



# Assisted Dying Service – Ngā Ratonga Mate Whakaahuru

Registrar (assisted dying) Annual Report  
to the Minister of Health – June 2022



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# Foreword

Tēnā koutou,

The Ministry of Health (the Ministry) established a new assisted dying service for New Zealand Aotearoa on 7 November 2021. This is my first annual report as Registrar (assisted dying) as required under the End of Life Choice Act. It is a privilege to undertake this important safeguarding role, to ensure the service is one of quality.

From the outset, the Ministry recognised that a trained and dedicated workforce would be the foundation of the service. Support, engagement, guidance and training for the whole health and disability workforce was critical.

We worked closely with the wider sector, ensuring the health and disability workers had an understanding of how the service would operate in practice, and what it meant for them. On behalf of the Ministry, I would like to thank all of those who have had a role in the implementation of the assisted dying service so far.

Many areas of the health sector were involved at different stages of designing, and implementing, the new assisted dying service. This includes health service providers, nursing and medical councils and colleges, support and advocacy groups, and members of the public. The significant time, commitment, and expertise provided by these groups was an integral part of ensuring the service was fit for purpose. Your contribution is appreciated particularly given the ongoing pressures of the COVID response

I want to recognise Te Apārangi: Māori Partnership Alliance. They were requested to work in partnership with the Ministry in establishing the assisted dying service by providing expert Māori advice, framed by Te Tiriti o Waitangi. Te Apārangi now provides strategic and oversight to the assisted dying Secretariat, through which Te Apārangi will support the secretariat's role in monitoring quality and equity.

The service would not be possible without the skilled workforce behind it. I acknowledge the professionalism, compassion and dedication of the medical and nurse practitioners who provide the direct person-centred care through the assisted dying service - Ngā Ratonga Mate Whakaahuru.

Finally, an acknowledgement to the people who have considered or chosen an assisted death, and their whānau, loved ones and others who have supported them. Assisted dying is emotive and a very personal decision – it is a privilege to safeguard and support people through this part of their life.

Ngā mihi nui

**Dr Kristin Good**  
**Registrar (assisted dying)**

# Introduction

## 1. About this report

The Ministry of Health is responsible for administering the End of Life Choice Act 2019 (the Act).

The Registrar (assisted dying) is required to report on the assisted dying service, as per Section 27(7) of the Act.

Reporting is due to the Minister of Health by the end of 30 June each year, and covers:

- the total number of deaths occurring under the Act
- the number of deaths occurring through each of the methods of administration of medication
- the number of complaints received about breaches of this Act and how those complaints were dealt with
- any other matter relating to the operation of the Act that the Registrar thinks appropriate.

This report covers the period from 7 November 2021 to 31 March 2022 and is the first published since the Act came into force on 7 November 2021. In addition to the information outlined above, it contains a summary of the implementation of the Act, stakeholders involved in the service, service usage, workforce, feedback and complaints.

The next report will be the first to cover a full year, from 1 April 2022 to 31 March 2023.

## 2. Role of the Registrar (assisted dying)

The Registrar is a statutory role under the Act, appointed by the Director-General of Health. The Registrar's responsibilities include:

- reviewing the assisted dying forms completed by practitioners, to ensure compliance with the Act prior to the prescription being released
- maintaining a register of approved forms for the assisted dying process, including consulting the Privacy Commissioner as appropriate
- receiving and managing complaints, including referring them to the Health and Disability Commissioner, New Zealand Police, and/or other appropriate authorities
- acting on feedback from the Review Committee.

The Registrar also plays an important role in the delivery of the assisted dying service by providing support and advice to health practitioners, clinical advisors and the Assisted Dying Secretariat.



# Introducing an assisted dying service in New Zealand Aotearoa

## 1. Mate whakaahuru

The Ministry is using mate whakaahuru as the te reo Māori translation for assisted dying. This means 'to die in a warm and comforting manner'.

This kupu was used by Māori media and proficient te reo speakers prior to the Act coming into force. The Ministry of Health (the Ministry) consulted with Te Apārangi: Māori Partnership Alliance and the Support and Consultation for End of Life in New Zealand (SCENZ) Group before this translation was adopted.

## 2. The End of Life Choice Act 2019

The Act was passed by Parliament on 13 November 2019 on the condition that a public referendum would be held at the 2020 General Election seeking public opinion on whether the Act should come into force. 65% of eligible voters voted in favour of an assisted dying framework, and the Act came into force on 7 November 2021.

The Act gives a person with a terminal illness the option to request medication to end their life. The Act outlines the legal framework for assisted dying, including eligibility criteria and some key safeguards.

To be eligible for an assisted death, a person must be:

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

The decision to have an assisted death must be made by the person with a terminal illness. A health practitioner is not permitted to raise this option with them unprompted.

The Act is available on the [New Zealand Legislation website](#).

### 3. Implementing the Act

Following the referendum results, the Ministry was responsible for implementing the Act and establishing an assisted dying service in New Zealand Aotearoa. The Ministry remains responsible for this legislation.

The principles of Te Tiriti o Waitangi, as understood by the Ministry in **Whakamaua: Māori Health Action Plan**, were considered and incorporated as part of the planning and deliverables during the implementation of the Act. This included focused engagement with Māori-led health and disability organisations, ensuring Te Tiriti o Waitangi commitments were reflected in all aspects of the service; and including Māori in formal partnerships and governance roles.

Engagement with the health and disability sector was a key priority throughout the implementation to ensure that a broad spectrum of perspectives and concerns were considered within the implementation work programme. This included meeting with professional colleges, responsible authorities, workforce unions, district health boards, Māori-led primary care organisations, and organisations representing, palliative care, aged residential care and the disability sector, including Te Ao Mārama.

