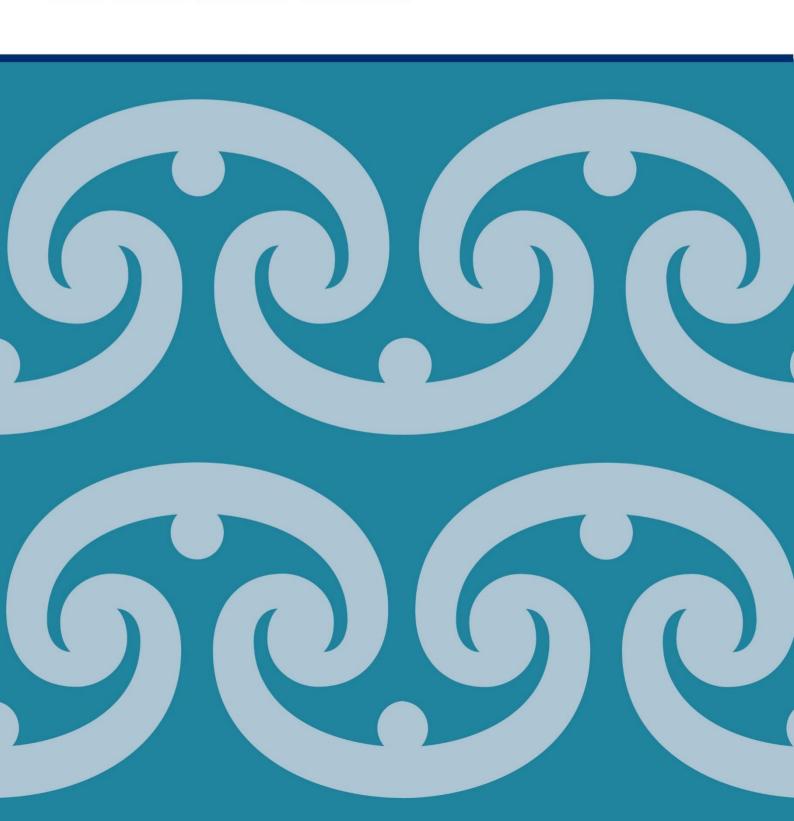




Assisted Dying Service – Ngā Ratonga Mate Whakaahuru

Registrar (assisted dying) Annual Report to the Minister of Health –June 2023



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Foreword

Tēnā koutou,

I am pleased to share the first full year report for the Assisted Dying Service. This report covers the period from 1 April 2022 to 31 March 2023. It outlines key elements of the service and provides a summary of service activity for the reporting period. For more detailed information about the establishment of the service I encourage you to read my previous report.

This year has seen the assisted dying service continue to mature. Building on the work undertaken as part of implementation, there has been a strong focus on providing a safe, quality and trusted service. I am encouraged by the positive feedback from patients and whānau, health professionals, and other stakeholders involved in the service so far. This feedback has enabled continuous quality improvement and optimisation of service provision. I look forward to seeing the service progress over the next year.

I'd like to acknowledge the patients and whānau who have chosen to engage with the service. I continue to see and hear positive stories about how the service has allowed people at the end of their life to have control and dignity over their death.

I want to thank the practitioners involved in providing the service for their passion, empathy and hard work. Taking part in a new health service can be a complex challenge and their experience and high-quality work has been heartening.

On 6 March 2023, the operational aspects of the service were transferred to Te Whatu Ora. This provides an exciting opportunity for our agencies to collaborate and improve the service for New Zealanders. I look forward to continuing my work with the Assisted Dying Secretariat at Manatū Hauora and our renewed focus on monitoring and regulation.

Ngā mihi nui

Dr Kristin Good Registrar (assisted dying)

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Introduction

About this report

Manatū Hauora - the Ministry of Health (the Ministry) 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 required by 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 1 April 2022 to 31 March 2023 and is the first full year report published since the Act came into force on 7 November 2021.

A copy of the last report is available on the Ministry's website.

