuss assisted dying and make a formal request. There are several things that need to be discussed at this stage, so more than one appointment might be needed.

#### Discussing your health and end-of-life care options

Your attending medical practitioner will talk to you about your illness and your understanding of your current health. They will look at your medical records and will ask you about the care you have already received. They may suggest other options to help manage your symptoms, if you want this.

You can also ask them questions about your illness and other care options. Talking to your whānau or other people about what is important to you before this appointment might help you think of what you'd like to ask at this stage.

Here are some examples of questions you might like to ask.

- What happens to people with my illness?
- How long do I likely have left to live?
- What can I expect as my illness gets worse?
- What support or treatment is available to manage my symptoms?
- What does dying look like for someone with my illness?

#### Discussing assisted dying

Your attending medical practitioner will explain the assisted dying process, and what this might mean for you.

You can ask your attending medical practitioner questions about assisted dying or for further information about this option.

Here are some examples of questions you might like to ask.

- What is involved in the assisted dying process?
- What happens if I'm not eligible?
- Can I decide when and where to die?
- What happens during an assisted death?
- What does an assisted death look like and how long does it take?
- How can I involve my whānau? Can you help me with this?
- What will my death certificate say?
- What happens after I die?

#### Talking to your whānau

It is up to you if you involve your whānau, family, or friends in the assisted dying process. Your attending medical practitioner will explain this to you. If you have not done so already, they will encourage you to talk to your whānau about your choice.

You may also want to talk to other people who are important to you, such as community, cultural or spiritual leaders. You may also want to speak to a social worker or counsellor. Your attending medical practitioner can help you access a social worker or counsellor if you don't have one already.

Your attending medical practitioner will ask you for permission to speak to your whānau. This can help them understand why you are choosing assisted dying, and that you not being pressured by anyone. You can choose who they speak to.

You might also want to speak to your whānau and your attending medical practitioner together to talk about how your whānau will be involved throughout the process.

#### Involving other health professionals

Your attending medical practitioner will also want to talk to other health professionals involved in your care. This might be your general practitioner or specialist (if they are not your attending medical practitioner), as well as nurses, carers or support workers.

This will help the attending medical practitioner gather all the information they need for your assessment, as well as making sure that you are not being pressured into choosing assisted dying.

#### **Deciding whether to continue**

If you choose to continue the process and find out if you are eligible for assisted dying, you will need to sign a request form.

Signing the form does not mean you must have an assisted death if you are eligible. You can change your mind at any time up until the medication is administered.

If you are not able to sign the form, someone else can sign for you, with your permission. They must be over 18, be mentally competent, not benefit from your death, and not be a health professional who is currently providing care to you.

# The eligibility assessment

Your attending medical practitioner will assess whether you meet all eligibility criteria first. If they think that you do, an independent medical practitioner will carry out a second assessment.

You must be competent to make an informed decision about assisted dying. If either, or both, of the medical practitioners is unsure about this, you will also be seen by a psychiatrist (a doctor who specialises in mental health).

#### **Eligibility criteria**

The eligibility criteria are explained below to help you understand what kind of questions the medical practitioners might ask you during the assessments.

You must meet **all** of the criteria to be eligible for assisted dying. The criteria will be explained to you in more detail at your appointments.

#### Be aged 18 years or over

• The doctor will likely be able to access this information from your medical records. In some cases, you may have to provide evidence, such as a birth certificate.

#### Be a citizen or permanent resident of New Zealand

• You may have to provide evidence, such as a passport or other proof of residency, if this information is not in your medical records.

#### Suffer from a terminal illness that is likely to end your life within six months

- The doctor will need to assess you and review your medical records to work out how long you have left to live. They may ask you questions about how your health has changed over time.
- The doctor may also speak to other people who have been caring for you, such as your specialist.
- It can be difficult to determine how long someone has left to live, and sometimes a person may have slightly more or less time left to live than a doctor may think. This is something you might want to consider when choosing assisted dying.

#### Be in an advanced state of irreversible decline in physical capability

- Your illness must be getting worse and affecting your physical abilities.
- It may be affecting your ability to do everyday tasks, like washing or eating by yourself.
- The doctor may talk to you about your current quality of life and abilities, and how these have changed over time.