#### Overview of implementation work programme

The work programme was overseen by a governance group with representation from Ministry executive leadership (which included representation from the Deputy Director General Māori Health Directorate, the Ministry of Health senior Māori leader), a district health board, the Council of Medical Colleges and Te Apārangi: Māori Partnership Alliance.

In addition, an informal advisory group, made up of health practitioners from various backgrounds and work environments, provided insight and advice across various aspects of the work programme.

A timeline of the key milestones related to the implementation is outlined below.

January – March 2021	April – June 2021	July – September 2021	October – December 2021
<ul style="list-style-type: none"> <li>• Governance Group and advisory network established</li> <li>• Treaty analysis</li> <li>• Assessment of workforce interest</li> <li>• Key system-level policy settings defined (eg service provision, accountability, funding)</li> </ul>	<ul style="list-style-type: none"> <li>• Medications selected</li> <li>• Initial consultation with the Privacy Commissioner</li> <li>• Funding and accountability arrangements defined</li> <li>• Workforce training and support needs assessed, and first training module launched</li> </ul>	<ul style="list-style-type: none"> <li>• SCENZ Group established</li> <li>• Expression of interest for SCENZ lists opens</li> <li>• Forms, systems and processes to support compliance developed</li> <li>• Operational processes and guidance developed</li> </ul>	<ul style="list-style-type: none"> <li>• Assisted dying secretariat established, including Registrar (assisted dying)</li> <li>• Review Committee appointed by Minister</li> <li>• All training available and workforce forum held</li> <li>• Public information available</li> </ul>

January – March 2021	April – June 2021	July – September 2021	October – December 2021
<ul style="list-style-type: none"> <li>Budget Bid</li> </ul>		<ul style="list-style-type: none"> <li>Section 88 Notice in place</li> <li>Standards of Care and Clinical Guideline developed</li> <li>Medications procured and available</li> </ul>	<ul style="list-style-type: none"> <li>Processes and systems in place to support operation and oversight of assisted dying service</li> </ul>

## Processes for implementing Te Tiriti o Waitangi

The Ministry acknowledges that, as assisted dying is a relatively new health service across the globe, there is limited knowledge of the impact a person choosing assisted dying has on their whānau and communities. This is particularly acute in respect of assisted dying and indigenous peoples, including Māori and whānau Māori. Twelve people that applied for assisted dying are Māori and will have been supported by whānau Māori.

The service has the following mechanisms in place that contribute to meeting the principles of Te Tiriti. The Ministry's strategies in **Whakamaua: Māori Health Action Plan** were considered and incorporated as part of the planning and deliverables during the implementation of the Act. This included:

- adopting mate whakaahuru as the te reo Māori translation for assisted dying. This means 'to die in a warm and comforting manner'.
- engagement with Māori health and disability organisations including Te Ao Mārama and Kaupapa Māori health and disability service providers as part of the establishment of assisted dying
- ensuring the Te Tiriti o Waitangi commitments are incorporated in the service design and reflected in the guidelines, standards of care, care pathway, clinical guidelines, Section 88 notice (funding mechanism); training for the sector, and information about the service.
- formal partnerships and statutory governance that provide ongoing guidance and direction alongside the Ministry of Health. These are:
  - The Support and Consultation for End of Life in New Zealand (SCENZ) Group includes two Māori members and a Māori co-chair. All members are expected to be knowledgeable on Te Tiriti.
  - The End of Life Review Committee has a Māori member. All members are expected to be knowledgeable on Te Tiriti.
  - Te Apārangi: Māori Partnership Alliance has taken an advisory role during the implementation period. Te Apārangi was consulted and provided advice on a wide range of implementation matters, including incorporating whānau and te ao Māori worldview in the service and approach to Māori engagement.
  - An initial governance group with representation from Ministry executive leadership (which included representation from the Deputy Director General

Māori Health Directorate, the Ministry of Health senior Māori leader), and Te Apārangi: Māori Partnership Alliance.

- continuing to work to grow the workforce, with a particular focus on ensuring the workforce represents the diversity of New Zealand Aotearoa, including increasing the number of Māori practitioners.
- ensuring that cultural safety of the practitioners providing assisted dying services is a priority as this underpins good practice.
- Facilitating a body of knowledge to develop around assisted dying that is specific to New Zealand Aotearoa through a research strategy. This knowledge can inform both how assisted dying is provided in practice, but also wider conversations and understandings about the social and cultural implications of assisted dying, including for Māori and whānau Māori.

## Designing for equity

New Zealand Aotearoa is one of an increasing number of jurisdictions that has legalised assisted dying, and the Ministry is grateful to overseas colleagues who offered advice and expertise from their own experiences of introducing an assisted dying service. It was vital that the implementation also considered the specific New Zealand context, particularly the needs of Māori and people living in rural areas.

The Ministry is committed to ensuring that the assisted dying service is person-centred, equitable and accessible to all New Zealanders. This means that a person's location or situation will not affect their ability to access assisted dying, and the service will be responsive to the individual person's needs, including supporting Māori self-determination and mana motuhake, meaning services are person-centred and whānau-centred. This was a central consideration in the design of the service and how it has been funded.