Role of the Registrar (assisted dying)

The Registrar is a statutory role under the Act, who is 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
- establishing and maintaining a register of approved forms for the assisted dying process, including consulting the Privacy Commissioner as required under the Act
- receiving and managing complaints, including referring them to the Health and Disability Commissioner, New Zealand Police, and/or other appropriate authorities
- taking any action as directed by the End of Life Review Committee.

The assisted dying service in New Zealand Aotearoa

Mate whakaahuru

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

These kupu were used by Māori media and proficient te reo speakers prior to the Act coming into force. Manatū Hauora 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.

The End of Life Choice Act 2019

The Act came into force on 7 November 2021. It 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
- 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.

Standard of Care and Clinical Guideline

The assisted dying service operates 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.

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.

Supply of medications

Two hospital pharmacies are responsible for dispensing the prescriptions for the assisted dying medication. This centralised approach supports consistency, safety, and access. The medication kits are delivered securely, directly to practitioners across the country in a timely manner. The pharmacies are also responsible for medication reconciliation and disposal.

As a result of the transfer of some functions to Te Whatu Ora, as part of the reforms of the health and disability system, Te Whatu Ora has the continued relationship with these pharmacies.

The Support and Consultation for End of Life in New Zealand Group, the End of Life Review Committee and Te Apārangi: Māori Partnership Alliance

The Support and Consultation for End of Life in New Zealand (SCENZ) Group, the End of Life Review Committee and Te Apārangi: Māori Partnership Alliance continue to be critical groups supporting the assisted dying service.

The SCENZ group and Te Apārangi continued to provide advice and expertise as the assisted dying service began maturing over the last year. Te Apārangi will shift its focus towards providing governance and strategic oversight to support the Secretariat's role of monitoring and regulating the service.

More information about the **SCENZ group** and the **End of Life Review Committee** can be found on the Ministry's website and in the previous Registrar's report. Further information about Te Apārangi can also be **found on the Ministry's website**.

The Regulatory Services Māori Caucus

The Māori Caucus was established in late 2022 and is supported by the Assisted Dying Secretariat. The caucus was established at the request of Māori members of Te Apārangi and SCENZ. This provides a forum for Māori members of Regulatory Services committees to collaborate on topics of common interest, to promote Te Tiriti and equity lenses to the Regulatory Services work and to support the Regulatory Services directorate's responsibilities under section 7 of the Pae Ora (Healthy Futures) Act 2022.

The Caucus membership is drawn from the statutory and other committees supporting the Regulatory Services workplan, specifically, the Support and Consultation for End of Life Choice in New Zealand (SCENZ), the End of Life Review Committee (Review Committee), and Te Apārangi.

The Caucus meets on a regular basis.

The Assisted Dying Secretariat

The Assisted Dying Secretariat (the Secretariat) is part of the Regulatory Assurance team at Manatū Hauora. The Secretariat has a regulatory and monitoring function to ensure compliance with the Act. The Registrar (assisted dying) sits within the Secretariat.

Implementing the Act

Following the 2020 referendum, Manatū Hauora was responsible for implementing the Act and establishing an assisted dying service in Aotearoa New Zealand. The Ministry remains the responsible agency for administering this legislation.

The principles of Te Tiriti o Waitangi, as understood by the Ministry in the 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 health and disability organisations led by Māori, ensuring Te Tiriti o Waitangi commitments were reflected in all aspects of the service, and including Māori in formal partnerships and governance roles.

For more detailed information about the establishment of the service, please refer to the previous report available **here**.

Functions transfer

Some functions of the Regulatory Assurance team within the Ministry transferred from Manatū Hauora to Te Whatu Ora on 6 March 2023 as part of the wider reforms to the health and disability system of New Zealand.

This means most of the clinical and operational functions that previously sat within the Assisted Dying Secretariat at Manatū Hauora are now the responsibility of Te Whatu Ora. This has allowed the Ministry to re-focus on regulation of the Act, and reviewing and monitoring the assisted dying service independently from service provision.

The functions officially transferred on 6 March 2023. Both agencies continue to work closely to ensure services are safe, accessible and equitable.

A renewed focus on monitoring and regulation

With its renewed focus on monitoring and regulation, the Assisted Dying Secretariat, as part of Manatū Hauora, is maintaining existing regulatory functions and creating new monitoring processes. This aligns with the Ministry's core role as chief steward of the health system.

