

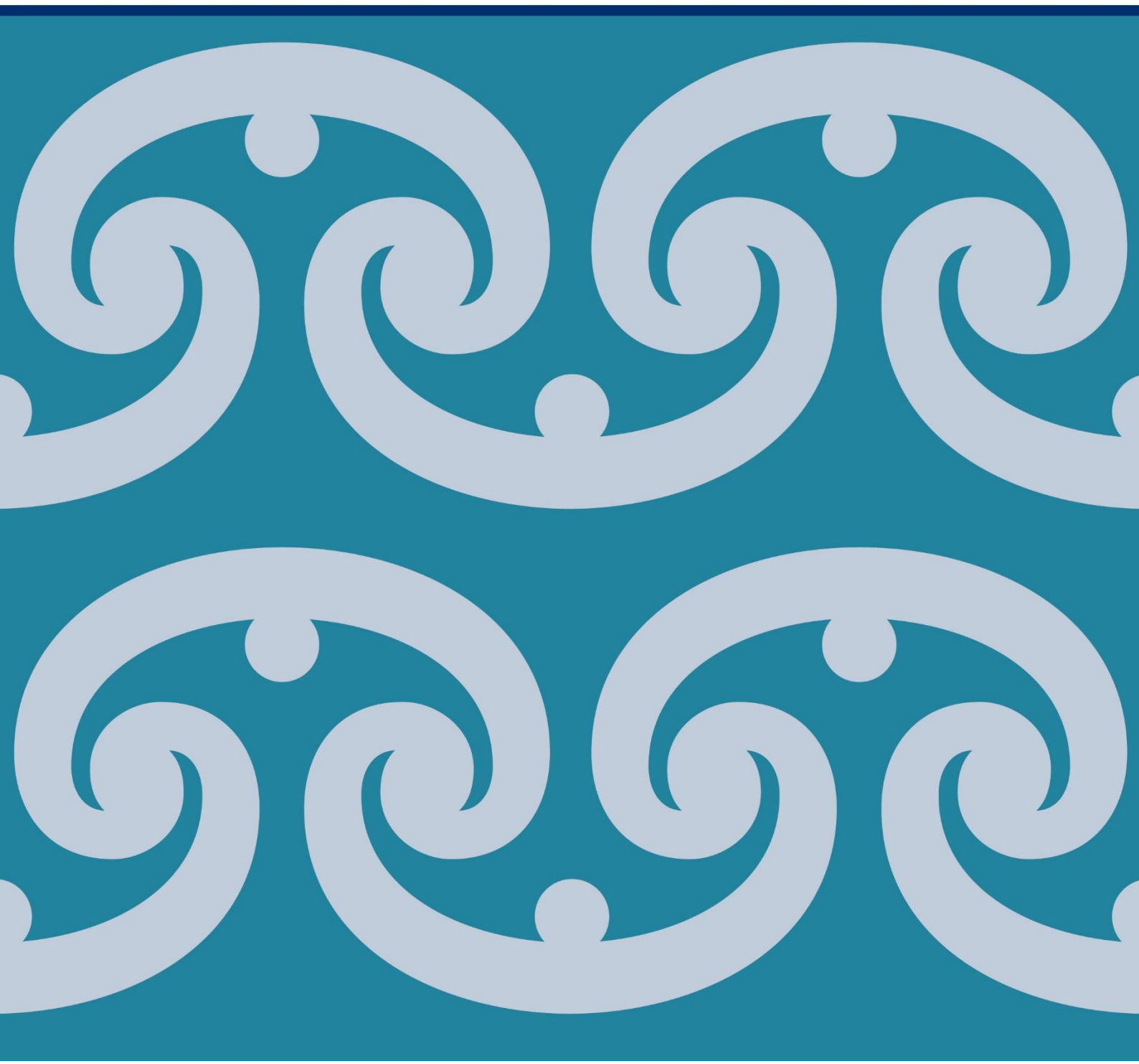


**Te Kāwanatanga o Aotearoa**  
New Zealand Government



# **Review of the End of Life Choice Act 2019**

2024





# **Review of the End of Life Choice Act 2019**

2024

Presented to the House of Representatives  
pursuant to section 30 of the End of Life Choice  
Act 2019



## Need to talk?

This report includes content that readers may find distressing, including detailed references to suffering at the end of life, and suicide.

Assisted dying is a sensitive topic and may be difficult for some people. Phone or text **1737** to speak with a counsellor anytime, for free.

## Acknowledgements

The Ministry of Health – Manatū Hauora acknowledges the important and valuable contributions made to this review by all participants.

We would particularly like to acknowledge the contributions of people who were interviewed about their experiences supporting loved ones to receive assisted dying, and the practitioners we spoke to who provide the Assisted Dying Service.

Ngā mihi nui ki a koutou katoa. Thank you to you all.

Citation: Ministry of Health. 2024. *Review of the End of Life Choice Act 2019*.  
Wellington: Ministry of Health.

Published in November 2024 by the Ministry of Health  
PO Box 5013, Wellington 6140, New Zealand

ISBN 978-1-991324-09-2 (print)  
ISBN 978-1-991324-07-8 (online)  
HP 9100



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# Glossary of terms

Term	Meaning
Attending medical practitioner / attending practitioner	A person's primary practitioner who provides assisted dying services. Note that in this report, 'attending medical practitioner' is used interchangeably with 'attending practitioner'. 'Attending medical practitioner' is referenced when discussing the current system, and 'attending practitioner' is referenced when discussing recommended changes to the system, because the report recommends changes to the types of practitioners that may act in this role.
Attending nurse practitioner	A nurse practitioner who, under the instruction of an attending medical practitioner, may prescribe and administer assisted dying medication.
Assisted dying	The End of Life Choice Act sets out that assisted dying, in relation to a person, means: <ul style="list-style-type: none"><li>• the administration by an attending medical practitioner or an attending nurse practitioner of medication to the person to relieve the person's suffering by hastening death</li><li>• the self-administration by the person of medication to relieve their suffering by hastening death.</li></ul>
Assisted Dying Secretariat (the Secretariat)	Part of the Regulatory Assurance team in the Ministry's Regulation and Monitoring – Te Pou Whakamaru directorate. The Secretariat supports statutory bodies established under the End of Life Choice Act, and has a regulatory and monitoring function to ensure compliance with the Act.
Assisted Dying Service	The service that delivers assisted dying in New Zealand. This service is provided by Health New Zealand – Te Whatu Ora. Clinical advisors (Senior Nurses) in Health New Zealand provide information and support, alongside practitioners, to help a person and their whānau navigate the assisted dying process.

Term	Meaning
Care facility	In this report, 'care facility' is used to refer to public hospitals, private hospitals, hospices, residential aged care facilities, disability residential care facilities, and rest homes or other similar facilities where care is provided to a person (e.g., due to illness, disease, incapacity, or disability).
Code of Health and Disability Services Consumers' Rights	Establishes the rights of consumers, and the obligations and duties of providers to comply with the Code. It is a regulation under the Health and Disability Commissioner Act 1994.
End of Life Choice Act 2019	The legislation that provides the legal framework for assisted dying in New Zealand. The Act sets out who is eligible for assisted dying, the process to access assisted dying, and some important safeguards.
End of Life Review Committee (the Review Committee)	A statutory body under the End of Life Choice Act responsible for considering the death reports sent to it by the Registrar (assisted dying) under section 21(3) of the Act. The Review Committee decides whether the death report shows satisfactory compliance with section 21(2) of the Act. Its function is to make recommendations to the Registrar (assisted dying) about the death report information should that be necessary.
Independent medical practitioner	The practitioner that undertakes a second, independent assessment of the person seeking assisted dying.
Pae Ora (Healthy Futures) Act 2022	<p>Health legislation that provides for the public funding and provision of services in order to:</p> <ul style="list-style-type: none"> <li>• protect, promote, and improve the health of all New Zealanders</li> <li>• achieve equity by reducing health disparities among New Zealand's population groups, in particular for Māori</li> <li>• build towards pae ora (healthy futures) for all New Zealanders.</li> </ul> <p>This Act establishes a set of health system principles to provide common expectations across the health system.</p>

Term	Meaning
Registrar (assisted dying) (the Registrar)	<p>A statutory role under the End of Life Choice Act. The Registrar’s responsibilities under the Act include:</p> <ul style="list-style-type: none"> <li>• reviewing the assisted dying forms completed by practitioners to ensure compliance with the Act before the prescription for the assisted dying medication is released</li> <li>• establishing and maintaining a register of approved forms for the assisted dying process, including consulting the Privacy Commissioner as required under the Act</li> <li>• receiving and managing complaints, including referring them to the Health and Disability Commissioner, New Zealand Police, and/or other appropriate authorities</li> <li>• taking any action as directed by the End of Life Review Committee.</li> </ul>
Support and Consultation for End of Life in New Zealand Group (the SCENZ Group)	<p>A statutory body under the End of Life Choice Act. Members are appointed by the Director-General of Health for a period of two years. The SCENZ Group maintains a list of health practitioners willing to provide assisted dying services in New Zealand, and is responsible for the clinical guidelines for administering medication for an assisted death and the standard of care for assisted dying in New Zealand.</p>

# Introduction

This report presents advice and findings from the Ministry of Health – Manatū Hauora following a review of the operation of the End of Life Choice Act 2019 (the Act) which took place during 2024. It notes where things are working well and makes recommendations on changes that could be made to the Act to improve its effectiveness.