To support an equitable and accessible service, the Ministry focused on:

- **enabling a person to exercise choice about their practitioner and maximising the size, spread and diversity of the assisted dying workforce** by allowing any willing and appropriately trained medical or nurse practitioner to access funding for providing assisted dying services
- **providing funding for practitioners to travel to provide services**, which enables access throughout New Zealand and means a person can receive care in their own home, regardless of where they live
- **supporting the use of telehealth, where appropriate, in the process**, offering people options, and improving timeliness and access for people in rural areas or where there are few assisted dying practitioners
- **providing public information in various languages and formats and supporting the use of interpreters** to increase accessibility and support a culturally safe service for all people and their whānau
- **incorporating Te Tiriti o Waitangi principles in the assisted dying training, *Standard of Care and Clinical Guideline for administering assisted dying medication*** to support practitioners to provide services that recognise and support Māori models of care

- **supporting practitioners to provide culturally safe assisted dying services** by creating a care plan and ensuring training resources reflect how the assisted dying process may look different depending on the person accessing the service
- **ensuring feedback channels were in place** to enable continuous quality improvement based on a person's experience of the service.

## 4. Standard of Care and Clinical Guideline

The assisted dying service exists within the context of the wider health and disability system. Professional standards and frameworks, such as the Code of Health and Disability Services Consumers' Rights, continue to apply to assisted dying services and should be followed to ensure quality service provision to people and their whānau.

Specific guidance for the assisted dying service is provided by the *Standard of Care*, and the *Clinical Guideline* for administering assisted dying medication in New Zealand Aotearoa. These frameworks support consistent, safe and quality services and incorporate Te Tiriti o Waitangi principles.

The *Standard of Care*, created in partnership by the Support and Consultation for End of Life in New Zealand Group (SCENZ) and the Ministry, has been developed to outline best practice in providing care and support to a person and their whānau when administering assisted dying medication in New Zealand Aotearoa. The *Standard of Care* is available through **the Ministry's website**.

The *Clinical Guideline*, created by the Ministry, covers the considerations and requirements to be followed by the attending medical practitioner (AMP) or attending nurse practitioner (ANP) when administering the assisted dying medication. The *Clinical Guideline* is only available to practitioners who are directly involved as it contains sensitive information related to the medications. The *Clinical Guideline* is reviewed and updated, based on feedback.

Both the *Standard of Care* and the *Clinical Guideline* are intended to be read alongside ***Ngā Paerewa: Health and Disability Services Standard NZS 8134:2021***. *Ngā Paerewa*, which was developed with the health sector, sets out the minimum requirements for care and support within services specified in the Health and Disability Services (Safety) Act 2001.

# Groups and organisations involved in the assisted dying service

## 1. The Assisted Dying Secretariat

The Assisted Dying Secretariat, within the Regulatory Assurance team at the Ministry, is responsible for overseeing the assisted dying service. The Secretariat has a regulatory and monitoring function to ensure compliance with Act, and an operational function to support the delivery of assisted dying services. The Registrar (assisted dying) sits within the Secretariat.

### Support throughout the process

The Secretariat includes clinical advisors who provide information and support to the person, their whānau, and the practitioners providing services. Their role also includes connecting people with practitioners from the SCENZ lists. The clinical advisors are senior registered nurses.

The clinical advisor roles were established based on the success of the Care Navigator Service in Victoria, Australia, which provides a central point of contact and support for people and practitioners navigating this process.

The clinical advisors have been a vital part of the assisted dying service from the very beginning and have received consistently positive feedback from people, whānau and practitioners who value their compassion, expertise, and dedication to their roles.

The service started with two clinical advisors, and there are plans to expand the team, due to increasing workload. This will also enable the clinical advisors to better support activities related to service improvement, quality and whānau engagement.

### Ongoing service improvement

The Secretariat has a work programme in place to monitor and improve the service over time. This includes establishing a Continuous Quality Improvement framework and Quality Plan.

The Quality Plan supports the first year of the operation of the service and provides a framework for clinical governance, risk mitigation, accountabilities and monitoring. It focuses on seven measures that capture all aspects of the assisted dying service. Data from the first year of activity will be used to inform the quality focus moving forward.

In addition, the Ministry is undertaking a self-initiated internal review from November 2022, which will examine how the Act has been implemented, including identifying what has worked well and where there may be scope for improvement.

The Ministry is also responsible for conducting a legislative review within three years of the Act coming into force and making recommendations to the Minister of Health of any appropriate amendments. Following this review, the Act will be reviewed at least every five years.

## 2. The Support and Consultation for End of Life in New Zealand Group

The Support and Consultation for End of Life in New Zealand (SCENZ) Group is a statutory body appointed by the Director-General of Health. The SCENZ Group is comprised of medical practitioners, a psychiatrist, a pharmacist, a nurse practitioner, and members that represent consumer and whānau perspectives. The Group brings collective experience in clinical practice, Te Ao Māori and Tikanga Māori, ethics and law, and the disability sector. It includes two Māori members and a Māori co-chair.

The SCENZ Group's responsibilities include:

- maintaining lists of medical practitioners, psychiatrists and nurse practitioners willing to be involved in the assisted dying service
- connecting people to these medical practitioners, psychiatrists, and nurse practitioners as appropriate throughout the process
- preparing standards of care in relation to the administration of the medication and appropriate medical, legal or practical advice related to this.

The SCENZ Group has met regularly since it was established and has provided advice and input on a number of topics, including the *Standard of Care*, the forms required during the process, the IT system and the research strategy.

The Secretariat supports the SCENZ Group, including connecting people to practitioners on behalf of the Group. More information about the SCENZ Group, including its membership, is available on [the Ministry's website](#).

## 3. The End of Life Review Committee

The End of Life Review Committee is a statutory body appointed by the Minister of Health. The Review Committee is comprised of a medical ethicist, a doctor specialising in end-of-life care, and one other health practitioner. One member is Māori. Membership will be reviewed after two years.

The Review Committee's responsibilities include:

- considering death reports provided by the AMP or ANP about an assisted death

- reporting to the Registrar whether the report shows satisfactory compliance with the requirements in the Act
- directing the Registrar to follow up on any information where the report does not show satisfactory compliance.

