

End of Life Choice Act Frequently Asked Questions

On 7 November 2021 the End of Life Choices 2019 Act comes into force. The Act gives competent adults experiencing unbearable suffering from a terminal illness the option of legally requesting medical assistance to end their lives. This is known as 'assisted dying'.

This document includes answers to common questions. If you have a question that is not answered here, please email us at: assisted.dying@tdhb.org.nz

Who can request assisted dying from 7 November?

There are strict criteria to be eligible for assisted dying. To be eligible, a person must meet all of the following criteria:

- be aged 18 years or over
- be a citizen or permanent resident of New Zealand
- suffer from a terminal illness that is likely to end their life within six months
- be in an advanced state of irreversible decline in physical capability
- experience unbearable suffering that cannot be relieved in a manner that the person considers tolerable
- be competent to make an informed decision about assisted dying.

A person can't access assisted dying solely because they are suffering from a mental disorder or mental illness, have a disability, or are of advanced age.

How many people will be eligible for this service within the TDHB region?

Based on data from countries providing assisted dying, it is estimated that 300-350 people in Aotearoa New Zealand may access the service each year. Given our population size (2.5% of that of New Zealand), we estimate that around 9 people will be eligible in our region per annum.

Who is responsible for assessing a person's eligibility for assisted dying?

Only medical practitioners who have registered with the Support and Consultation for End of Life in New Zealand (SCENZ) will assess a person's eligibility for assisted dying.

Under the Act, the Attending Medical Practitioner (AMP) (the medical practitioner who starts the assessment process for assisted dying as above) and a second Independent Medical Practitioner (IMP) must both assess the person and agree that the person is eligible for assisted dying.

The person must be found to be competent to make an informed choice about assisted dying. This means that the person can understand, retain, use, and weigh relevant information about assisted dying, and can communicate their decision in some way.

If either of the two medical practitioners are unsure that the person is competent to make an informed decision, a psychiatrist would then assess the person to determine if they are competent.

The person must also be considered competent at the time of request and must also be competent at the time the medication is administered.

Advance directives or Advance Care Plans cannot be used for assisted dying in New Zealand.

Who can initiate the conversation about assisted dying?

The decision to request assisted dying can only be made by the individual person seeking it as an option. It must be the person's informed choice and they must have made this choice without pressure from anyone else.

Whānau, carers, welfare guardians, or holders of an enduring power of attorney, cannot request assisted dying on behalf of another person.

Can a health practitioner start the conversation with a person about assisted dying?

No. A health practitioner cannot discuss assisted dying unless that person raises it with them first. A health practitioner providing a health service to the person may be subject to disciplinary proceedings or proceedings for breaching patient rights if they initiate a discussion about assisted dying.

Can the person change their mind?

Yes. A person can change their mind at any time up until the medication is administered, and their AMP (the doctor managing their application for assisted dying) must ensure they are aware they can change their mind.

Who administers the medication?

The medication is administered by an Attending Medical Practitioner (AMP) or Attending Nurse Practitioner (ANP) who has registered with the Support and Consultation for End of Life in New Zealand (SCENZ) to provide assisted dying. It is most likely that the first practitioner will have the most contact and closest relationship with the person. The second practitioner (Independent Medical Practitioner (IMP)) will, in general, just provide the second opinion. The administration of the medication can be performed by the person requesting assisted dying themselves, one of those two practitioners AMP, IMP or alternatively by an ANP. If the medication is self-administered the practitioner is expected to be present close by – not necessarily in the room but in the next room or equivalent.

What medications are likely to be used for assisted dying?

The medicines to be used for assisted dying are safe and effective medicines. Use of these medicines for assisted dying is what is referred to as an 'off-label' use. That means a medicine is prescribed for an indication or a patient group that is not included in the product information sheet. Prescribing off label is very common.

For safety reasons, the detail of the medicine regimes will only be provided directly to the practitioners providing the service, that is either the AMP or ANP. Details and names of the medicines will not be made publicly available due to restrictions on promotion and legislative criteria.

There are 4 options for the medicine regimes:

- Oral administration – self-administered by the person or administered by the AMP/ANP
- Intravenous administration – self-administered or administered by the AMP/ANP

There are back up options for the medications provided to the AMP/ ANP each time the service is provided. Should the initial administration of medication not be effective (which is unlikely) there is a second medication that can be given.

What cause of death will be recorded on the Death Certificate for a person who has chosen assisted dying? Is it assisted dying or the illness?

The person's terminal illness will be documented as the cause of death. Assisted Dying will not be mentioned. Choosing assisted dying will not impact on any life insurance claims as the person will be seen as having died from their underlying terminal illness.

What if I don't want to be involved with assisted dying?