The Ministry acknowledges that assisted dying is still relatively new in New Zealand, and that this is a subject where there are different philosophical, moral, and ethical views.

This report fulfils a statutory requirement under section 30 of the Act, which requires that the Ministry of Health review the operation of the Act within three years of its commencement, and report its findings to the Minister of Health, who is then required to present a copy of this report to parliament.

The recommendations made by the Ministry in this report are based on the current scope and purpose of the Act and address the intent of the Act as passed by Parliament.

In the event that changes are considered that would change the intent or scope of the Act, it may be necessary to contemplate alternative or additional changes to support this.

# Executive summary

## Background

The End of Life Choice Act 2019 (the Act) is the law that makes assisted dying legal in New Zealand. The Act came into force on 7 November 2021, following a public referendum held alongside the 2020 General Election. The Act is administered by the Ministry of Health – Manatū Hauora (the Ministry).

Under the legislation, the Ministry must undertake a review of the operation of the Act within three years of it coming into force, and every five years following. This report provides the Ministry's findings and a set of recommendations for changes that the Ministry considers would improve the operation of the Act.

The review examined whether the Act as currently written is operating effectively and achieving its intended purposes. In reviewing the Act, the Ministry considered whether changes could:

- increase clarity around the meaning and interpretation of rules or settings in the Act
- improve the effectiveness of mechanisms in the Act, such as those intended to address issues of access and safety
- support effective administration of assisted dying
- provide clarity around the roles and responsibilities of those involved
- improve alignment of the Act with other relevant pieces of legislation, and the wider health system (including the Pae Ora (Healthy Futures) Act 2022).

The review was informed by:

- targeted engagement with organisations and individuals that are directly referenced in the Act or that have a role directly related to the Act, that are directly involved in the provision of assisted dying or that regulate or represent workforces that are, and that have particular knowledge or expertise relevant to the operation of the Act
- interviews and feedback from people who have sought or supported someone to receive an assisted death in New Zealand (see a summary of this feedback at **Appendix 1**)
- research received on the experiences of whānau Māori with assisted dying (see a summary at **Appendix 2**)
- a list of identified issues and potential issues with the Act that was developed during the first two years of its operation, and feedback received by the Assisted Dying Service
- a clause-by-clause analysis of the Act, and an equity analysis
- an environmental scan of recent developments in overseas jurisdictions for experiences or lessons that might be relevant here (see **Appendix 3**)
- legal, academic, and public discourse about the Act.

The Ministry also provided an online process to give the public an opportunity to share their views on what changes could be made to the Act. Feedback provided through the online process was analysed separately and summarised in the report *Summary of Online Submissions received on the End of Life Choice Act 2019*, which has been provided alongside this report.

## The End of Life Choice Act is achieving its primary purpose

The End of Life Choice Act 2019 (the Act) has largely been operating well, and has achieved its primary purpose of giving people with a terminal illness who meet certain criteria the option to request and receive medical assistance to end their lives. More than 2,400 people have requested an assisted death, and more than 970 have received an assisted death since the Act came into force on 7 November 2021.

The core processes in the Act to apply, be assessed for, and receive an assisted death are clear and robust. The eligibility requirements to receive an assisted death are also reasonably clear, noting that some of these criteria involve a level of subjectivity in the judgements that practitioners must make when they are assessing people.

The intended limitations on people seeking an assisted death are also clear in the wording of the legislation – that the decision to seek an assisted death must be made by the individual, that a person cannot receive an assisted death if they do not meet the eligibility criteria, and an assisted death cannot be approved or consented to in advance.

The additional scrutiny provided by the Registrar has been a valuable safeguard in the process.

The practical provision of assisted dying has also worked well. There is an effective and responsive workforce that is well supported by the Assisted Dying Service. Funding of the service has supported access to assisted dying, and supported practitioners to travel to people who are often not able to travel themselves.

The level of compliance with requirements in the Act has also been very high, though there have been a small number of potential breaches. The Ministry is confident that everyone who has received an assisted death met the eligibility requirements set out in the Act and had chosen an assisted death.

## There is scope for improvement to the Act across a number of areas

The End of Life Choice Act is a relatively new piece of legislation, seeking to regulate a complex and sensitive health service that is new to New Zealand society and the health system.

While the Act has enabled people to access assisted dying, there are a number of areas where the Ministry considers that changes could be made to improve the operation of the Act. These are organised into five areas:

- Supporting access and safety.
- Improving the process to receive assisted dying.
- Aligning the Act with the wider health system.
- Ensuring a capable and effective workforce for assisted dying.
- Clarifying organisational roles and responsibilities in the Act.

In each of these areas, the Ministry has identified a number of issues that have come up during the review process. Recommendations are made in each area that the Ministry considers would address the issues discussed, and improve the operation and effectiveness of the Act in achieving its purposes. Many of these recommendations are interconnected and mutually supporting.

## Supporting access and safety in the Act

A central objective of the assisted dying system is the need to support timely and equitable access to assisted dying, while also providing for sufficient safeguards<sup>1</sup> to protect those who are involved. Balancing these factors is key to the system working effectively.

The following issues were identified during the review:

- The requirement that a health practitioner cannot raise assisted dying until a person does is contrary to health consumer rights, and is creating a significant barrier to access for some people. This requirement has also resulted in very limited information being available on assisted dying throughout the health system, which means it is difficult for people who do not already know about assisted dying to become aware of it or access it.
- The requirement on practitioners to 'do their best' to detect pressure is unusual and unclear. This is not a recognised legal threshold and links the determination of whether this requirement has been met to the capabilities of the particular practitioner. Different practitioners will have different interpretations of what it means to 'do their best'. This requirement could also be interpreted to mean that a practitioner must only look for pressure at one point during the process (rather than in an ongoing way).
- Beyond the eligibility assessment, the Act is not explicit about whether and how a person's competence is to be determined throughout the rest of the process.
- There is a lack of clarity about the core and ongoing duties on practitioners in the Act. The Act is relatively prescriptive and drafted in a way that emphasises the completion of individual procedural requirements to achieve the purposes of the Act, rather than overarching duties to be satisfied throughout the process. There is a need for a set of duties on practitioners, both to indicate expectations to practitioners, and to clarify enforcement pathways for breaches of those duties or expectations.

<sup>1</sup> Safeguards are legal provisions, professional requirements, and other mechanisms intended to protect people, practitioners, and the public in the delivery of assisted dying.

- The Act takes a one-size-fits-all approach to breaches of the requirements of the Act, and is not clear about when an activity is criminal. The Act should more clearly set out enforcement pathways for breaches of different types of requirements, in order to clarify which actions are appropriate to result in criminal liability and which other, less serious actions should result in other disciplinary proceedings.
- The Act could be more specific about what details cannot be published related to assisted deaths. The current restrictions may unnecessarily limit reporting on information that does not breach the privacy of individuals or affect the safety of the public.

## Improving the process to receive assisted dying

Central to the availability of assisted dying under the Act is the process for people to seek, be assessed for, and receive an assisted death. The Act is prescriptive in the process that it sets out for this to happen.<sup>2</sup>

The following issues were identified during the review:

- The Act is not sufficiently clear on what should happen when a person is declined assisted dying in different circumstances – i.e., when the process to seek an assisted death should cease, and when the person should be required to make a new request.
- The Act does not provide sufficient direction for whether and how the responsibilities of an attending medical practitioner may be transferred to another attending medical practitioner during the process, if the practitioner is unable to continue in their role.
- The time period during which a person can receive an assisted death after being found eligible for assisted dying is not sufficiently clear under the Act.
- The requirements in the Act for setting and moving the date of an assisted death are unnecessary, and can prolong suffering for people who need to bring the date forward.
- The Act includes a level of operational prescription in places that is unnecessary in primary legislation, and could have unintended effects on how assisted dying is provided over time.