The Review Committee has met regularly since it was established. As of 31 March 2022, it has signed off 10 death reports. It has not yet made any recommendations to the Registrar.

The Secretariat supports the Review Committee. More information about the Review Committee, including its membership, is available on **the Ministry's website**.

## 4. Te Apārangi: Māori Partnership Alliance

Te Apārangi: Māori Partnership Alliance was established to work in partnership with HealthCERT and Regulatory Assurance teams to provide expert Māori advice, framed by Te Tiriti o Waitangi.

At the request of the implementation governance group, Te Apārangi took on an advisory role during the implementation period. Te Apārangi was consulted and provided advice on a wide range of implementation matters, including incorporating whānau and te ao Māori worldview in the service and approach to Māori engagement. The Ministry is pleased that Te Apārangi has agreed to continue to provide support and expertise now the assisted dying service is operational. Te Apārangi's focus will shift towards providing governance and strategic oversight to support the Secretariat's role of monitoring and improving the service over time.

More information about Te Apārangi is available on **the Ministry's website**.

## 5. Contracted pharmacies

Two hospital pharmacies have been contracted by the Ministry of Health to fulfil the prescriptions for the assisted dying medication. This centralised approach supports consistency, safety, and access, with medication kits delivered directly to practitioners across the country.

The Ministry appreciates the dedication of the pharmacy teams in supporting the development of best practice guidelines, and robust processes for the fulfilment and distribution of assisted dying medication kits.

Their committed engagement and responsiveness to feedback is also recognised, particularly considering the challenges of COVID-19 and associated courier delays.



# Assisted Dying Service Activity

The Ministry collects data about the assisted dying service as part of its role in overseeing and monitoring the service. This data is drawn from the application forms for assisted dying, which are held centrally by the Secretariat.

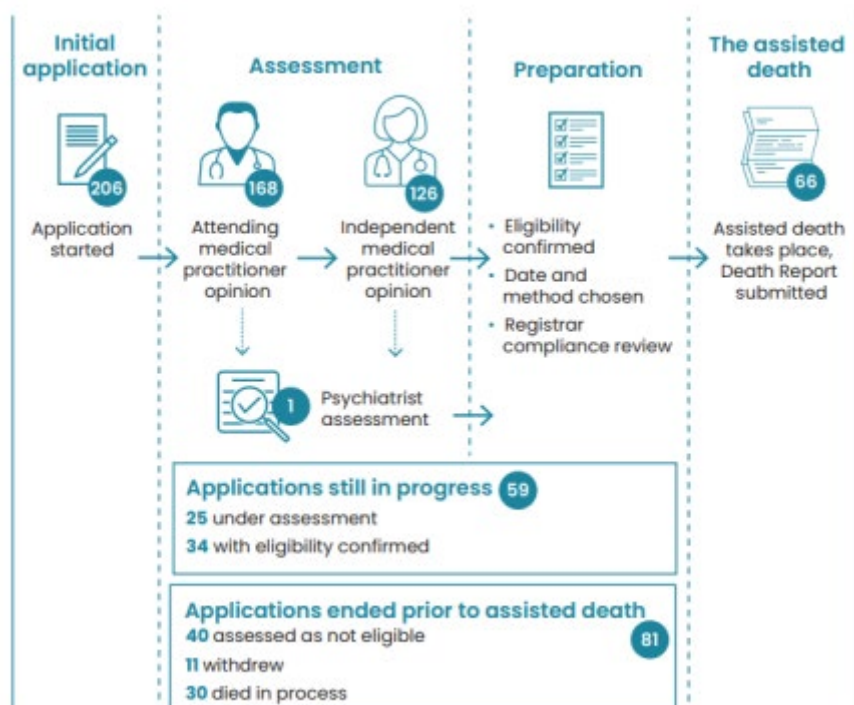
A summary of this data will be released on a quarterly basis. The first set of reporting was published on **the Ministry’s website** in April 2022. It covered the period 7 November 2021 – 31 March 2022, which is the period covered in this report.

## 1. Overview of assisted dying applications

Between 7 November 2021 and 31 March 2022, 206 people formally applied for assisted dying. As of 31 March:

- 59 people were still in the process of assessment or preparation for assisted dying
- 81 people did not continue the process (due to being ineligible, withdrawing or dying of their condition)
- 66 people had an assisted death.

**Figure 1: Overview of the pathway from initial application to an assisted death**



The assisted dying service is person-centred, and the time taken from application through to assisted death varies based on their personal situation. People requesting assisted dying are nearing the end of their life, which means they may feel a sense of urgency about moving through the process quickly.

Assisted dying is not an acute or urgent service, and the Secretariat sets realistic expectations with people that the process may take up to four to six weeks from when the request is made. The pathway must allow for all appropriate safeguards and processes to be followed.

The number of people dying during the process reflects that some people are already very close to the end of their life when applying for assisted dying, as opposed to there being delays in accessing services.

## 2. Demographics of applicants

The Ministry is collecting information about the demographics of applicants, including gender and ethnicity data, which is collected based on health sector standards and protocols.

The assisted dying service is relatively new, and numbers are small. It is expected that the percentage breakdowns will change over time.

As of 31 March 2022:

- 6% of people that applied for assisted dying are Māori
- 79% are NZ European/Pākehā
- 55% were women
- 74% were aged 65 years or older
- 65% had a cancer diagnosis
- 80% of applicants for assisted dying were receiving palliative care at the time of application.

As part of the assisted dying process, the Attending Medical Practitioner (AMP) must ensure the person understands their other options for end-of-life-care. The Ministry notes that in some situations a person's request for assisted dying has led to them exploring other options, including optimising palliative care or accessing additional social or wraparound supports.