# Experience unbearable suffering that cannot be relieved in a way that you consider tolerable

- Unbearable suffering will look different for different people. Suffering might be based on your physical symptoms or how you feel about your current health.
- The doctor may talk to you about what suffering means to you, including how it makes you feel and how you cope with it.
- The doctor may ask you about the care you have tried to relieve your suffering, and anything that helps you feel better.
- The doctor may also suggest other options for helping relieve your suffering if you would like to try any other options.

#### Be competent to make an informed decision about assisted dying

- You must be able to make a free and informed decision about assisted dying.
- Being competent means you can understand, remember, use, and consider relevant information about assisted dying, and can communicate your decision in some way.
- The doctor will ask you questions, talk to you about assisted dying and your other options, and ask you to explain your choice.

# The first assessment of eligibility

Your attending medical practitioner will do the first assessment of eligibility.

Tell your attending medical practitioner if you want to have someone there for support. Your attending medical practitioner may want to speak to you by yourself at certain points during the assessment.

They will assess you against the eligibility criteria by talking to you and asking you questions, as well as looking at your medical records. They will also check that you are not being pressured by anyone else.

#### **Outcome of the first assessment**

You will be told at the end of the assessment, or in a follow-up appointment, whether you are eligible. There are three possible outcomes.

- The attending medical practitioner does not think you are eligible. They will explain the reasons and make sure you are connected to appropriate care. The process stops.
- The attending medical practitioner thinks you are eligible. Next, you will be assessed by an independent medical practitioner.
- The attending medical practitioner isn't sure if you are competent to make the decision. If the attending medical practitioner thinks you meet the other eligibility criteria but is not sure if you are competent, you will be assessed by an independent medical practitioner and a psychiatrist.

### The second, independent assessment of eligibility

An independent medical practitioner, taken from the list held by the SCENZ Group, will do the second assessment of eligibility. Your clinical advisor at the Ministry of Health will help connect you to an independent medical practitioner.

The second assessment will be similar to the first one. The independent medical practitioner will ask you questions and talk to you about the eligibility criteria. They will also check that you are not being pressured by anyone else.

Your independent medical practitioner will have your medical records, but they will not be able to see the attending medical practitioner's notes from first assessment. This means the independent medical practitioner may ask you for the same information or ask you the same questions.

Having two detailed, independent assessments is a very important safeguard in making sure you are eligible for assisted dying.

Tell the independent medical practitioner if you want to have someone there for support. The independent medical practitioner may want to speak to you by yourself at certain points during the assessment.

#### **Outcome of the second assessment**

Again, you will be told at the end of the assessment, or in a follow-up appointment, if you are eligible. There are three possible outcomes.

- The independent medical practitioner does not think you are eligible. They will explain the reasons. Your attending medical practitioner will also talk to you and make sure you are connected to appropriate care. The process stops.
- The independent medical practitioner thinks you are eligible. Your attending medical practitioner will talk to you about making plans for your assisted death.
- The independent medical practitioner isn't sure if you are competent to make the decision. If the independent medical practitioner thinks you meet the other eligibility criteria but is not sure if you are competent, you will then be assessed by a psychiatrist.

#### Competency assessment, if needed

If either, or both, of the medical practitioners who completed the two eligibility assessments has concerns about your competency, they will request a psychiatrist assesses you. The psychiatrist is taken from the list held by the SCENZ Group. Your clinical advisor at the Ministry of Health will help connect you to a psychiatrist.

The psychiatrist will assess you to make sure you are competent to make an informed decision about assisted dying. They will also check that you are not being pressured by anyone else.

The psychiatrist will not check the other eligibility criteria as this has already been done in the two eligibility assessments.

Tell the psychiatrist if you want to have someone there for support. However, they may want to speak to you by yourself at certain points during the assessment.

#### **Outcome of the competency assessment**

At the end of the assessment, the psychiatrist will tell you if they think you are eligible and let your attending medical practitioner know the outcome. There are two options at this stage.

- You are eligible for assisted dying. The psychiatrist will explain the outcome of their assessment. Your attending medical practitioner will talk to you about making plans for your assisted death.
- The psychiatrist does not think you are eligible. They will explain the reasons. Your attending medical practitioner will also talk to you and make sure you are connected to appropriate care. The assisted dying process stops.

# **Decision on eligibility**

# If you are not eligible

If you are not eligible for assisted dying, your attending medical practitioner will meet with you to make sure you understand why. They will provide you with options and support, and will make sure you are connected to the appropriate care for your situation. This might mean letting your general practitioner know that you are not eligible for assisted dying.