## Aligning the Act with the wider health system

Assisted dying is a service under the Pae Ora (Healthy Futures) Act 2022 (the Pae Ora Act). This means that assisted dying should be aligned with other health services and standards governing the wider health system, including workforce regulations, the Code of Health and Disability Consumers Rights (the Code), and the expectations on health agencies and health entities in undertaking their roles.

However, due to its nature, assisted dying is also distinct from other services in the health system. There is a careful balance to be struck between aligning assisted dying with the wider health system, while also maintaining some systems and processes that remain specific to assisted dying.

<sup>2</sup> Note that the level of prescription in the Act is similar to legislation in other jurisdictions that enables assisted dying, such as Australia and Canada.



The following issues were identified during the review:

- The framing of the Act assumes that all health practitioners will provide assisted dying services unless they have a conscientious objection, which is out of step with the health system and how the service operates. The Act also conflates provisions around how people are able to access assisted dying with how practitioners are able to conscientiously object.
- The Act does not strike an appropriate balance between conscientious objection and health consumer rights. The Act is relatively broad in the way that it addresses how a person may conscientiously object, enabling health practitioners to decline to do anything that they consider might assist a person in any way to access assisted dying. In some circumstances this has included obstructing a person's access to the service, or in the most extreme cases, actively seeking to dissuade people from accessing an assisted death.
- The Act is silent on the obligations of care facilities<sup>3</sup> in relation to assisted dying, and particularly the ability of people to receive assisted dying in these locations. This means that it is unclear where the balance lies between the rights of organisations to refuse to allow assisted dying, and the rights of individuals in care facilities to access assisted dying as a health service.
- Some people accessing assisted dying in hospitals can face barriers to care.
- People accessing assisted dying and their family or whānau, particularly people who have been found ineligible, need more support.
- The protections for employees who decide to provide or not provide assisted dying could be made clearer.

## Ensuring a capable and effective workforce for assisted dying

As for the health system as a whole, the provision of assisted dying relies on having a workforce that is skilled, capable, and sufficient to meet the needs of those who are seeking the service. The availability and accessibility of the workforce is critical to assisted dying, as the process relies on the involvement of, and decisions by, assisted dying practitioners.

The following issues were identified during the review:

- The threshold at which practitioners can provide assisted dying services is too low given the consequential nature of assisted dying for patients and practitioners. Because the requirements for a practitioner to act as an attending medical practitioner under the Act are relatively permissive, some practitioners may put themselves forward to provide assisted dying services who may not be appropriate to provide these types of services.
- There is no legislative requirement to complete training as a condition of providing assisted dying. This is relatively unusual compared to other legislation internationally that enables assisted dying.
- The workforce to provide assisted dying is insufficient. The small size and uneven distribution of the workforce has impacted on the ability of people to access assisted dying, and has impacts for practitioners who may need to travel

<sup>3</sup> In this report, 'care facilities' means public hospitals, private hospitals, hospices, residential aged care facilities, disability residential care facilities, and rest homes or other similar facilities where care is provided to a person (e.g., due to illness, disease, incapacity, or disability).

long distances to see people. There are particularly low numbers of psychiatrists to complete additional competence assessments.

- The role of nurse practitioners under the Act places them in a difficult situation and does not support continuity of care. Attending nurse practitioners are limited to providing the final part of the process, meaning that an attending nurse practitioner may first meet a person seeking assisted dying, and those who support them, on the day that they arrive to administer the medication to end the person's life.
- There is insufficient support available for practitioners providing assisted dying services. Practitioners providing assisted dying have noted that while this work can be personally fulfilling, it can also be isolating and emotionally draining.

## Clarifying organisational roles and responsibilities in the Act

In addition to processes and requirements needed to enable assisted dying, the Act also establishes three entities to support and monitor the provision of assisted dying: the Registrar, the SCENZ Group, and the Review Committee. It also refers to roles for other health entities, including the Health and Disability Commissioner and the Ministry of Health.

The following issues were identified during the review:

- The SCENZ Group has service delivery functions that do not align with its structure, or with the way similar groups operate in the health system.
- The meaning of the requirement that the Registrar must 'check' whether processes have been complied with under the Act is unclear, and the Registrar lacks explicit powers to fulfil its safeguarding function.
- With its current scope, the Review Committee is unable to be an effective oversight body.

## Recommendations

The next section provides a high-level overview of the recommendations made by the Ministry and the rationale for change.

Recommendation	Rationale
<b>Recommendation 1</b> Amend section 10 of the Act so health practitioners cannot raise assisted dying, except as part of discussions about a person's treatment and end-of-life care options.	This approach strikes a reasonable balance between enabling practitioners to make people aware of assisted dying as an option (in line with good clinical practice), while acknowledging that assisted dying is a sensitive subject that requires thoughtful and nuanced conversations to protect people and support patient choice. This approach would also better align assisted dying with the wider health system and health consumer rights.

Recommendation	Rationale
<p><b>Recommendation 2</b></p> <p>Add a provision to the Act stating that nothing in section 10 prevents the publication or provision of public information about assisted dying, or the assisted dying service.</p> <p>The provision could state that the Ministry of Health and Health New Zealand may publish information related to assisted dying services, including requirements, safeguards, the time involved, as well as available supports and contact details.</p>	<p>While section 10 does not prohibit the publication of information about assisted dying, adding a provision of this nature would explicitly enable it. This change would support the provision of information about assisted dying, including in health settings and other settings (such as for community or advocacy groups), and more easily enable practitioners who have a conscientious objection to providing assisted dying to provide information on how people can access the service (e.g., by giving a person who makes a request a card or pamphlet).</p>
<p><b>Recommendation 3</b></p> <p>Clarify the threshold for when the process must stop if the practitioner detects pressure. The Act could specify that:</p> <ul style="list-style-type: none"> <li>• practitioners must ‘take reasonable steps’ to ensure that a person is expressing their wish free from pressure. This could include by conferring with other health practitioners who are in regular contact with the person and conferring with members of the person’s family or whānau approved by the person (as currently set out in the Act)</li> <li>• the person’s practitioner must not provide or support an assisted death if they know that the person’s consent has been obtained due to another person citing, counselling, or procuring the person to access an assisted death.</li> </ul>	<p>Requiring practitioners to ‘take reasonable steps’ to ensure that a person is expressing their wish free from pressure would apply a more consistent standard for practitioners to detect pressure under the Act, connected to what is reasonable in the circumstances rather than the capability of individual practitioners. A change to this effect would also provide a more objective basis for assessing a practitioner’s compliance with the requirement, as reasonableness tests are common in other legislation.</p> <p>The second part of the recommendation would add clarity to the Act by linking with provisions in the Crimes Act 1961 and existing case law. This would clarify that a breach of this requirement occurs when a practitioner continues with an assisted death while <i>knowing</i> that a person had not consented freely, rather than if they had missed a sign of pressure.</p>
<p><b>Recommendation 4</b></p> <p>Clarify in the Act that the person must be competent and informed to make a decision at key points in the process where the person is making a decision about assisted dying. This includes at the point of assessments, and on the day of the assisted death.</p> <p>Also, specify some factors that by themselves are insufficient to find that a person is not competent to make an informed decision. These factors could include:</p> <ul style="list-style-type: none"> <li>• the person’s age</li> <li>• the person’s appearance</li> <li>• any aspect of the person’s behaviour or manner</li> <li>• whether the person is disabled</li> </ul>	<p>This change would clarify that a person must be considered competent at key points in the process when they are required to make an informed choice or give informed consent. This recognises that a person’s competence may fluctuate throughout the process between decision points, while also being explicit about competence being required on the day of the assisted death.</p> <p>Specifying factors that by themselves are insufficient to find that a person is not competent to make an informed decision would increase clarity in the Act about what is relevant to determining competence, and support equitable access.</p>