The clinical advisors liaise with other health services, such as the person's general practitioner, to help co-ordinate this care or support. This has led some people to then choose to withdraw their application for assisted dying as they felt this option was no longer needed.

**Table 1: Demographics of people that have applied for assisted dying**

		Number of people	% of applicants
Ethnic group	Māori	12	5.8
	Pacific	0	0.0
	Asian	5	2.4
	NZ European/Pākehā	162	78.6
	Other ethnic groups	27	13.1
Gender	Female	114	55.3
	Male	92	44.7
	Gender diverse	0	0.0
Age group	18-44 years	9	4.4
	45-64 years	44	21.4
	65-84 years	110	53.4
	85+ years	43	20.9
Diagnosis category	Cancer	133	64.6
	Neurological condition	21	10.2
	Other diagnosis	14	6.8
	Diagnosis not known	38	18.4
Receiving palliative care at time of application?	Yes	164	79.6
	No	39	18.9
	Not stated	3	1.5
<b>Total</b>		<b>206</b>	

Notes:

'Diagnosis not known' includes people that applied but had not yet had their first assessment with their AMP as well as those that withdrew, died before this assessment was completed, or were ineligible due to not having a terminal illness.

**Prioritised ethnicity** has been used. This means that people with more than one ethnicity have been allocated to a single ethnic group in an order of priority.

### 3. Assisted deaths

Between the Act's commencement and 31 March 2022, 66 people had an assisted death.

The Ministry is aware that people opting for an assisted death have made this experience personal to them and their whānau. Some people have chosen to include cultural or spiritual practices, such as karakia or prayer, prior to or during the administration of the medication, while others have chosen to play music that was

significant to them. People have chosen who they would like to be present, including whānau, friends, and pets, and where their death will occur.

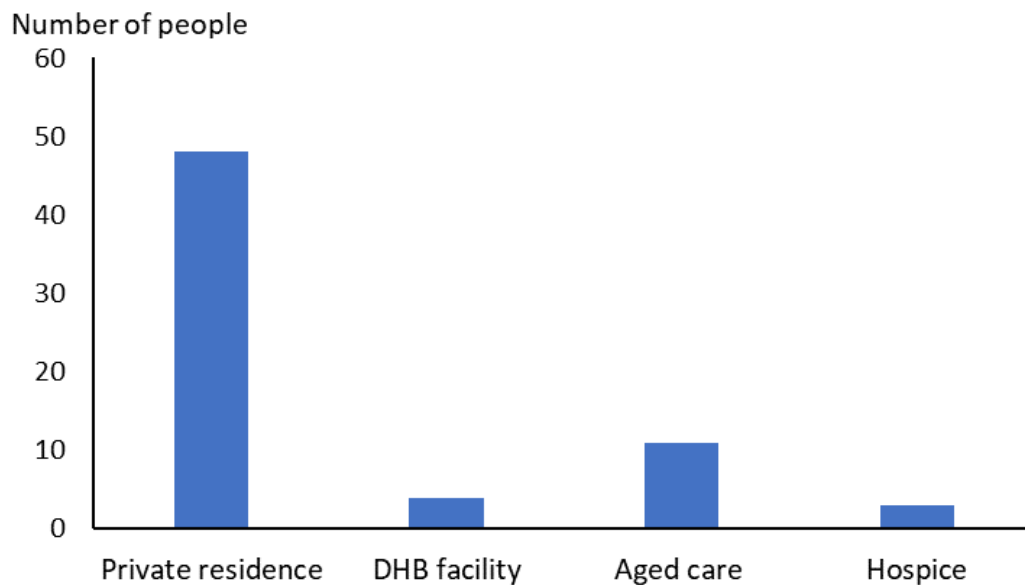
The Secretariat encourages medical and nurse practitioners to discuss these choices with the person to ensure that the service is responsive to their cultural, spiritual and social needs. Resources are provided to support these conversations in the practitioner training site.

## Locations for assisted deaths

Assisted deaths have mainly taken place in a person's home or another private residence. The breakdown by location is:

- 73% at the person's home or another private residence
- 17% in aged care facilities
- 6% in district health board facilities
- 4% in hospice facilities.

**Figure 2: Assisted deaths by location**



While most assisted deaths have taken place in a private home, some deaths have occurred in community facilities (rest homes and hospice) and district health board (DHB) facilities/public hospitals. The Ministry understands that for some community providers, allowing assisted deaths within its facility may be a complex decision due to differing viewpoints within the organisation.

The Secretariat continues to support and encourage providers to consider how to support person-centred access to assisted dying should a person in a provider's care request assisted dying. The Ministry is also continuing to work with public hospitals to streamline processes and strengthen relationships between practitioners involved in assisted dying, and hospital staff.

## Method of administration

Under the Act, there are four available options for the administration of the assisted dying medication. The person can choose from these four options and is provided with advice on the options by the AMP or Attending Nurse Practitioner (ANP). For the 66 assisted deaths, as of 31 March 2022:

- 6 people have chosen ingestion, triggered by the person
- 4 people have chosen intravenous delivery, triggered by the person
- 0 people have chosen ingestion through a tube, triggered by the AMP or ANP
- 56 people have chosen injection administered by the AMP or ANP

Each medication method has a standard administration protocol to ensure consistent, safe and quality services. As of 31 March 2022, there have been no major complications related to the administration of the medication and all deaths have occurred within expected timeframes.

The details of the protocol are only provided to practitioners involved in the assisted dying service.

## People assessed as ineligible

A person must meet strict eligibility criteria to have an assisted death. As of 31 March 2022, 40 people had been assessed as ineligible for assisted dying. In most cases, the person is found ineligible at the first assessment by the AMP.

