

This guide explains your rights under the Code of Health and Disability Services Consumers' Rights (the Code) if you choose to receive the assisted dying service, and how to make a complaint if you feel your rights have been breached.

Assisted dying: People's rights under the Code

Since 7 November 2021, a person who has a terminal illness and meets strict eligibility criteria has been entitled to request medication to relieve their suffering and end their life. If you choose to receive assisted dying, you will be protected by the Code of Health and Disability Services Consumers' Rights (the Code). If you have not received a quality service, you or a friend, carer, or family member can complain to the Health and Disability Commissioner (HDC).

The right to quality care

We know that assisted dying is a sensitive topic that can be difficult to talk about. But just as for any other form of health care, if you choose to receive assisted dying, you have certain rights under the Code.

These include the right to be treated fairly and with respect, to care and support that meets your needs, to make choices about your care, to discuss your care in a way that you understand, and to receive good quality care. If you feel your rights have not been upheld, then you can complain. (The full Code of Rights is available at www.hdc.org.nz.)

Rights under assisted dying law

The End of Life Choice Act 2019 (the Act) gives people who experience unbearable suffering from a terminal illness the option of legally asking for medical assistance to end their life. Some parts of the Act affect your rights under the Code in important ways. These relate to your right to be fully informed, and your right to make an informed choice and give informed consent.

➤ You will need to ask your doctor or nurse for information

Under the Code, usually you would have the right to all the information you need to make an informed decision about your care, including all of the options available to you.

But the End of Life Choice Act says that your doctor, nurse, or any other health practitioner, cannot start a discussion with you about assisted dying unless you ask them about it first. This is because of concerns that you may feel pressured into choosing the service. So if you want to talk about assisted dying, you need to say so very clearly. Once you have raised the topic of assisted dying, you are entitled to all of the information you need to make decisions, including information about all of your options.

Note that only a registered doctor or nurse practitioner can provide you with assisted dying, although not all will provide this service.

➤ **You must be assessed as being “competent” to be eligible for the service, and at different points in the process.**

“Competent” means you can understand, retain, use, and balance information to make an informed decision about assisted dying, and that you can communicate that decision in some way.

Under the Code, it is presumed that you are competent to make an informed choice and give informed consent to your care, unless there are reasonable grounds for the doctor to think you are not competent.

The End of Life Choice Act states that your competence to make decisions about assisted dying must be determined by two doctors as part of assessing whether you are eligible for the service. If either is unsure, a psychiatrist would then assess you to determine your competence.

➤ **You cannot request assisted dying in an advance directive.**

The Code states that you may use an advance directive to set out your wishes for care in situations where you are no longer able to speak for yourself.

However, under the End of Life Choice Act, you cannot make an advance directive for assisted dying. This is because the doctors assessing you for the service must be satisfied that you are competent at the time you make your request and throughout the process.

➤ **Your doctor does not have to provide assisted dying if they have a conscientious objection to doing so.**

In this case, they must tell you that they object and that you have a right to contact the Support and Consultation for End of Life in New Zealand Group (SCENZ) for the name and contact details of a replacement doctor who is willing to provide the service. Information about SCENZ is on the Ministry of Health website.

Even if your doctor cannot provide the service, under the Code they must ensure that your care continues. For example, if the doctor who is providing the assisted dying service to you needs your records or to discuss your care, your usual doctor will need to cooperate.

Making a complaint



Assisted dying is a new service, and the Health and Disability Commissioner is keeping a close eye on how it is working for people who choose to receive it.

If you choose to receive assisted dying and you feel your rights under the Code have not been upheld, you can make a complaint.

You can also complain if you are the whānau, family, friend, or caregiver of the person choosing to receive the service.

➤ Information for whānau

Family members, whānau, and carers can play an important role in supporting a person through the process, **if the person wants them to.**

A person who chooses to receive assisted dying does not have to discuss it with anyone else if they don't want to. The decision to receive assisted dying is the person's choice. Family members, whānau, and welfare guardians do not have any power to make decisions on behalf of a family member.

However, the doctor should encourage the person to discuss their wish with family and whānau, and ensure that there is opportunity for them to do that. The doctor assessing the person for the service may speak to family and whānau if they have the person's permission.

How your complaint will be managed



Depending on how serious or urgent your issue is, we may suggest you first talk to the health professional concerned, as they may be able to sort out the problem quickly.

If you are not comfortable doing this, you may prefer to get help from a health and disability advocate to raise your concerns.

The Nationwide Health and Disability Advocacy Service operates independently of healthcare and disability services providers, the Ministry of Health, and HDC. It is a free and confidential service. Your advocate will work alongside you to resolve the issue, to provide information about your rights, and to support you to raise concerns with the health professional concerned.

To contact the Advocacy Service, please telephone **0800 555 050** or email **advocacy@advocacy.org.nz**.

Otherwise, you can approach HDC. We will consider your complaint carefully, including the issues you raise and the information available. This can take some time. Where you require a response quickly, we may contact you to discuss what options are available to you, or you can contact the Registrar (assisted dying) at the Ministry of Health. The registrar can also receive complaints, and can refer them to HDC or to any other appropriate authority, such as the Medical Council, the Nursing Council, or to the Police.

You can find more information on how HDC resolves complaints on our website: **www.hdc.org.nz**.

If your concern is urgent or you require a response quickly, contact the Registrar (assisted dying) and the Ministry of Health: **AssistedDying@health.govt.nz** or telephone **0800 223 852**.

For more information



The End of Life Choice Act 2019 sets out the legal framework and a high-level process for accessing assisted dying, including strict eligibility criteria and safeguards.

You can read more about the End of Life Choice Act on the New Zealand Legislation website: www.legislation.govt.nz.

The Ministry of Health has led the implementation of the End of Life Choice Act 2019. You can find full information on the Ministry of Health's website: www.health.govt.nz.

You can also contact the Registrar (assisted dying) or the Assisted Dying Secretariat with any concerns you may have: AssistedDying@health.govt.nz or phone **0800 223 852**.

Contact

» The Nationwide Advocacy Service

Free Phone: 0800 555 050
Email: advocacy@advocacy.org.nz
Hours: 8.00 am to 8.00 pm, Monday to Friday

» The Health and Disability Commissioner

PO Box 1791, Auckland
Free Phone: 0800 11 22 33
Email: hdc@hdc.org.nz
Website: www.hdc.org.nz
Hours: 8.30 am to 8.00 pm, Monday to Friday

If your concern is urgent or you require a response quickly, contact the Registrar (assisted dying) at the Ministry of Health: AssistedDying@health.govt.nz or telephone **0800 223 852**.