Feedback about the service and data insights will continue to drive improvements to the way we monitor and regulate the service. We will also work closely with Te Whatu Ora, when needed, for any operational improvements that might be signalled from the feedback and data.

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. The review will begin over the next year. The Act will then be reviewed at least every five years.

Reporting and Service Activity

The Ministry, through Te Whatu Ora, collects data about the assisted dying service as part of its role in overseeing and monitoring the service. Collecting this information 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. This drives continuous improvement of the service and results in better outcomes for those accessing the service.

This data is drawn from the application forms for assisted dying, which are held centrally by the Secretariat.

Reporting

Manatū Hauora recognises the interest in the performance of the service by media, the public and academics and has routinely published quarterly updates which provide a snapshot of service activity for the period it relates to. A report summarising the first year of service (7 November 2021 – 6 November 2022) is also available on the Ministry website **here**. Service activity reporting is now the responsibility of Te Whatu Ora.

The level of detail that can currently be reported is limited, due to the need to protect confidentiality of individuals using the service when there are a low number of cases to date. The Ministry and Te Whatu Ora will consider expanding reporting as numbers increase over time.

Overview of assisted dying applications

The data provided below reflects a summary of individuals' interactions with the Assisted Dying Service, from 1 April 2022 to 31 March 2023. Accordingly, medical assessments and outcomes may refer to applications initiated in the Registrar's prior report. Between 1 April 2022 and 31 March 2023, there were 807 new formal applications for assisted dying. The current report also contains information for 45 applications which were ongoing at the end of the last Registrar report.

As of 31 March 2023, 111 people were still in the process of assessment or in preparation for assisted dying, and 328 people had had an assisted death. The remaining applications had not progressed to an assisted death due to:

- The application being found to not comply with the Act
- The applicant withdrawing their application

- The applicant being found ineligible or not competent to give consent at or following assessment
- The applicant dying as a result of underlying conditions.

The assisted dying service is person-centred, and the time taken from application through to assisted death varies based on the applicant's 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 aims to set realistic expectations with people, that the process from initial application through to determination of eligibility may take up to six weeks. The Act stipulates the processes and steps that need to be followed to ensure a safe and quality service. For those found eligible following assessment, the average time between initial formal application and eligibility approval is 18 days.

While individual circumstances specific to each case can impact the length of time between application and determination of eligibility, the number of people dying during the assessment process is reflective of how close to the end of life some applicants are, as opposed to there being significant delays in accessing services.

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. The Ministry and Te Whatu Ora will consider expanding reporting as more data is collected.

Of the 807 new applications received over the year:

- 81% were NZ European/Pākehā
- 5% were Māori
- 52% were female/wāhine
- 77% were 65 years or older
- 76% were receiving palliative care at the time of the application
- 68% had a diagnosis of cancer.

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. This may include optimising palliative care or accessing additional social or wraparound supports, and this has resulted in them rescinding their application for assisted dying.

Additionally, the clinical advisors liaise with other health services, such as the person's general practitioner, to help co-ordinate their 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: Demographic summary of new applications

Demographic summary: New Applications (N= 807) Number of % of					
1 April 2022 – 31 March 2023 people ³ applications					
Ethnic group ¹	Māori	40	4.96		
	Pacifica	5	0.62		
	NZ European/Pākehā	654	81.04		
	Asian	15	1.86		
	Other	109	13.51		
Sex	Female/wāhine	420	52.04		
	Male/tāne	387	47.96		
	Gender diverse	0	0		
Age group	18-44 years	8	0.99		
	45-64 years	179	22.18		
	65-84 years	471	58.36		
	85+ years	149	18.46		
Diagnosis ²	Cancer	546	67.66		
	Neurological condition	88	10.90		
	Chronic respiratory disease	41	5.08		
	Cardiovascular condition	51	6.32		
	Other organ failure	25	3.10		
	Other diagnosis	51	6.32		
	Not known ⁴	117	14.50		
Receiving palliative care at	Yes	615	76.21		
time of application?	No	189	23.42		
	Not stated	3	0.37		
Reported a disability at	Yes	153	18.96		
time of application?	No	645	79.93		
	Not stated	9	1.12		

Notes:

- Total ethnicity has been used. This means that individuals reporting more than one ethnicity are included within each category to which they identify. In the current report, individual identification as 'European' has been included within the 'Other' category, distinct from NZ European/Pākehā
- 2. Total diagnosis has been used. This means that individuals presenting with multiple diagnoses are included within each applicable diagnostic category.
- 3. Repeat applications are included as unique instances. This means that in cases where an individual submits multiple applications during this period, their information is recorded in the demographic data each time.