The most common reason for a person to be ineligible for assisted dying was that they did not have a terminal illness likely to end their life within six months. A person can reapply later should their circumstances change, for example, shortened prognosis. Reapplications are considered by the Registrar on a case-by-case basis.

**Table 2: Applications assessed as ineligible by reason and assessing practitioner**

		Number of people	% of those not eligible
Reason ineligible (which criteria from the Act not met)	Not aged 18 years or over	0	0.0
	Not a New Zealand Citizen or permanent resident	2	5.0
	Not experiencing unbearable suffering unable to be relieved in a tolerable manner	16	40.0
	Not in an advanced state of irreversible decline in physical capability	17	42.5
	Does not suffer from a terminal illness that is likely to end their life within six months	26	65.0

		<b>Number of people</b>	<b>% of those not eligible</b>
	Not competent to make an informed decision about assisted dying	7	17.5
Which practitioner	Attending medical practitioner (AMP)	32	80.0
	Independent medical practitioner (IMP)	8	20.0
	Psychiatrist	0	0.0
<b>Total people assessed as ineligible</b>		<b>40</b>	<b>40</b>

Note:

A person may be found ineligible for more than one reason. The sum by reason is greater than the total number of people assessed as ineligible.

## 4. Future reporting and research

The Ministry has systems in place to collect information about assisted dying and is collecting both quantitative and qualitative data, recognising that this helps us understand both who is accessing the service and how it is being provided. Data also gives information on how the process is experienced by people, their whānau, and practitioners who provide the service.

The level of detail that can currently be reported is limited, due to the need to protect confidentiality given the low number of cases to date. The Ministry intends to include further detail in this annual report over time, with a view to supporting transparency by providing public information on the operation of the assisted dying service.

### Supporting research related to assisted dying

During the implementation, the Ministry drew from knowledge and experiences in other jurisdictions where assisted dying is available (most notably Victoria in Australia, and Canada).

The Ministry recognises that there will be a need for a body of knowledge to develop around assisted dying that is specific to New Zealand Aotearoa. This knowledge can inform both how assisted dying is provided in practice, but also wider conversations and understandings about the social and cultural implications of assisted dying, including for Māori and whānau Māori.

The Ministry considers that the development of locally relevant research and evidence related to assisted dying is best led by researchers. It plans to develop a strategy document that sets out how the Ministry will support research in this area.

# Assisted dying workforce

The delivery model for the assisted dying service enables any willing medical practitioner, nurse practitioner or psychiatrist to choose to provide the service. The practitioners involved in providing assisted dying services are from a diverse range of backgrounds – 40% specialist doctors, 40% working in general practice, 20% other (no specialist scope).

Most practitioners providing assisted dying services are on the approved SCENZ lists. (Note: practitioners must be on the list to provide services as an Independent Medical Practitioner (IMP) or psychiatrist.) Practitioners do not need to be on the SCENZ lists to provide services as an AMP or ANP, and in some cases general practitioners who are not on the SCENZ list have chosen to provide assisted dying services to their own patients at their request.

The Ministry considers supporting general practitioners to provide assisted dying services to their own patients an important factor in supporting continuity of care and choice for people accessing the service, growing the assisted dying workforce, and reducing the demand on the practitioners on the SCENZ list.

Practitioners can claim funding via a section 88 notice if services are provided outside of their existing contract with a public hospital (subject to meeting eligibility criteria). To receive funding under the Section 88 notice, practitioners must have completed the training modules. As of 31 March 2022, all practitioners had claimed funding through the section 88 notice. Assisted dying services are not currently being provided within a practitioner's contract with a public hospital.

Whether to provide assisted dying services is an individual and personal choice. Every health practitioner has the right to conscientiously object to being involved in the service. However, this does not absolve them of their obligations under the **Code of Health and Disability Services Consumers' Rights**.

## 1. SCENZ Group practitioner lists

The SCENZ Group holds lists of practitioners willing to be an attending medical or nurse practitioner, independent medical practitioner, or psychiatrist in the assisted dying process. Some practitioners elect to provide this service only to their own patients and they are not on the SCENZ list.

Expressions of interest to be on the lists opened in August 2021. The lists remain open and eligible practitioners may register to be on the lists or withdraw themselves from the lists at any time. The Ministry has a process in place with the Medical Council to confirm a practitioner's eligibility to be on the lists. The SCENZ lists and information they contain are held securely and practitioners' details are only provided with their permission.

As of 31 March 2022, 130 practitioners are registered to be on the SCENZ list. The breakdown of roles is as follows:

- 91 registered to be an attending medical practitioner
- 83 registered to be an independent medical practitioner
- 11 registered to be a psychiatrist
- 10 registered to be an attending nurse practitioner.

Medical practitioners can be on the SCENZ list for more than one role, depending on their scope of practice (AMP, IMP, psychiatrist). Most medical practitioners are choosing to be both an AMP and an IMP. Therefore the sum of counts for each role will be greater than the number of unique practitioners.

Table 3 shows the distribution of health practitioners registered on the **SCENZ Group lists** by the DHB region of their usual working location and the role(s) for which they are available.

Many practitioners are willing to travel to provide assisted dying services. Areas with low numbers of practitioners are being served by practitioners who are willing to travel to provide services and to use telehealth consultations, where appropriate.

Note: Figures below three have been suppressed for privacy reasons and are replaced with an 'S' in the table.