You do not have to be involved in assisted dying services if you do not wish to due to your personal beliefs (conscientious objection). However, you **MUST RESPOND** with respect and compassion if assisted dying is raised with you by a patient. Your role would be to direct them to where they can find information about assisted dying. If a health practitioner with a conscientious objection is asked by a patient about assisted dying, they have certain responsibilities under the Act. They must:

- inform the person of their objection, in a courteous and appropriate way following the guidance in the Ministry's Handbook on "Responding When a person raises assisted dying".
- tell the person that they have the right to ask the Support and Consultation for End of Life in New Zealand (SCENZ) Group for the name and contact details of a medical practitioner who is willing to participate in assisted dying.

An online learning resource is available to support health professionals to respond respectfully and appropriately when a person raises assisted dying you can access this [here](#).

What role do patient-facing staff have in the assisted dying service?

If a person starts a conversation or asks you about assisted dying in the course of your job, you must either refer them to where they can find more information (this could be a colleague or information online) or talk to the person themselves about it. We strongly recommend all staff prepare to have that conversation. An online learning resource is available for this purpose you can access this [here](#).

What if there is a language barrier when a person starts the conversation about assisted dying?

The service needs to be equitably available across our population. If English is not the first language of the person requesting the service a professional interpreter should be used to appropriately assess eligibility and competence as well as to fully explain the process. Family members should not be used for this purpose.

What role do whānau have in the process?

Whānau and carers can play an important role in supporting someone through the process, if the person seeking assisted dying wishes this. This could include:

- helping someone understand and consider their end-of-life options.
- attending medical appointments with someone (although the AMP/IMP will want to speak to the person being assessed for assisted dying on their own at some times in the process).
- providing personal care, such as bathing and feeding.
- offering care and support when the medication is administered.

What's the wrap around support for the whānau before the decision is made, where will it come from?

Work is underway in both the community and hospital space to determine how to best support people and their whānau. This involves social work, Māori organisations, primary and secondary care and consumer groups.

What if a person's carer, whānau or friend asks you about assisted dying?

You can direct them to general information about the service [End of Life Choice Act - Information for the public \(health.govt.nz\)](https://www.health.govt.nz/our-services/end-of-life-care). Where appropriate, you can also make them aware that they cannot make a request on another person's behalf and that assisted dying must be requested by the person and must be the person's choice based on their informed consent.

Whānau, carers, welfare guardians or holders of an Enduring Power of Attorney cannot request or make a decision about assisted dying on someone's behalf.

What if a person has requested assisted dying in their Advance Care Plan – Is this enough?

No. An assisted dying request is totally separate from an Advance Care Plan (ACPlan) or Advance Directive (AD). Even if a person, when competent, has written in their ACPlan or AD a request for assisted dying, this cannot be upheld. The person requesting the service must do so verbally to an appropriate clinician.

Is “not wanting to be a burden” a reason to get assisted dying?

No. The criteria are very clear as outlined on the MoH website.

There are multiple reasons why people may request assisted dying. We will not know all of them, which is why it is necessary to go through the process and make sure people are making informed decisions. They need to be eligible to receive assisted dying support and also competent to make their own decisions.

As part of the conversation around the request for assisted dying, there will be an exploration of their reasoning for the request which in this case would include why they think they're a burden – in particular, anything that might suggest coercion needs investigating. It may be that the conversation then moves towards an Advance Care Planning conversation.

Where can patients and whānau find information about the service?

Information for the public can be found on the Ministry of Health website [here](#).

How do I register to provide Assisted Dying?

There are four roles for practitioners involved in Assisted Dying as follows:

- attending medical practitioners (AMP)
- independent medical practitioners (IMP) (to provide the second opinion),
- psychiatrists (to provide competency assessments where required)
- attending nurse practitioners (ANP) (to administer the medication)

The Support and Consultation for End of Life in New Zealand (SCENZ) group is responsible for maintaining the list of medical practitioners, psychiatrists and nurse practitioners involved in providing assisted dying services; providing contact details for replacement, or independent medical practitioners as part of the service; and providing the contact details for when psychiatrists may be required. Medical practitioners, nurse practitioners, and psychiatrists interested in being included on the SCENZ lists can find more information and express interest here: [Access the Expression of Interest](#) or email eolc@health.govt.nz

Can I choose to provide Assisted dying for just my patients only?

Yes. Practitioners registered with SCENZ can put criteria around who they are willing to provide this service to.

How will the service be funded?

Assisted dying will be publicly funded in New Zealand and the Ministry of Health will be responsible for overseeing the funding and provision of assisted dying services. The service will be free at the point of care to those receiving it.

AMP/IMP and ANP employed by TDHB who wish to provide this service will need to do it in a private capacity, taking leave of absence to work through the application process. Payment for this will be via a section 88 agreement with the Ministry of Health, not through the TDHB.

What wellbeing support will be available for staff?