4. 'Diagnosis not known' includes individuals who have applied but have not yet completed their first assessment with their AMP, as well as those who have withdrawn before assessment, died before this assessment was completed, or were ineligible due to not having a terminal illness.

Assisted deaths

Between 1 April 2022 to 31 March 2023, 328 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.

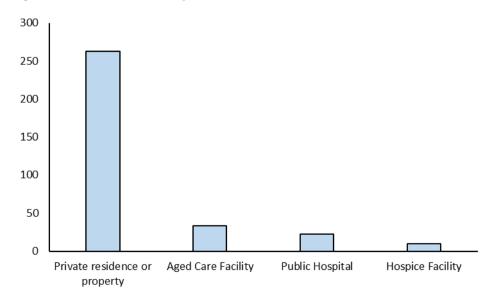
The Secretariat encourages medical and nurse practitioners to discuss these choices with the person to ensure that the service is responsive to their cultural, spiritual and social needs. Resources are provided to support these conversations in the practitioner training.

Locations for assisted deaths

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

- 80% at the person's home or another private property
- 10% in an aged care facility
- 7% in a public hospital
- 3% in hospice facilities.

Figure 1: 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 hospices) and facilities/public hospitals managed by Te Whatu Ora. 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 Te Whatu Ora to streamline processes and strengthen relationships between practitioners involved in assisted dying, and hospital staff.

Method of administration

Under the Act, there are four options for the administration of the assisted dying medication. The person is provided with advice on each of the options by the AMP and then selects their preferred option. For the 328 assisted deaths, between 1 April 2022 to 31 March 2023:

- 15 people have chosen ingestion, triggered by the person
- 7 people have chosen intravenous delivery, triggered by the person
- 4 people have chosen ingestion through a tube, triggered by the AMP/ANP
- 302 people have chosen injection administered by the AMP/ANP.

Each medication method has a standard administration protocol to ensure consistent, safe and quality services. As of 31 March 2023, 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.

Assessments completed during this period

A person must meet strict eligibility criteria to have an assisted death.

After an application is submitted, an initial assessment is made by an AMP. This practitioner reviews eligibility against the criteria as outlined in the Act. The IMP provides an independent second assessment. For more information relating to practitioner roles, please refer to the **Ministry's website** or the End of Life Choice Act 2019.

Applications may be found ineligible at each of these assessments for a variety of reasons. For more information on ineligibility outcomes at assessment for this first year of service please see Table 2.

Following eligible outcomes at both AMP and IMP assessments, the AMP meets with the applicant for further discussion relating to eligibility and the assisted dying process. At this time, some previously eligible applicants may be found not competent to continue.

Table 2: Assessment outcomes

	Outcome of assessment	Number of assessments
AMP Assessments	Eligible	682
(N = 794)	Ineligible	112
IMP Assessments	Eligible	558
(N = 578)	Ineligible	20
Eligibility Discussion Following Assessment	Eligible	515
(N = 520)	Ineligible	5

Ineligibility summaries: Assessed by AMP and IMP

Not all applications made to the Assisted Dying Service will result in an assisted death; some individuals may be assessed as ineligible. Reasons for ineligibility vary, and may relate to an applicant's age, status as a New Zealand citizen/resident, or considerations relating to their health and physical decline. For more information about eligibility criteria, please refer to our **website**.

Table 3 outlines a summary of ineligibility decisions at each stage of assessment by AMP and IMPs. Being found eligible at AMP assessment stage and ineligible at IMP assessment stage may occur due to a number of reasons, including but not limited to a change in personal circumstances impacting eligibility and/or a change in prognosis.