Recommendation	Rationale
<ul style="list-style-type: none"> <li>the person's methods of communication</li> <li>the person's cultural and linguistic circumstances.</li> </ul>	
<p><b>Recommendation 5</b></p> <p>More clearly set out in the Act the core duties that practitioners must fulfil to ensure that the person accessing assisted dying is eligible, actively seeking and consenting to it, is competent to consent to it, and that this consent is provided free from pressure from others.</p> <p>More clearly define ongoing procedural requirements on practitioners that may constitute steps towards the practitioner's core duties.</p>	<p>Grouping the requirements on practitioners together into core duties in the Act would achieve the purposes of Act in a simpler and more cohesive way than the current approach, which is based on the completion of forms.</p> <p>Practitioners' core requirements would be simpler to understand, and ensuring that practitioners have fulfilled these requirements could be used as a mechanism to ensure compliance with the underlying requirements of the Act. This would both support practitioners to understand and make sure that they meet these requirements, while also simplifying prosecution if necessary.</p>
<p><b>Recommendation 6</b></p> <p>Clarify the enforcement pathways for breaches of particular requirements in the Act, linked to the core duties and requirements as referenced in recommendation 5. There would be three enforcement pathways set out in the Act:</p> <ul style="list-style-type: none"> <li>Intentional breaches of core duties in the Act would be linked to new, specific offences in the Crimes Act 1961. These would apply when a practitioner had knowingly administered (or would have knowingly administered) an assisted death to someone who was not eligible or who did not consent to it.</li> <li>Breaches of certain procedural requirements that are necessary to maintain the integrity of the assisted dying process could be linked to specific lesser regulatory criminal penalties under the Act.</li> <li>Professional misconduct or where a practitioner has not complied with the requirements of the Code of Health and Disability Services Consumers' Rights (where those actions are not linked to a practitioner intentionally not fulfilling their core duties under the Act) would result in referral to the Health and Disability Commissioner, or the practitioner's responsible authority, and possible disciplinary proceedings by the Health Practitioners Disciplinary Tribunal.</li> </ul> <p>The current immunity provisions in the Act would be removed.</p>	<p>In combination with recommendation 5, this recommendation would clarify the enforcement pathways for actions that are criminal and serious enough to be related to the Crimes Act 1961, and enforcement pathways for actions which are less serious and could be linked to breaches of the Code of Health and Disability Services Consumers' Rights, or of other requirements under the End of Life Choice Act.</p> <p>These changes would group the requirements on practitioners into categories based on a spectrum of harm, resulting in more intentional and proportionate responses to breaches of duties and requirements under the Act.</p> <p>Enforcing breaches of core duties would be simplified, as breaches would be less linked to procedural errors. Creating new offences in the Crimes Act 1961 linked to these would improve alignment and integration with existing provisions in that Act, particularly for provisions around defences.</p> <p>Failing to meet procedural requirements in the Act could also be evidence that contributes to the prosecution of a serious offence under the Crimes Act 1961.</p>

Recommendation	Rationale
<p><b>Recommendation 7</b></p> <p>Amend section 36 of the Act to be more specific about what details about an assisted death cannot be published, including:</p> <ul style="list-style-type: none"> <li>• the name of assisted dying medications</li> <li>• the identity of the person who received an assisted death or any details that could reasonably be expected to identify the person</li> <li>• the name of the person who administered the medication to the deceased, and the name of the facility where the person received an assisted death.</li> </ul>	<p>This change would improve clarity around what details of an assisted death can and cannot be published. This would more effectively protect the privacy of individuals who access and provide assisted dying services, while allowing for any details outside of these to be published to support transparency.</p> <p>Specifically preventing the publication of the names of assisted dying medications would support public safety.</p>
<p><b>Recommendation 8</b></p> <p>Add a provision stating that a person who is found ineligible for assisted dying, or who has rescinded their request to exercise the option of assisted dying, must submit a new request if they wish to reapply at a later date.</p>	<p>This recommendation would increase clarity about the procedure for when the assisted dying process ends, and a person must make a new request. This approach would ensure that where someone is found ineligible for some reason, they are required to go through the full process again for a new request, including assessments by an attending practitioner and independent medical practitioner.</p>
<p><b>Recommendation 9</b></p> <p>Add a provision that enables the functions, responsibilities, and duties of an attending practitioner to be transferred to another attending practitioner, provided that the new attending practitioner agrees to take on the role.</p> <p>When the new attending practitioner takes on the role, they must advise the Registrar.</p> <p>The provision would state that the role of attending practitioner cannot be transferred to the independent medical practitioner.</p>	<p>This change would provide clarity around the ability for an attending practitioner to transfer their functions, responsibilities, and duties to another attending practitioner in situations where they are no longer willing or able to continue to act as a person's attending practitioner, or where the applicant does not want to continue with their current practitioner.</p> <p>The responsibilities and duties of the original practitioner would be transferred to the new practitioner. This means they would need to be comfortable that the person still meets the requirements in the Act.</p>
<p><b>Recommendation 10</b></p> <p>Add a provision that establishes a six-month period within which a person is able to set a date and receive an assisted death, following approval by the Registrar. This six-month period would commence from the date when the Registrar determines that compliance requirements have been met.</p> <p>Further, add a provision providing that an additional six-month extension of this period may be granted by the Registrar if at the end of the initial six-month period:</p>	<p>This provision would provide greater clarity about the time period during which a person can receive an assisted death under the Act. It would replace existing provisions that reference the ability for the person to change the date of the assisted death, which are unclear and can be applied inconsistently.</p> <p>This approach is recommended because it most closely reflects what is currently provided for in the Act, but with greater clarity and consistency.</p>

Recommendation	Rationale
<ul style="list-style-type: none"> <li>the attending practitioner is of the opinion that the person continues to be eligible for assisted dying, and</li> <li>the Registrar is satisfied that the attending practitioner has provided sufficient information demonstrating continued compliance with the requirements of the Act.</li> </ul>	
<p><b>Recommendation 11</b></p> <p>Remove the requirement for the person to choose a date and time for administration of the medication after they have been found eligible (section 18).</p> <p>Remove references in the Act to the “date initially chosen” (sections 17(2)(e)(ii), 19(2)(c) and 20(2)(b)).</p> <p>Remove the requirement to choose a method for administration of the medication after a person has been found eligible (section 19(2)(a-c)).</p> <p>Remove the 48-hour rule and related provisions requiring the Registrar to check compliance and confirm compliance with requirements in the Act (section 19(3), 19(4), and 19(5)).</p> <p><i>Note that the ‘check’ by the Registrar referenced in this recommendation is strengthened through recommendation 22.</i></p>	<p>The requirement for a person to choose a date immediately after they have been found eligible, and the process requirements related to moving this date, do not provide tangible benefits to the process and can result in additional delays to the process, resulting in people experiencing prolonged pain and suffering.</p> <p>Some of these provisions are currently required in the Act, as they establish the time period within which a person can receive an assisted death. However, if a provision is added specifically setting out this period (as per recommendation 10), these provisions are no longer required.</p> <p>Further, the requirement for a person to choose a method for administration does not provide benefits to the process and limits flexibility. The recommendation would remove an unnecessary compliance step, and improve flexibility on the day of the assisted death if the method for administration needed to change (e.g., if the initial method chosen became clinically unsuitable).</p>
<p><b>Recommendation 12</b></p> <p>Expand the regulation-making power in the Act to state that regulations must be made to specify:</p> <ul style="list-style-type: none"> <li>what a practitioner is required to do when they ‘examine’ a person as part of the assessment process</li> <li>the methods for administration of the medication</li> <li>requirements for the management of prescriptions made under the Act.</li> </ul> <p>Remove the following provisions from the Act (on the basis that these will be covered by regulations instead):</p> <ul style="list-style-type: none"> <li>The list of methods for administration of the medication (section 19(2)).</li> </ul>	<p>While the Act currently includes a regulation-making power, the scope of this power is limited.</p> <p>Expanding the regulation-making power and moving some of the prescribed operational details from the Act into regulation would enable more flexibility in each of the areas to be set out, while still maintaining a level of regulatory oversight and control.</p> <p>Having regulations specify what a practitioner would be required to do when they ‘examine’ a person would address an area where the Act is currently silent.</p>