**Table 3: Count of practitioners by role and DHB region as of 31 March 2022**

Region	DHBs	Total unique practitioners	Attending medical practitioner	Independent medical practitioner	Psychiatrist	Nurse practitioner
Northern	Northland	40	25	28	3	6
	Waitematā					
	Auckland					
	Counties Manukau					
Midlands	Waikato	21	13	14	5	5
	Lakes					
	Bay of Plenty					
	Tairāwhiti					
	Taranaki					
Central	Hawke's Bay	25	21	15	5	5
	Whanganui					
	MidCentral					
	Wairarapa					
	Hutt Valley					
	Capital & Coast					
Southern	Nelson Marlborough	44	32	26	5	5
	West Coast					
	Canterbury					
	South Canterbury					
	Southern					
	<b>Total</b>	<b>130</b>	<b>91</b>	<b>83</b>	<b>11</b>	<b>10</b>

## 2. Workforce capacity

The number of medical and nurse practitioners willing to provide assisted dying services is sufficient to meet current demand and has remained stable since the service became available. However, the Ministry is continuing to work to grow the workforce, with a particular focus on ensuring the workforce represents the diversity of New Zealand Aotearoa, including increasing the number of Māori practitioners. Cultural safety of the practitioners providing assisted dying services is a priority as this underpins good practice. The Ministry will support practitioners' learning in this area by funding workforce training activities.

As with other areas of the health system, the capacity of the workforce has faced some pressures due to the ongoing COVID-19 response. In particular, this has affected ability and willingness to travel to provide the service. However, the option for some appointments to be through telehealth has been a helpful solution in some cases and overall COVID-19 has had minimal impact on service access and responsiveness.

It should also be noted that the number of practitioners willing to provide services is higher than was expected at the outset of the implementation, based on the experience overseas of limited practitioner availability in the first few months of service provision. The Ministry considers the significant engagement with professional groups during the implementation, as well as the availability of training and funding for providing the service, as crucial in securing an appropriately sized workforce from the beginning.

The Ministry also had the advantage of learning from overseas jurisdictions and understanding that in those countries some practitioners stopped being involved in the service after the first few months or after the first administration of the medication. The Ministry proactively put support and engagement approaches in place to prevent this, and the workforce has remained stable since the service was introduced.

## 3. Workforce training

During the implementation of the Act, the Ministry developed a variety of information and training resources for the workforce, including guidance documents, webinars, e-learning modules and an online workforce forum. This included information and resources for medical and nurse practitioners willing to provide assisted dying services, the wider health workforce, and those working in planning and management roles in health service providers.

These resources are enduring and continue to be available through **the Ministry's website** and **LearnOnline**, the Ministry's e-learning platform for health professionals. A review of the e-learning modules is planned for 2023.

## Training for medical and nurse practitioners

A set of five e-learning modules is available to medical and nurse practitioners willing to provide assisted dying services. Completing this training is one of the eligibility requirements for claiming funding under the section 88 notice.

These modules take around 1 hour 45 minutes to complete and cover the assessment process, planning for the assisted death, the administration of the medication, wellbeing and support, and a review of learning.

As of 31 March 2022, 137 medical and nurse practitioners have completed these modules. The modules have been well received by practitioners involved in the service.

## Training for the wider health workforce

It is important that all health care professionals understand their rights and responsibilities under the Act, even if they are not involved directly in providing assisted dying services. For example, a person may raise the topic of assisted dying with any health practitioner, and the health practitioner needs to be able to respond appropriately, including in cases where the practitioner may conscientiously object.

There are three e-learning modules that it is recommended all health care professionals complete if they care for or support people who may access this service. These modules cover the End of Life Choice Act, the assisted dying care pathway, and responding when a person raises assisted dying.

The module about responding when a person raises assisted dying is based on a conversation guide and handbook that was developed by clinical communication experts. These resources were co-designed with clinicians and consumers and are shaped by the principles and articles of Te Tiriti o Waitangi.

Table 4 outlines uptake on the three training modules available to the wider health workforce as of 31 March 2022.

Note: These figures are likely to underestimate the total workforce trained, as the Ministry is aware that some professionals completed the modules with their team as part of a group learning and discussion session.

**Table 4: Number of people accessing the wider health workforce training**

Module	Number completed, as 31 March 2022
The End of Life Choice Act 2019: Overview	9501
The Assisted Dying Care Pathway: Overview	3180
Responding when a person raises assisted dying	2943

## 4. Supporting practitioners

The Ministry is aware that providing an entirely new health service may be challenging and unpredictable for practitioners. Choosing to provide an assisted dying service may also have additional complexities due to the sensitive nature of this mahi, and that practitioners are providing services as individuals, and often in unfamiliar environments, such as people's homes. The Ministry is working to address these concerns and reduce isolation for practitioners by offering opportunities for support and connection.

The clinical advisors are in regular contact with the practitioners throughout the process. Together with the Registrar, the advisors provide clinical and pastoral support, including offering follow-up conversations after the administration of the medication. In addition to one-on-one support, the clinical team run regular sessions that allow practitioners to meet each other and discuss any questions or concerns.

Virtual peer network sessions run by the Ministry enable practitioners to share case studies and discuss their experiences of being involved in the service. In response to practitioner feedback, these sessions are run on a quarterly basis. Practitioners have given consistently positive comments about the value of these events in providing an opportunity for both connection and learning.

The Ministry also plays a role in supporting regional peer networks connecting practitioners with others in their local area. These peer networks are run by practitioners and in some areas are already well established. However, this varies due to the spread of practitioners across the country. Strengthening support for these less established areas is a focus for the Ministry moving forwards.

There is ongoing work to develop further approaches to support practitioners and ensure the sustainability of the workforce. These include creating a practitioner handbook to offer practical advice about the different steps in the assisted dying process and running an in-person workforce forum in late 2022 that allows practitioners to connect *kanohi ki te kanohi* (face to face).