Table 3: Ineligible decisions

The applicant is	Ineligible at AMP assessment (112)	Ineligible at IMP assessment (20)
Not a New Zealand Citizen/Permanent resident	5 (4.5%)	0
Not aged 18 or over	0 (0%)	0
Not experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable	60 (53.6%)	13 (65.0%)
Not in an advanced state of irreversible physical decline	54 (48.2%)	7 (35.0%)
Not suffering from a terminal illness that is likely to end their life within 6 months	82 (73.2%)	13 (65.0%)

Note:

Total reasons for ineligibility have been applied. This means that individuals may be found to be ineligible across multiple criteria, and each observed reason is included in the report.

Application not progressed to an assisted death

Table 4 summarises applications where an assessment had occurred (at AMP or IMP), but the applicant had not progressed to an assisted death. This table specifically relates to applications not accounted for as ineligible at the AMP or IMP assessments (as per Table 3). Additionally, this table includes applications which are still open at the time of review and are therefore not associated with a known outcome.

There are several reasons why an individual may not continue their application to an assisted death. These include being found ineligible following a prior eligible outcome or becoming unable to make an informed decision/give consent. Individuals may also withdraw their application or die of an underlying condition/terminal illness at any point during the application process or before their scheduled assisted death. Furthermore, individual applications may be found non-compliant with the Act during final review before an assisted death may occur.

Table 4: Assessment outcomes

	Number of assessments
Died in process	202
Lost competence	48
Lost eligibility	5
Decided to withdraw	17
Application found to be not compliant with the Act at final review	4
Application is still open at the time of review	111

Assisted dying workforce

The Act enables any willing medical practitioner, nurse practitioner or psychiatrist to choose to provide assisted dying services as described in the legislation. The practitioners involved in providing assisted dying services are from a diverse range of backgrounds.

Ensuring the workforce represents the diversity of Aotearoa New Zealand, including increasing the number of Māori practitioners, remains a focus for both Manatū Hauora and Te Whatu Ora. Cultural safety of the practitioners providing assisted dying services is a priority as this underpins good practice.

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**.

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.

Medical practitioners can be on the SCENZ list for more than one role, depending on their scope of practice (AMP, IMP, Psychiatrist). The SCENZ group also holds a list of Nurse Practitioners. For more information about the SCENZ group and practitioner roles, please refer to the **Ministry's website**. The SCENZ lists and information they contain are held securely and practitioners' details are only provided with their permission.

A growing number of health practitioners have chosen to provide services as an AMP for their own patients without registering to be included as a SCENZ member, and this is our fastest growing workforce. Some of these health practitioners have subsequently chosen to join the SCENZ list, and to make themselves available to additional patients.

As of 31 March 2023, 148 practitioners are registered to be on the SCENZ lists. Sixtynine practitioners have elected to perform both the attending medical practitioner (AMP) and independent medical practitioner (IMP) roles. The breakdown of roles is as follows:

- 103 registered to be an attending medical practitioner
- 88 registered to be an independent medical practitioner
- 13 registered to be a psychiatrist
- 13 registered to be an attending nurse practitioner.

Table 5: Count of practitioners by role and region as of 31 March 2023

Region	Attending medical practitioner	Independent medical practitioner	Both AMP and IMP	Psychiatrist	Nurse practitioner
Northern	27	26	20	S	6
Midlands	17	19	12	S	S
Central	24	16	15	S	S
Southern	35	27	22	5	S
Total	103	88	69	13	13

^{*}Note: Due to low numbers, precise numbers by region of Nurse Practitioners and Psychiatrists are suppressed.

Workforce training

During implementation of the Act, the Ministry developed a variety of information and training resources for the workforce. These resources continue to be available to practitioners and other health care professionals to understand their rights and responsibilities under the Act. Details of each of the modules can be found in the previous report.

Table 6 outlines uptake on the three training modules available to the wider health workforce as of 31 March 2023.

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 6: Number of people accessing the wider health workforce training

Module	Number completed, as 31 March 2022	Number completed, as 31 March 2023
The End of Life Choice Act 2019: Overview	9501	10881
The Assisted Dying Care Pathway: Overview	3180	3930
Responding when a person raises assisted dying	2943	3503

Workforce training is now the responsibility of Te Whatu Ora and includes training for medical and nurse practitioners providing assisted dying services, training for the wider health workforce and support for practitioners.