Recommendation	Rationale
<ul style="list-style-type: none"> <li>Provisions involving the way that prescriptions are managed (section 19(3)(a) – also removed by the recommendation above – and section 22).</li> </ul>	
<p><b>Recommendation 13</b></p> <p>Amend the Act to separate conscientious objection provisions from how a person accesses the Assisted Dying Service, and clarify obligations on all health practitioners to provide details of the Assisted Dying Service if a person makes a request.</p> <p>Section 11(1)<sup>4</sup> would be replaced with wording to the effect of: ‘If a person informs a health practitioner that they would like to exercise the option of receiving assisted dying, that health practitioner must provide the contact details for the Assisted Dying Service or contact the service on their behalf.’</p>	<p>This change would provide clarity for people applying for assisted dying, and for practitioners and other people working in the health system, about the process to access assisted dying services and what practitioners must do in response to a request.</p> <p>It would also simplify provisions about conscientious objection, as these would be separated from provisions relating to access to the service (see recommendation 14).</p>
<p><b>Recommendation 14</b></p> <p>Amend the Act to set out what practitioners are able to conscientiously object to, that conscientious objection does not override a practitioner’s duty to act in accordance with the Code of Health and Disability Services Consumers’ Rights, and specific actions that health practitioners must take to facilitate continuity of care.</p> <p>Section 9 would be removed.<sup>5</sup> Section 8(1)<sup>6</sup> and section 8(2)<sup>7</sup> would be replaced with wording to the effect of:</p> <p>‘A health practitioner that conscientiously objects to assisted dying, or who is not able or willing to provide assisted dying services, is not required to:</p> <ul style="list-style-type: none"> <li>perform any of the functions or duties of an attending practitioner, independent medical practitioner or third assessor</li> </ul>	<p>This change would clarify how conscientious objection interacts with health consumer rights, what practitioners are able to object to, and what actions a practitioner must take to fulfil their duties under the Code of Health and Disability Services Consumers’ Rights (the Code). This would clearly indicate expectations for health practitioners that may interact with assisted dying services.</p> <p>This change would improve the timeliness and ease of access to assisted dying for people seeking the service.</p> <p>Breaches of this requirement would be linked to a breach of the Code, and may be subject to investigation by the Health and Disability Commissioner.</p> <p>This change would also remove the requirement for a practitioner to inform a person of their conscientious objection, as targeted engagement highlighted that this</p>

<sup>4</sup> Section 11(1): “A person who wishes to exercise the option of receiving assisted dying must inform the attending medical practitioner of their wish.”

<sup>5</sup> Section 9 sets out that if a person informs the attending medical practitioner that they wish to access assisted dying, and the practitioner has a conscientious objection to providing that option, the practitioner must tell the person of their conscientious objection and of their right to ask the SCENZ Group for the contact details of a replacement practitioner.

<sup>6</sup> Section 8(1): “A health practitioner is not under any obligation to assist any person who wishes to exercise the option of receiving assisted dying under this Act if the health practitioner has a conscientious objection to providing that assistance to the person.”

<sup>7</sup> Section 8(2): “Subsection (1)— (a) applies despite any legal obligation to which the health practitioner is subject, regardless of how the legal obligation arises; but (b) does not apply to the obligation in section 9(2).”

Recommendation	Rationale
<ul style="list-style-type: none"> <li>supply, prescribe, or administer an assisted dying medication</li> <li>be present at the time of administration.’</li> </ul> <p>The Act would include that:</p> <ul style="list-style-type: none"> <li>conscientious objection does not override a health practitioner’s duty to act in accordance with the Code of Health and Disability Services Consumers’ Rights</li> <li>in response to a request for information about assisted dying, all health practitioners must provide the person with the contact details of the Assisted Dying Service</li> <li>a health practitioner who holds relevant health information about a person must, upon request from any practitioner operating under the Act for the purposes of an assessment under the Act, provide that information as soon as practicable.</li> </ul>	<p>requirement could be uncomfortable for practitioners and implies a judgement on the person’s decision.</p>
<p><b>Recommendation 15</b></p> <p>Require care facilities to provide reasonable access to assisted dying to those who request it, particularly for those where the facility is the person’s home (‘care facilities’ means public hospitals, private hospitals, hospices, residential aged care facilities, disability residential care facilities, and rest homes or other similar facilities where care is provided to a person (e.g., due to illness, disease, incapacity, or disability)).</p> <p>Care facilities would be required to do the following:</p> <ul style="list-style-type: none"> <li>Provide the contact details of the Assisted Dying Service to a person if they request it.</li> <li>Allow assisted dying practitioners access to a person on site for assisted dying appointments and assessments, or facilitate transfer of the person to the practitioner.</li> <li>Allow assisted dying practitioners access to the person on site for administration of the assisted dying medication <b>if they are a permanent resident or inpatient</b> (i.e., the care facility is their home).</li> <li>If transfer of a person who is not a permanent resident or inpatient to another suitable location would not be reasonable in the circumstances (e.g., where the transfer would cause harm to the person, undue delay, or prolonged suffering), allow the</li> </ul>	<p>This provision would make the obligations of care facilities and related organisations to comply with the Code of Health and Disability Services Consumers’ Rights explicit, and clarify where the balance sits between the rights of health consumers and care facilities. The Ministry considers that the balance of rights should favour the rights of consumers accessing healthcare, including assisted dying services.</p> <p>While adding these requirements to the Act would have implications for care facilities that do not currently support or allow assisted dying to take place on site, it is important to note that this change would not require staff from these facilities to be directly involved in the assisted dying process. The Act already provides for assisted dying practitioners through other mechanisms.</p> <p>This change would:</p> <ul style="list-style-type: none"> <li>promote equitable access for people in care facilities for whom the facility is their home, and for people who need to access palliative care in addition to exercising their wish to receive an assisted death</li> <li>support people to be aware of and access all options for end-of-life care available to them, regardless of where they are living</li> <li>remove the use of transfers in situations where transfers would not be appropriate</li> <li>create consistency of practice across the range of care facilities</li> </ul>



Recommendation	Rationale
<p>practitioner reasonable access to the person on site for any part of the service.</p> <ul style="list-style-type: none"> <li>• Have a policy for how the care facility will give effect to the above requirements (noting that Health New Zealand facilities would have a single national policy).</li> </ul> <p>Non-compliance could be linked to existing certification policies (i.e., required certification to the Ngā Paerewa Health and Disability Service Standard). The Ministry or Health New Zealand would publish information and provide education and guidance about the obligations of care facilities to support those wishing to access assisted dying.</p>	<ul style="list-style-type: none"> <li>• support integration of assisted dying as a recognised health service.</li> </ul> <p>Care facilities would also be required to demonstrate how they are giving effect to this change. If progressed, the Ministry and Health New Zealand would work with and support facilities to enact this change.</p>
<p><b>Recommendation 16</b></p> <p>Amend the Act to more clearly articulate that a practitioner should not be treated any more or less favourably than any other similarly qualified health provider by an employer, regardless of whether they provide assisted dying services or not.</p>	<p>This change would more clearly articulate the continuation of rights for practitioners who conscientiously object, and practitioners who provide the service, than the current provision (section 8(3-4)).</p>
<p><b>Recommendation 17</b></p> <p>Require medical and nurse practitioners providing assisted dying services to have held a practising certificate for a minimum period of:</p> <ul style="list-style-type: none"> <li>• five years for medical practitioners, following general registration</li> <li>• five years for nurse practitioners, where they have practised as a nurse practitioner.</li> </ul> <p>The five-year period would not be required to be consecutive, recognising that some practitioners may take breaks (e.g., for parental leave).</p>	<p>This change would remove the ability for relatively new doctors and nurse practitioners to provide assisted dying services. This recognises that providing assisted dying requires some skills and capabilities that develop through experience, including having difficult conversations with people, cultural competence, the ability to engage with and support family or whānau, and professional judgement.</p> <p>This change would also provide some protections for new practitioners from offering assisted dying, which from a legal perspective is riskier for practitioners than other areas of medicine.</p>
<p><b>Recommendation 18</b></p> <p>Add an explicit requirement that practitioners who provide assisted dying services must complete required training, including any refresher training, which must cover their duties under the Act.</p>	<p>Adding this requirement to the Act would address a notable gap in the current legislation. While an interim solution is currently in place linking training requirements to funding, it is important that the Act signals that practitioners must complete required training to ensure the quality and safety of the service. This also links to the duties approach described in recommendation 5.</p>
<p><b>Recommendation 19</b></p> <p>Allow the third assessment (to determine competence) to be provided by:</p>	<p>This change would provide some additional flexibility in terms of the health practitioners who can provide an assessment of competence where either the attending practitioner or the</p>