# Feedback, queries, and complaints

## 1. Receiving feedback, queries, and complaints

Feedback, queries, and complaints are an important part of understanding the experiences of accessing and providing assisted dying, as well as public perception of and interest in the service.

The Ministry welcomes feedback in all forms, and there are several channels for providing it. These include:

- through the ongoing conversations a person, their whānau or the practitioner has with the clinical advisor
- to the Secretariat directly via email ([AssistedDying@health.govt.nz](mailto:AssistedDying@health.govt.nz)) or phone (0800 223 852), or by requesting a follow-up phone call/meeting
- by making a formal complaint.

People can also contact the Ministry about the assisted dying service through existing channels, such as writing to the Ministry directly or submitting an Official Information Act (OIA) request.

Feedback, queries, and complaints are logged as part of ongoing quality improvement processes.

## 2. Complaints process and responsibilities

Anyone can make a complaint about their own or someone else's experience when using the assisted dying service. Complaints can be made directly to the Secretariat by email, phone or filling in an online form. Complaints are considered by either the Registrar or the Manager for Regulatory Assurance, depending on the topic of the complaint.

The Registrar is responsible for overseeing all complaints related to practitioners providing the Assisted Dying Service. The Registrar may also refer complaints to an appropriate authority should that be required. This may include the Medical Council, the Nursing Council, the Health and Disability Commissioner (HDC), or the New Zealand Police.

The Registrar works closely with the HDC, and the Ministry has a memorandum of understanding in place to support co-operation and appropriate information sharing between these organisations.

### 3. Summary of complaints

As of 31 March 2022, the Secretariat has not received any complaints about breaches of the Act.

As of 31 March 2022, the Secretariat has received four formal complaints related to the assisted dying service. Three of these complaints have been closed, one remains open and under investigation. Table 5 outlines a summary of these complaints and how they were actioned.

**Table 5: Complaints summary**

Complainant	Subject of the complaint	Action	Outcome
Applicant	A practitioner’s interpersonal style and communication	This complaint was upheld and was resolved between the applicant and the practitioner with assistance from the Secretariat. The Registrar provided mentoring to the practitioner. The complaint was not referred to another regulatory body.	Closed
Applicant	Delay in being connected with an attending medical practitioner	This complaint was upheld and resolved with an apology from the Secretariat. The applicant was connected within a day of making the complaint. The complaint was not referred to another regulatory body.	Closed
Applicant	Found ineligible and was unhappy with the outcome	This complaint was not upheld as the decision of ineligibility was found to comply with the Act. Feedback was logged and will be considered when the Act is reviewed in 2024.	Closed
Family member	Experience of assisted death in a public hospital	This complaint was upheld and was referred to the Health and Disability Commissioner.	Under investigation by the HDC

### 4. Summary of feedback

Some people and their whānau have proactively provided feedback to the Ministry about their experiences. The feedback has been predominantly positive to date. The Ministry acknowledges that as this feedback is proactively provided, it may not be reflective of all people’s experiences of the service.

The Ministry has also received constructive feedback from people, their whānau and practitioners on other topics that have not been lodged as formal complaints.

Analysis of the feedback received to 31 March 2022 reveals three general themes:

**1. Positive outcomes**

This theme is characterised by people being pleased with the availability of the option and the process, as well as the support from the clinical advisors and quality of the care provided by the involved practitioners. Whānau describing the assisted death being 'peaceful' and 'dignified'. Practitioners felt supported and competent.

**2. More integration with wider health services**

There were observations from whānau and practitioners that existing health services (palliative, hospice, DHB, GP, oncology etc) were still working out how assisted dying interacted with existing services and how to work effectively with the assisted dying service. Understanding how the assisted dying service processes interact with their systems was still in a preliminary stage.

**3. Legislation**

The legislation is welcome, and applicants were relieved that this service is available. The legislation is not as enabling as some people were hoping for with the criteria making an assisted death more restrictive than overseas jurisdictions. This was coupled with hope for a broadening of criteria over time.

The feedback suggesting changes to the End of Life Choice Act 2019 has been noted for consideration when the Act is reviewed in 2024. Other feedback will be used to inform the secretariat's work programme through the year.

## Learning from person and whānau experiences

The Ministry plans to keep assessing and undertaking work to understand how to best capture insights from people to improve the experiences of people accessing assisted dying or those supporting someone seeking an assisted death. This process must be carefully managed given the sensitive nature of this topic, and the need to reflect and uphold the emotional wellbeing of any participants.

## 5. Summary of queries and Official Information requests

The Ministry notes that there is public interest in assisted dying outside of people who are accessing or providing the service. This is reflected in the queries and Official Information requests from individuals, interest groups and the media since the service became available on 7 November 2021.

Queries and requests have generally been related to service usage, practitioner availability, and the application and assessment process.

Common themes from these queries and requests are considered as part of ongoing improvement of public information and reporting.

Table 6 outlines a summary of the queries and requests as of 31 March 2022.

**Table 6: Queries and requests related to Assisted Dying**

Query type	Number
OIA requests	10
Media requests	25
Written Parliamentary Questions	12

## 6. Concluding Remarks

The Ministry has implemented the End of Life Choice Act 2019 and has established the assisted dying service in New Zealand Aotearoa. In the coming year, the Ministry will continue to improve the service through working with Te Apārangi and the statutory committees, using invaluable feedback and applying any recommendations from the implementation review. Quality improvement will provide an opportunity to refine the support provided to people and whānau who engage with the service.

The Ministry will seek to undertake collaborative research to contribute to the body of knowledge to deliver an effective, compassionate, person-centred service. It is also important to grow the diversity of the workforce providing assisted dying services in New Zealand Aotearoa.