Supporting practitioners

Choosing to provide an assisted dying service may be challenging for practitioners 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.

Virtual peer network sessions offered by Manatū Hauora ran throughout 2022 and early 2023 and enabled practitioners to share case studies and discuss their experiences of being involved in the service. In response to practitioner feedback, these sessions were run on a quarterly basis. As a result of the functions transfer, Te Whatu Ora has been facilitating these discussions since March 2023.

The Assisted Dying Forum 2022

Manatū Hauora successfully hosted a workforce forum on 26 and 27 November 2022 in Wellington to mark the first year of the Assisted Dying Service being available. The forum provided an opportunity for people from the health and disability sector to come together to share their experiences of the assisted dying service and look ahead to the ongoing development of the service. The setting provided a safe space for practitioners to have open discussions, network with their peers and meet the Assisted Dying Secretariat in person.

The forum included presentations, panel discussions and practical breakout sessions presented by both Manatū Hauora staff and guest speakers. The guest speakers included the Human Rights Commission, Te Apārangi: Māori Partnership Alliance, assisted dying service providers and practitioners from other end of life care services such as palliative care.

There is ongoing work to develop further opportunities to support practitioners and ensure the sustainability of the workforce.

Feedback, queries, and complaints

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
- via email (AssistedDying@health.govt.nz) or phone (0800 223 852), or by requesting a follow-up phone call/meeting
- by completing a feedback form
- 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.

Complaints process and responsibilities

Anyone can make a complaint about their own or someone else's experience when using the assisted dying service.

The Registrar is responsible for all complaints about the appropriateness of the conduct of any health practitioner under the Act. The Registrar may also refer complaints to Te Whatu Ora or an appropriate authority should that be required. This may include the responsible authority, 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.

Complaints

The Registrar and Secretariat keep a central record of all complaints directly received about the service. The Registrar (assisted dying) will also receive details of complaints about the assisted dying service made to the HDC, an Authority or the New Zealand Police under section 28 of the Act.

The tables below contain a summary of all complaints received by the Registrar (assisted dying) and the Secretariat at Manatū Hauora, the Medical Council and the HDC between 1 April 2022 and 31 March 2023.

No complaints have been received by the New Zealand Police or the Nursing Council in relation to the assisted dying service during the reporting period.

Table 7: Summary of complaints received by the Registrar (Assisted Dying) and the Secretariat at Manatū Hauora directly

	Complainant	Subject	Action	Outcome
1	Public	A media outlet making public the details of an assisted death.	Substantiated. Secretariat worked with media outlet to amend their information to align with the Act.	Closed
2	Public	A media outlet screening details about assisted deaths.	Not substantiated. No action was required.	Closed
3	Applicant	Desire for urgency with IMP assessment.	Not substantiated. Secretariat actively worked with applicant to assign doctor and time to second appointment was not excessive.	Closed
4	Practitioner	Difficulty accessing patient medical notes under urgency.	Partially substantiated. Secretariat engaged with complainant, recognised area for improvement.	Closed
5	Practitioner	Requirements for death report.	Partially substantiated. The detail needed was clarified with the Review Committee and distributed to practitioners.	Closed
6	Practitioner	Difficulty accessing case management system.	Not substantiated. Practitioner provided with support by the Secretariat to access and use the system.	Closed
7	Public	Complaint about mental health services.	Not substantiated. Referred to relevant mental health service by the Secretariat.	Closed
8	Whānau of Applicant	Delay accessing service through health practitioner.	Substantiated. Referred to HDC for investigation by the Registrar.	Under investigation by HDC