Recommendation	Rationale
<ul style="list-style-type: none"> <li>• a psychiatrist (as currently set out in the Act), or</li> <li>• a health practitioner with specialist vocational registration in an area set out by the Director-General of Health.</li> </ul> <p>This would be accompanied by a provision stating that the Director-General of Health may, by notice in the <i>New Zealand Gazette</i>, specify a person or class of person with a particular vocational registration as people authorised to provide competence assessments for assisted dying, if the Director-General is satisfied that the person or class of person has undergone training in, and is competent in, competence assessments.</p>	<p>independent medical practitioner are not satisfied that the person seeking assisted dying is competent to make an informed decision. This recognises that the current workforce of psychiatrists available to provide competence assessments is constrained, and that there are other individuals within the wider health workforce who have the skills and training to make these assessments.</p> <p>The proposed wording would allow the Director-General of Health to identify additional individuals or groups of individuals with particular specialist registrations to provide these assessments, where they are deemed to be sufficiently competent and capable.</p>
<p><b>Recommendation 20</b></p> <p>Allow nurse practitioners to fulfil all of the responsibilities that are currently undertaken by an attending practitioner, but not fulfil the role of the independent medical practitioner.</p> <p>As part of this change, remove wording in the Act that refers to attending nurse practitioners operating under the instruction of attending medical practitioners.</p>	<p>This change would address the issue that the current role for nurse practitioners in the Act does not enable nurse practitioners to build a relationship with the person and those supporting them, or good continuity of care throughout the process.</p> <p>This change would recognise the skills and capabilities of nurse practitioners by enabling them to provide the main role in the assisted dying process, and would help to address the insufficient size of the workforce. Nurse practitioners are a highly skilled workforce that undergo significant training to become registered,<sup>8</sup> such that in other settings nurse practitioners can be a person's primary healthcare provider. This workforce can be utilised to better support access to assisted dying, including in rural areas.</p> <p>Nurse practitioners seeking to provide assisted dying services would also be subject to requirements related to experience and training set out in the previous recommendations.</p>
<p><b>Recommendation 21</b></p> <p>Amend section 25 of the Act to make the SCENZ Group an expert advisory group which provides specialist advice and support for practitioners, the Ministry of Health, and Health New Zealand on the processes under the Act. The SCENZ Group would be responsible for providing expert advice on:</p>	<p>This change would see the SCENZ Group become an expert advisory group that provides specialist advice and support to Health New Zealand and the Ministry. This would mean the SCENZ Group loses some of its administrative functions, noting that in practice these are already undertaken by the Ministry and Health New Zealand.</p>

<sup>8</sup> Becoming a nurse practitioner requires a three-year nursing or health science degree, four years of work experience as a registered nurse, completing advanced training through a clinically focused two-year Master's degree approved by the Nursing Council of New Zealand, and passing an approved assessment against a set of nurse practitioner competencies.

Recommendation	Rationale
<ul style="list-style-type: none"> <li>• workforce skills and competence requirements</li> <li>• guidance on specific areas of clinical practice and the administration of medications</li> <li>• training and support provided to practitioners.</li> </ul> <p>The name of the SCENZ Group would be changed to reflect its functions – for example, the Assisted Dying Expert Advisory Group.</p>	<p>This change reflects the value of an expert advisory group which can support agencies to work through complex decisions related to the provision of assisted dying. Expert advisory groups are commonly used to inform a number of other complex areas of health practice.</p>
<p><b>Recommendation 22</b></p> <p>Amend section 27 of the Act to require the Registrar to make a determination of compliance based on whether the documentation and information provided by practitioners demonstrates compliance with the requirements under the Act.</p> <p>Further work would need to be done to frame the Registrar’s compliance review in the Act, but it is likely that the Registrar would look to apply a reasonableness standard to confirm, for example, that:</p> <ul style="list-style-type: none"> <li>• the forms have been completed</li> <li>• the information provided to inform an assessment is logical and supports the practitioner’s opinion</li> <li>• a factual basis is documented that the person meets the criteria</li> <li>• the practitioner’s assessment is documented adequately.</li> </ul> <p>A provision would be added stating that the Registrar’s authorisation is required before an assisted death can proceed.</p> <p>Section 27 of the Act would also be amended to provide powers for Registrar to:</p> <ul style="list-style-type: none"> <li>• seek additional information when reviewing the documentation</li> <li>• pause the process until sufficient information has been provided, and</li> <li>• stop the process if the additional information is not sufficient to demonstrate compliance with the Act, or if it becomes apparent that other aspects of the legislation have not been complied with.</li> </ul>	<p>This change would address a lack of clarity around the requirement that the Registrar must ‘check’ whether processes have been complied with.</p> <p>In summary, the Registrar would be required to:</p> <ul style="list-style-type: none"> <li>• review all forms and documentation provided</li> <li>• if required, pause the process to seek additional information from practitioners</li> <li>• make a formal determination that the attending practitioner and independent medical practitioner have provided sufficient evidence that non-clinical eligibility criteria have been met, and a rationale to substantiate their opinion that clinical eligibility criteria have been met.</li> </ul> <p>This would not be an assessment of whether a person is eligible for assisted dying, or an appraisal of the accuracy of the practitioners’ assessments. Rather, the Registrar would assess the sufficiency of the information provided.</p> <p>This change would also clarify and reinforce the role of the Registrar as a safeguard in the process, and ensure that the Registrar has powers to request further information and pause or stop the process if needed. This change would ensure that the requirements of the Act are complied with and better protect health consumers.</p>

Recommendation	Rationale
<p><b>Recommendation 23</b></p> <p>Amend section 26 of the Act to clarify that the purpose of the Review Committee is to:</p> <ul style="list-style-type: none"> <li>consider all documentation produced during the course of individuals seeking and/or receiving an assisted death</li> <li>determine whether the information recorded shows satisfactory compliance with the requirements of the Act</li> <li>as necessary, make recommendations to the relevant organisations and entities to support quality or practice improvements, and indicate where information may be insufficient to demonstrate compliance with the requirements of the Act.</li> </ul> <p>The relevant organisations and entities are:</p> <ul style="list-style-type: none"> <li>Health New Zealand (the Assisted Dying Service), as the agency responsible for the operation of the Act – this could include feedback to individual practitioners</li> <li>the SCENZ Group, as the expert body advising on the operation of the Act</li> <li>the Registrar, in their capacity to review information and make determinations on compliance under the Act</li> <li>the Ministry of Health, as the agency responsible for regulation of assisted dying and the End of Life Choice Act.</li> </ul> <p>Where the Review Committee considers that a matter identified in relation to assisted dying may warrant formal investigation, it may refer the matter to the relevant entity, such as:</p> <ul style="list-style-type: none"> <li>the Health and Disability Commissioner</li> <li>the Medical Council of New Zealand or Nursing Council of New Zealand</li> <li>the New Zealand Police.</li> </ul>	<p>These changes would align the role and functions of the Review Committee with what the Ministry understands Parliament intended, and clarify and strengthen the role and functions of the Review Committee.</p> <p>These changes would clarify that the primary purpose of the Review Committee is to provide an avenue for service and practitioner related improvements, and to raise any cases that cause concern with the relevant agencies that have investigative powers.</p> <p>To support its role, the Review Committee would have access to all material (e.g., forms) produced throughout the process when a person seeks and receives an assisted death.</p> <p>The Review Committee would not have powers to require the provision of further information from practitioners, beyond what is recorded as part of the process, noting that the Review Committee is not an investigative or fault-finding body.</p> <p>The Review Committee's referral function would not exclude the possibility that a person may, at any time, make their own complaint to the entities listed.</p>
<p><b>Recommendation 24</b></p> <p>Set out in the Act specific immunities for the Registrar and the Review Committee. The Act would also specify that judicial review is available as an accountability pathway.</p>	<p>This change would clarify the immunity protections for the Registrar and the Review Committee. This could be set out in a way that is tailored to the roles of the Registrar and Review Committee. Such a provision would enable these statutory bodies to operate more effectively, with clear accountability and without undue legal risk attached to their roles. This would be particularly necessary in the Act if the existing immunity provisions were removed, as set out in recommendation 6.</p>

Recommendation	Rationale
	This recommendation is aligned with immunity approaches in other New Zealand legislation.
<p><b>Recommendation 25</b></p> <p>Add a provision setting out the role of Health New Zealand in the Act. This would see Health New Zealand undertake a number of functions to support the operation of assisted dying as a health service. The provision would specify that Health New Zealand must provide an Assisted Dying Service which:</p> <ul style="list-style-type: none"> <li>• provides a point of contact for people seeking to receive an assisted death, or wanting more information about assisted dying</li> <li>• provides contact details for an attending practitioner</li> <li>• identifies and assigns an independent medical practitioner</li> <li>• identifies and assigns a psychiatrist or other approved practitioner to provide an opinion on competence, if required</li> <li>• provides training for practitioners.</li> </ul>	<p>This change would support the sustainability of assisted dying as a service by setting out clear responsibilities for a centralised administration and support function that enables the provision of assisted dying.</p> <p>This change also recognises that Health New Zealand is responsible for providing the front-end for the Assisted Dying Service (the point of contact) for people seeking assisted dying, and a number of administrative functions connected to this.</p>
<p><b>Minor recommended changes</b></p> <p>Improve clarity in the Act by making amendments to:</p> <ul style="list-style-type: none"> <li>• require the attending practitioner to examine a person before forming an opinion on whether they are eligible</li> <li>• specify that an Attorney acting under an Enduring Power of Attorney for personal care and welfare may not make decisions about assisted dying for another person</li> <li>• specify that an independent medical practitioner must not confer with the attending practitioner when they are assessing a person's eligibility</li> <li>• change the requirement for practitioners to 'send' forms to the Registrar, to a requirement that practitioners 'ensure that the required information is provided'</li> <li>• broaden section 35 to 'for the purposes of any contract, deed or other financial instrument'</li> <li>• add a requirement to section 12 that, where the form requesting an assisted death is signed and dated by another person (a proxy), that person's contact information must be recorded.</li> </ul>	<p>These changes make minor clarifications to the Act or remove unnecessary prescription.</p> <p>Changes to improve provisions in the Act related to the Review Committee would:</p> <ul style="list-style-type: none"> <li>• remove the existing requirement, which limits the membership of the Review Committee to three specialists or experts, and allow the Minister of Health to appoint additional members to the Review Committee if needed. This would align with the Review Committee's broader scope by allowing for an increased membership in future if needed to manage the Review Committee's workload</li> <li>• recognise that, as an independent review body, the Review Committee should have a mechanism that supports public transparency and accountability, which would help to build public confidence in assisted dying services.</li> </ul>