The decision on eligibility is binding, and the process must stop immediately.

You can reapply for assisted dying at a later date, if your situation changes. For example, if your life expectancy was assessed as being longer than six months, you could reapply when you are closer to the end of your life. Your attending medical practitioner can give you advice about reapplying.

If you are feeling upset or distressed about not being eligible for assisted dying, it is important to talk to someone about how you are feeling and get support. You could talk to your doctor or health care team, or someone else you trust. You can also call or text **1737** for free to speak to a trained counsellor at any time.

### If you are eligible

#### Planning for your assisted death

Your attending medical practitioner will meet with you again to discuss the next steps. There are a range of decisions that need to be made, such as the date and place for your assisted death.

Your attending medical practitioner will give you advice on the progress of your illness, and you may also want to consider other things, like if you have whānau or other people who would have to travel to be with you.

You can find out more in the *Planning for an assisted death* information sheet.

#### You can change your mind at any time

Being eligible means you have the option of an assisted death, but you don't have to go ahead with it.

This might happen if you find that other care, such as palliative or hospice care, can help manage your suffering in a way that you are comfortable with.

You can choose to stop the assisted dying process at any time up until the medication is administered. If you change your mind and want to stop the process, tell your attending medical practitioner or your clinical advisor at the Ministry of Health. You and your whānau will be given support and advice on other options available to you.

You can also choose to delay your assisted death by up to six months from the original date chosen, or bring it forward. You can talk to your attending medical practitioner about these options.

#### You can become ineligible for assisted dying

You must continue to meet all the eligibility criteria until your assisted death takes place. This means that even if you are eligible after the assessments, you could become ineligible if your situation changes.

The most likely reason for this would be if you are not considered competent to make an informed decision about assisted dying at the time of the assisted death. You must be competent and able to give informed consent at the time the medication is administered.

People with terminal illnesses sometimes lose the ability to make decisions as they get very ill and closer to death. You might want to talk to your attending medical practitioner about this, and consider this when choosing a date for your assisted death.

Advance directives cannot be used for assisted dying in New Zealand. An advance directive is a statement setting out what treatment the person wants, or does not want, to receive in the future.

# Throughout the process

#### You can continue to access other care and support

The assisted dying service does not replace existing end-of-life care options, such as palliative or hospice care. It provides another option for someone with a terminal illness in specific circumstances.

You can continue to receive other end-of-life care while using the assisted dying service. It is important you continue to access this care to help you manage your ongoing symptoms, in case you are not eligible for assisted dying, or you change your mind.

Your attending medical practitioner will make sure you understand your other options for end-of-life care.

The **Ministry of Health's website** has more information about palliative care (search 'palliative care') or you can visit Hospice New Zealand's website: **www.hospice.org.nz**.

# Someone at the Ministry of Health will support you and your whānau

You will be assigned a clinical advisor at the Ministry of Health at the start of the assisted dying process. This is a registered nurse who can answer questions and provide extra information or advice if you need it. They will help you and your whānau throughout the assisted dying process.

The clinical advisor will also help to connect you with the practitioners who will support the assessment process for assisted dying. These are:

- an attending medical practitioner, if your current doctor does not provide assisted dying services or if you prefer to have a different doctor for this process
- an independent medical practitioner for the second eligibility assessment
- a psychiatrist for an opinion on competency, if needed.

Tell your clinical advisor if you have preferences on the practitioners who will assess you. For example, you may prefer a practitioner of a certain gender, ethnic background or in a specific location. Your clinical advisor will try to meet your preferences as best as possible.

#### Your whānau can be involved

Whānau, friends and carers can play an important role in supporting you through the process. You can choose if and how other people are involved.

Whānau may mean different things for different people. It may be one person or many people, and could include your partner, children, siblings, extended family, friends or other people who are important to you.

Your whānau can support you by:

- helping you understand and consider your end of life options
- attending medical appointments with you (the doctors may want to speak to you on your own at some points in the process)
- providing personal care, such as helping you bathe or eat
- supporting planning for the assisted death
- providing comfort and pastoral care
- offering care and support when the medication is administered.

As part of the assessment process for assisted dying, your attending medical practitioner will talk to you about who you want to be involved. They will also make sure that you have had opportunity to speak to these people if you choose to.

Your attending medical practitioner will ask to speak to your whānau as part of the assessment. They can only do this with your permission.