	Complainant	Subject	Action	Outcome
9	Practitioner	Facility poorly accommodating applicant in their request for an assisted death.	Substantiated. Issue raised with facility management by Secretariat.	Pending closure
10	Public	Difficulty accessing information about the service.	Not substantiated. Member of the public provided with support by the Secretariat to navigate the system.	Closed
11	Practitioner	Facility not having adequate resources to support a request for assisted death.	Substantiated. Issue raised with facility management by Secretariat.	Closed
12	Practitioner	Concern about actions of another practitioner.	Being investigated by Registrar and Secretariat.	In progress
13	Practitioner	Concern about actions of another practitioner.	Referred to the HDC by the Registrar. HDC advised concluding due to lack of engagement.	Pending closure
14	Whānau of Applicant	Concern about the outcome of an assessment.	Not substantiated. Discussed concerns with complainant and provided further information.	In progress
15	Practitioner	Facility obstructive in engaging with practitioners involved in the service.	Redirected to facility involved with case.	Closed
16	Referral from HDC	Concern about practitioner behaviour.	Seeking further information, investigation ongoing.	In progress

Table 8: Summary of complaints received by the Medical Council directly

	Subject	Action
1	Complaint regarding the quality of information supplied by a doctor which was used in the assessment of an application for an assisted death.	Referred to the HDC by the Medical Council.

Table 9: Summary of complaints being considered by the HDC including those referred by the Registrar or sent from the Medical Council

1	The complainant raised concerns on behalf of the consumer about a competency assessment and the adequacy and communication of policies and procedures related to assisted dying at an Aged Residential Care facility.	Investigation: Reviewing responses
2	Received from the Registrar (assisted dying). The complainant raised concerns over the qualifications and professional conduct of a health practitioner involved in the assessment of a consumer.	Under assessment: With decision maker

3	Received from the Medical Council. The complainant raised concerns about the prognostic information supplied as part of an 'eligible' first assessment for assisted dying by another practitioner.	Under assessment: Receiving clinical advice
4	Received from the Registrar (assisted dying). The complainant raised concerns on behalf of the consumer about a lack of access to assisted dying.	Under assessment: Receiving clinical advice
5	The complainant raised concerns about their inability to access assisted dying.	Under assessment: Awaiting information from provider
6	Received from the Registrar (assisted dying). The complainant raised concerns on behalf of the consumer following the consumer's assisted death. The complainant is concerned about the actions and attitude toward the consumer and their family prior to the consumer's assisted death by a health practitioner involved in the consumer's care.	Assessment concluding due to lack of engagement by complainant and consumer's family
7	The complainant raised concerns about a health practitioner initiating a conversation about assisted dying with a suicidal young person.	Assessment concluding: Preparing provisional decision
8	The initial complaint was about the incompatibility of a provider's health record system with advance directives.	Under assessment: Awaiting further information from provider

Feedback

The Ministry and Te Whatu Ora continue to receive feedback from people and their whānau about their experiences with the assisted dying service. The feedback has been predominantly positive to date and has helped us to identify opportunities for improvement and to shape service delivery.

The Ministry acknowledges that as this feedback is proactively provided, it may not be reflective of all people's experiences of the service.

A feedback form which was introduced in late 2022 aims to reduce the barriers to people and whānau wishing to provide feedback about the service. The Ministry is aware of the sensitive nature of this topic, and the need to reflect and uphold the emotional wellbeing and privacy of anyone who shares their feedback.

Feedback is critical to improving the quality, safety and equity of the service and the Ministry retains its interest in receiving feedback on the service as part of good monitoring and regulation.

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/activity, practitioner availability, and the functions of practitioners involved in the service.

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

Table 10 outlines a summary of the queries and requests responded to during each reporting year. Please note, queries related to the operational aspects of the service were formally transferred to Te Whatu Ora for a response from 6 March 2023 onwards and are not reflected in these figures.

Table 10: Queries and requests related to Assisted Dying

Query type	7 November 2021 – 31 March 2022	1 April 2022 – 31 March 2023
OIA requests	10	14
Media requests	25	30
Written Parliamentary Questions	12	0

Concluding Remarks

I am pleased to be able to share some of the successes of the first full year of service provision and the knowledge that New Zealanders can access a safe and trusted service. The assisted dying service continues to mature. We will continue to grow our collaborative relationship with Te Whatu Ora as the operational arm of the service. I look forward to the next year with our continued focus on regulation, monitoring and improvement to ensure patients are receiving a safe, equitable and accessible assisted dying service.