Recommendation	Rationale
<p>Improve provisions in the Act related to the Review Committee by:</p> <ul style="list-style-type: none"> <li>• amending section 26 of the Act to allow more than three members to be appointed to the Review Committee by the Minister of Health if needed</li> <li>• specifying that the Minister must appoint a Review Committee consisting of a medical ethicist and <u>at least</u> two health practitioners, one of whom must be a medical practitioner who practises in end-of-life care</li> <li>• adding a provision requiring the Committee to provide an annual report of its activities to the Minister of Health.</li> </ul>	

## Other matters that Parliament may wish to consider

During the course of the review, a number of other matters were noted that Parliament may wish to consider if amendments are made to the Act. The Ministry has not made recommendations on these points, as they involve matters that are beyond the scope of the review. These are:

- including providing safeguards as an explicit purpose of the Act
- adding principles to underpin the Act
- changes to how the eligibility criteria are specified
- adding a definition for terminal illness
- considering whether a specific criminal offence is needed for inducing a person to seek an assisted death
- clarifying whether and how an Enduring Power of Attorney for personal care and welfare interacts with a person's competence to make an informed decision about assisted dying.

# About the review

The End of Life Choice Act 2019 (the Act) includes a requirement that the Ministry of Health – Manatū Hauora (the Ministry) must review the operation of the Act within three years after the commencement of the Act, and then at subsequent intervals of not more than five years, and consider whether any amendments to the Act or any other enactment are necessary or desirable.

The Ministry is required to report on its findings to the Minister of Health, who must then present a copy of the report to Parliament.

The Ministry has completed the first required review of the operation of the Act. This report presents the Ministry's findings and a set of recommendations for changes that the Ministry considers would improve the operation of the Act.

## The review process

The review examined whether the Act as currently written is operating effectively and achieving its intended purposes. The stated purposes of the Act are to:

- give persons who have a terminal illness and who meet certain criteria the option of lawfully requesting medical assistance to end their lives
- establish a lawful process for assisting eligible persons who exercise that option.

It is also apparent from the content of the Act that a third purpose of the Act is to provide for safeguards to ensure that assisted dying is only provided to those who are eligible, who actively seek and consent to it, and that this consent is provided without pressure from others.

The review process involved a number of stages, including:

- planning and preparation for the review (September 2023 – February 2024)
- work to establish the terms of reference for the review and gather initial information to inform the review (February – July 2024)
- targeted engagement on the review in two phases (March – May 2024, and July – August 2024)
- the core review process, including reviewing evidence, undertaking policy analysis, and identifying and assessing options (June – October 2024)
- preparation of this report (September – October 2024).

In reviewing the Act, the Ministry considered whether changes could:

- increase clarity around the meaning and interpretation of rules or settings in the Act
- improve the effectiveness of mechanisms in the Act, such as those intended to address issues of access and safety

- support effective administration of assisted dying
- provide clarity around the roles and responsibilities of those involved
- improve alignment of the Act with other relevant pieces of legislation, and the wider health system (including the Pae Ora (Healthy Futures) Act 2022).

The review did not consider matters that go beyond the scope of the Act as it exists now. This means that changes to the eligibility rules were out of scope, along with other changes which would fundamentally change the purpose or scope of the Act.

Inputs to the review included:

- a list of identified issues and potential issues with the Act that was developed by the Ministry during the first two years of its operation
- feedback received by the Assisted Dying Service from those who have interacted with assisted dying services
- targeted engagement (see below)
- a clause-by-clause legal analysis of the Act, and an equity analysis
- an environmental scan of recent developments in overseas jurisdictions for experiences or lessons that might be relevant in New Zealand (see **Appendix 3**)
- legal, academic, and public discourse about the Act.

## Targeted engagement

In addition to the above inputs, the Ministry undertook targeted engagement to inform the review, inviting and receiving submissions from:

- **organisations and individuals that are directly referenced in the Act, or that have a role directly related to the Act** – for example, the End of Life Review Committee (including previous members of the Review Committee), Registrar (assisted dying), Support and Consultation for End of Life in New Zealand Group, Health and Disability Commissioner, Privacy Commissioner, Chief Coroner, New Zealand Police, Department of Internal Affairs, and Health New Zealand – Te Whatu Ora
- **organisations and individuals that are directly involved in the provision of assisted dying, or regulate or represent workforces that are** – for example, health practitioners who provide assisted dying services, the Medical Council of New Zealand and Nursing Council of New Zealand, and relevant health workforce associations (e.g., Colleges and other organisations that represent health practitioners)
- **organisations and individuals with particular knowledge or expertise relevant to the operation of the Act** – for example, the Human Rights Commission, Health Quality and Safety Commission, Accident Compensation Corporation (ACC), Whaikaha – Ministry of Disabled People, other government agencies, Hospice New Zealand, Tōtara Hospice, the Assisted Dying Research Network, and kaupapa Māori researchers.

As part of targeted engagement, the Ministry ran focus groups with 28 health practitioners who have been providing assisted dying services. The Ministry also



extended an invitation to people who have sought assisted dying, and those who have supported someone who has sought and received an assisted death in New Zealand, to share their experiences to inform the review.

As a result of that invitation, between July and August 2024 the Ministry interviewed and received written feedback from 19 people who had supported others through the assisted dying process (including one person who had been found ineligible for assisted dying). Early research findings garnered from interviews with practitioners and people who had sought assisted dying, or supported others through the process, were also received to inform the review. A summary of feedback from the people interviewed for the review, and the research findings received, are provided in **Appendix 1** and referenced throughout the report.

Finally, early observations from two studies that are yet to be published were received which highlight the views and experiences of Māori and whānau Māori related to assisted dying. These findings are summarised in **Appendix 2**.

## Parallel process to collect public feedback on the End of Life Choice Act

Separate from the review of the operation of the Act, the Ministry also provided an online process to give the public an opportunity to share their views on what changes could be made to the Act. An online portal was set up on the Ministry website and was open for input from 1 August 2024 until 26 September 2024, a period of eight weeks.

Feedback provided through the portal was analysed separately and is summarised in the report *Summary of Online Submissions received on the End of Life Choice Act 2019*, which has been provided alongside this report. The views expressed through this portal were not considered by the Ministry as part of its review of the operation of the Act, as this was run as a parallel and separate process with a different purpose.

# Background

The End of Life Choice Act 2019 (the Act) was passed into law by Parliament in 2019, and came into force from 7 November 2021. This followed a public referendum as part of the 2020 General Election where 65% of votes were in favour of the referendum question: "Do you support the End of Life Choice Act 2019 coming into force?".

The Act gives a New Zealand citizen, or permanent resident, the option of requesting medication to end their life. The Act includes provisions that provide:

- eligibility criteria for people seeking assisted dying
- requirements for practitioners that provide assisted dying, including provisions allowing for conscientious objection
- a process that must be followed for a person to seek and receive an assisted death
- a number of requirements that are intended to act as safeguards
- entities to oversee and support the provision of assisted dying
- offences for breaching requirements in the Act and immunity provisions to protect practitioners who meet the requirements of the Act.

## Current settings and processes

Assisted dying is provided by the Assisted Dying Service at Health New Zealand – Te Whatu Ora (Health New Zealand). The Act establishes three statutory bodies that provide oversight of the Service:

- **The Registrar (assisted dying)** checks that the processes required by the Act have been complied with before an assisted death can take place, and manages complaints about the Assisted Dying Service. The Registrar must be a Ministry employee who is nominated by the Director-General of Health.
- **The End of Life Review Committee** considers summary reports of assisted deaths ('assisted death reports') to check compliance with the requirements of the Act, and may request that the Registrar follow up with practitioners if an assisted death report does not show satisfactory compliance with the Act. The Review Committee is appointed by the Minister of Health.
- **The Support and Consultation for End of Life in New Zealand (SCENZ) Group** is responsible for making and maintaining lists of health professionals who are willing to deliver assisted dying services, and preparing the standard of care for administering assisted dying medication. The SCENZ Group is appointed by the Director-General of Health.