Your attending medical practitioner may also ask you to choose someone in your whānau as a key contact who can answer questions and arrange appointments. It is up to you if you have a key contact, or if you would rather be contacted directly.

If you don't have whānau or other support people you want to include, you can talk to your attending medical practitioner about other ways to get support. You can also talk to your clinical advisor at the Ministry of Health.

# The process will stop if you change your mind or you are being pressured

If you change your mind and want to stop the process, tell your attending medical practitioner or your clinical advisor at the Ministry of Health. You and your whānau will be given support and advice on other options available to you.

Only you can choose to access assisted dying. It must be your informed choice, and you must make this choice without pressure from anyone else. Whānau, carers, welfare guardians or holders of an enduring power of attorney cannot request assisted dying on your behalf.

If the attending medical practitioner, or one of the other medical practitioners who is assessing your eligibility, thinks you are being pressured, then the process must stop. The attending medical practitioner will talk to you about this and can help you access care or support if you need it.

If you feel you are being pressured into assisted dying, you must tell your attending medical practitioner, another health professional you trust, or your clinical advisor at the Ministry of Health.

If you do not want to speak to a health professional, you can contact the Health and Disability Commissioner (HDC) by phone on 0800 11 22 33 or by email at **hdc@hdc.org.nz**. The HDC's role is to protect your rights when accessing health services and to resolve complaints.

If you ever feel unsafe or are worried that someone will hurt you, contact the Police.

# You can use an assisted dying care plan to record what is important to you

My Journey, My Needs is a care plan for the assisted dying service. Your attending medical practitioner will give you a copy, and you can also download one from the **Ministry of Health's website**.

The assisted dying care plan is to help you and your whānau think about what is important to you as go through the process. You can use this care plan to record questions, thoughts or decisions about assisted dying, to help you remember what you want to talk about at each stage of the process.

You can share this care plan with your attending medical practitioner, independent medical practitioner or psychiatrist, and your whānau or other people who are supporting you. The plan will ensure that everyone involved is aware of your needs and how best to support you through this process.

# More information and additional support are available

Additional support is available for you and your whānau throughout the assisted dying process. You can include the type of support you might need in your assisted dying care plan.

Some examples of support are explained below. If you have any other concerns or questions about what options are available, ask your attending medical practitioner or your clinical advisor at the Ministry of Health.

#### I need more information

Assisted dying is a complex process and it can be difficult to take it all in, especially when you are very ill.

You can ask your attending medical practitioner or clinical advisor to provide information in a way that helps you understand. This may mean repeating things, or explaining things in a different way.

You and your whānau can ask any questions about assisted dying that help you decide about your care.

#### **English is not my first language**

It is important you understand your options. This is part of making a free and informed decision.

If you prefer to speak in a language other than English, tell your clinical advisor early in the process. They may be able to help you find health professionals that speak your preferred language, or they can organise an interpreter.

You can find information about assisted dying in several languages and accessible formats on **the Ministry of Health's website**.

### I need help communicating

If you normally have help communicating during health appointments, the person who supports you with this (for example, a whānau member or a support worker) can still help you, or you can use a communication device.

In some cases, the medical practitioners assessing you may also ask for an independent person to support you to communicate. This can be important to make sure that you are making a free and informed decision.

# I have mobility issues or find travel difficult

You can ask the medical practitioners who assess you for assisted dying to come to your home, or you can get help to attend appointments. Telehealth appointments (such as by phone or video call) may be possible for some of the process.

You can discuss these options when making the appointment.

#### I need help with my personal care

If you have help with your personal care and think you might need help during your appointments, the person who supports you with this (for example, a whānau member or a carer) can still help you.

It's a good idea to tell your medical practitioner what you need, as they may want to speak to you alone at certain points during the assessment. They may also be able to take breaks in your appointments for any personal care needs.

#### I use supported decision-making

The decision about accessing assisted dying must be your own. You can still use supported decision-making if that's usually how you make decisions about your health. You might want help to understand the assisted dying process, or what your options are for your end-of-life care.

If you normally have support to make decisions, the person who supports you with this can still help you throughout this process. This might be a whānau member or a support worker.

In some cases, the medical practitioners assessing you may also ask for an independent person to help support your decision-making. This can be important to make sure that you are making a free and informed decision.

You can find easy-to-read information about assisted dying on the Ministry of Health's website.

Information about supported decision-making is on the Ministry of Social Development's website.



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