Assisted dying is a sensitive topic and may be difficult for some people. If this raises some distressing feelings for you, please know there is support available. You can call or text 1737 for free to speak to a trained counsellor at any time. You can also talk to an independent counsellor through TDHB's EAP programme (call 0800 360 364); call or text the Depression Helpline – 0800 111 757 or free text 4202 to talk to a counsellor.

A TDHB Working group has also been set up to design a pathway of care for patients requesting assisted dying in hospital. Support for staff is part of this design.

Who can be contacted to provide spiritual and pastoral support to a person requesting assisted dying or their family?

The Hospital Chaplain is available to provide this support as to also offer blessing and committal of the deceased at the passing. The Hospital Chaplain is also available to staff who require pastoral care. They can be contacted be via the TDHB Telephone Operators.

Where do people go if they want advice or assistance in relation to cultural support for an eligible person or their whanau?

The Pou Hāpai provides designated Māori health specific workers who can offer advocacy and cultural support for Māori tupāpaku and their whanau. The Pou Hāpai will also offer Karakia and blessing of the room as part of the tupapaku journey. They can be contacted be via the TDHB Telephone Operators or by phoning Maori Health on 8826.

How can clinicians obtain informed consent if they don't know what the assisted dying pathway will be?

Local details on pathways, particularly for those needing to be in hospital for the assisted dying intervention, are being developed and will be published on the TDHB Intranet in due course.

For staff who are not going to be providing assisted dying services however, their role will only be to provide information and onward referral to a colleague or contact details for the SCENZ group.

Online learning modules and a suite of resources have also been developed to support health professionals to respond with respect and compassion if assisted dying is raised by the patient. You can access those [here](#). You can also contact SCENZ via email eolc@health.govt.nz

How can clinicians obtain informed consent if they are not allowed to mention all the options for management?

Staff at TDHB are expected to act in a way that promotes cooperation among service providers to ensure quality and continuity of services, in line with the [Code of Health and Disability Services Consumers' Rights](#).

The provision of informed consent is an obligation on health professionals under the Code of Health and Disability Services Consumer's Rights. The End of Life Choice Act, however, specifically overrides the Code in three key areas. One of those is in the area of informed consent.

Under the Act, a health practitioner cannot raise assisted dying with a person. This overrides Right 6 (1)(b), which states that a person would expect to receive "an explanation of the options available". However, once the person raises assisted dying, Right 6 applies in full.

The other two areas where the Act overrides the Code of Rights are in the area of competence – where Right 7(2) states that a person must be presumed competent, unless there are reasonable grounds to believe that person is not competent, but under the End of Life Choice Act there is no such presumption and the person must be 'found to be competent' – and in the use of Advance Directives – where Right 7(5) states that 'advance

directives may be used in accordance with common law' but the Act specifically states that Advance Directives cannot be used for assisted dying in New Zealand.

Assisted dying does not replace the care a person is already getting. Instead, it provides another option in some circumstances. If a person chooses to access assisted dying services, this option will most likely be in addition to the care they are already getting, such as palliative care. It is important to continue a person's wider care so that their other health needs are addressed while the assessment for whether they are eligible for assisted dying occurs and/or up until their assisted death takes place. Continuing this care also means that if the assessment finds that a person is not eligible for assisted dying or the person chooses not to have an assisted death, service providers are still meeting their wider health needs.

How should conversations with a patient about assisted dying be documented? Do they need to be recorded?

All conversations and plans should be documented in the patient's clinical record. Good clinical documentation promotes patient safety and supports continuity of care. This is particularly important in the context of assisted dying, where multiple health professionals may be involved in further conversations and assessment.

Once a formal assessment process is underway however, there are forms at various stages of the pathway that will need to be completed.

Currently there is no requirement to video record these consultations.

How do we maintain confidentiality when assisted dying practitioners are coming onsite (and may be known to be assisted dying practitioners)?

This is an important issue and will be considered by the steering group in development of the DHB pathway. Once the AMP/ANP list is completed by SCENZ the names of local providers will be shared confidentially with TDHB. This will allow us to orientate them to the hospitals and determine ways they can access the appropriate clinical areas in a discreet fashion which will avoid drawing attention to their presence.

What is the current thinking about Ethics input?

The TDHB Clinical Ethics Advisory Group is available to give advice to clinicians on a case by case basis and can be contacted either directly, through TDHB Telephone Operators or via the assisted.dying@tdhb.org.nz email.

Significant issues within the assisted dying pathway will be escalated to the Ministry Secretariat and, where needed, the Registrar.

Is there any risk of EOLC becoming a privatised market?

There are no options to set the service up outside the Ministry structure within existing legislation.

What impact will the Health NZ Reforms have on this?

From the TDHB point of view, we are looking at pathways for each hospital. Community pathways will probably be based within existing relationships that will carry on through any transition.

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