To be eligible to receive an assisted death, a person must meet all the following criteria and 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 process to make a request for assisted dying is as follows:

- The person must raise assisted dying directly with a health practitioner, or contact the Assisted Dying Service directly.
- Not all health practitioners choose to or are able to provide assisted dying services. Only medical practitioners may provide assisted dying, and practitioners are able to conscientiously object to providing assisted dying services. If a person asks about assisted dying and the practitioner has a conscientious objection, the practitioner is required to tell the person of their conscientious objection and of the person's right to ask the SCENZ Group for the name and contact details of a replacement practitioner.
- The Assisted Dying Service then works with the SCENZ Group to help connect the person with an appropriate attending medical practitioner and coordinate the assessment process.

The assisted dying process itself involves several key steps:

- The attending medical practitioner will connect with the person making the request and talk about their options for end-of-life care. If the person still wants to proceed, they sign a form, and the process commences.
- The attending medical practitioner will assess the person to make sure they meet the eligibility criteria. This includes checking if the person is competent to make an informed decision and that they are making this choice free from pressure from other people.
- If the person is found eligible, an independent medical practitioner will undertake a second assessment to ensure that the person is eligible for assisted dying.
- If the attending medical practitioner and/or the independent medical practitioner find the person eligible but are uncertain about whether they are competent, the person will be referred to a psychiatrist. The psychiatrist will assess the person's competence.
- The attending medical practitioner will then talk to the person about the outcome of the second assessment and, if required, the competence assessment.
- If the person is eligible for assisted dying, they can start making plans for their assisted death, including deciding the date and time, preferred place, and method of administration.
- If the person is not eligible for assisted dying, their attending medical practitioner will explain the reasons and the process ends.
- The person can change their mind about choosing assisted dying at any time and stop the process, including on the day of the assisted death when the medication is due to be administered.

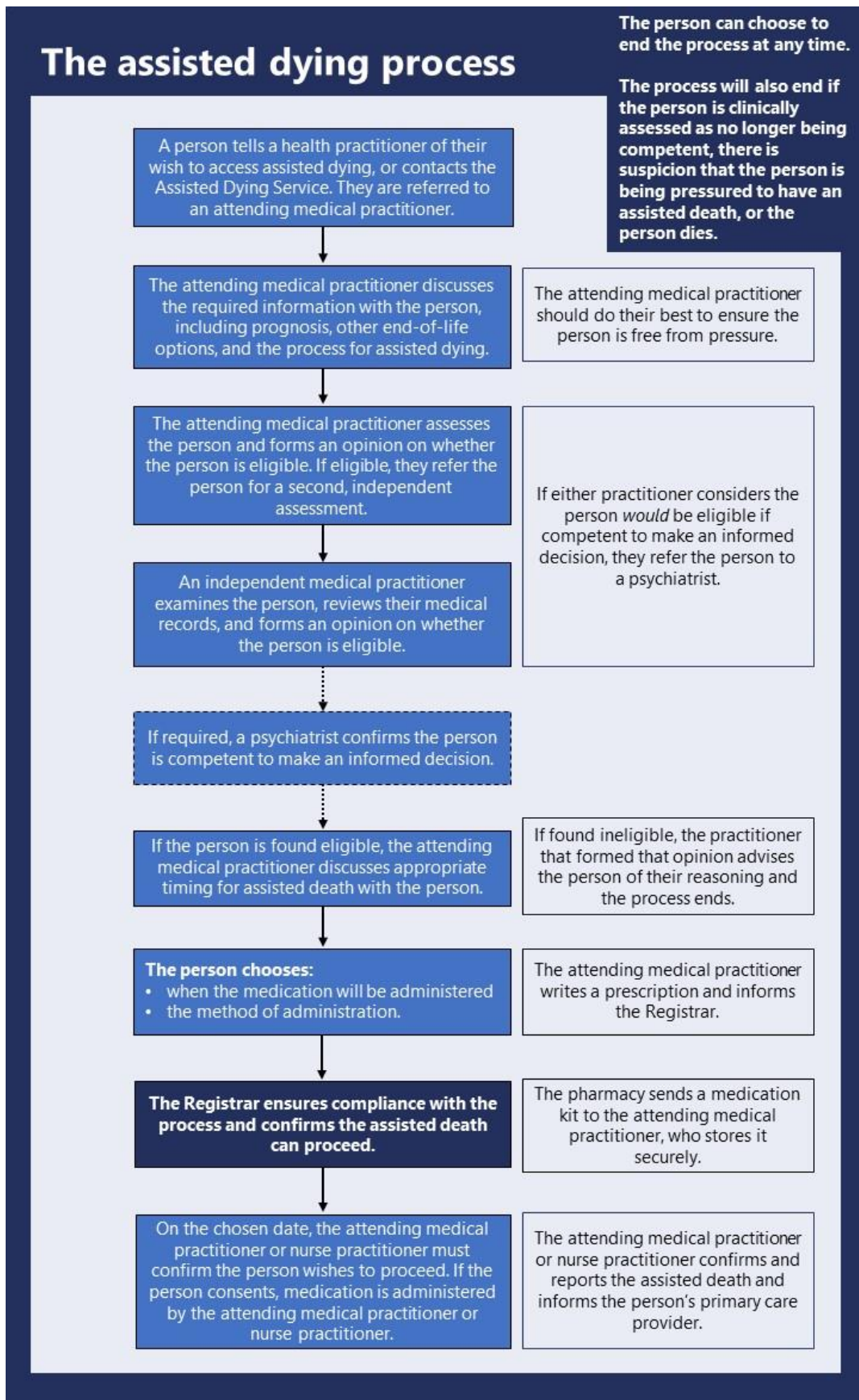
- After an assisted death, an 'assisted death report' is completed by the attending medical practitioner or the attending nurse practitioner capturing relevant details.

Family and whānau can play an important role in supporting a person through the process. While the legislation is clear that the decision about seeking assisted dying must be made by the person with the terminal illness, it does not prevent family or whānau from providing support to the person throughout the process. However, the person is not required to discuss assisted dying with their family or whānau if they do not want to.

The extent to which family or whānau are involved in the process may impact the experience of both the person seeking an assisted death, and the wellbeing of their whānau members. Guidance from the Health Quality & Safety Commission around care in the final days makes it clear that for Māori, the involvement of whānau is particularly important.

**Figure 1** on the following page summarises the process to access assisted dying. Note that this is a simplified version of the process set out in the Act, which includes additional steps and requirements (for example, if a person chooses the date of their assisted death).

**Figure 1: Overview of the assisted dying process**



# Implementing assisted dying as a health service

Following the results of the referendum on the Act at the 2020 General Election, the Ministry of Health – Manatū Hauora (the Ministry) had approximately a year to determine how the Act would apply in practice, and how assisted dying would be provided. There were a number of key questions that needed to be answered, including:

- whether and how assisted dying should be funded, as this is not explicitly required by the Act
- which parts of the health workforce should provide the service – e.g. medical practitioners working in primary care, secondary or hospital settings, palliative care, aged care, private health services, etc.
- whether this should be provided as a national service, or a range of regional or local services, and what the responsibilities of frontline health services should be
- where people would receive assisted dying – e.g. at home, in other community settings, hospitals, etc.
- what medications would be used, and how these would be procured and provided to practitioners
- what would be needed to support access to the service, and how assisted dying could be provided in a way that would support equity of access.

To help work through these questions, a framework was developed for what an effective system to provide for assisted dying needs to do, based on a combination of what is required in the Act, experiences in overseas jurisdictions, and the New Zealand context.

## **An effective system to provide for assisted dying is one that...**

...makes assisted dying **accessible and equitable** by:

- ensuring there is clear, accessible, and readily available information for people and their families wanting to know about assisted dying
- allowing applications to be made and for people to receive services in a variety of different settings, and close to where they live, or possibly even at home (avoiding the need for significant travel where possible)
- ensuring that cost is not a barrier to accessing services
- ensuring that the service is provided in a timely manner (to limit uncertainty and suffering), subject to the requirement for appropriate safeguards
- ensuring that processes after death are straightforward, respectful, and do not hinder normal grieving processes and cultural considerations.

...ensures that the **process to provide assisted dying is safe** by:

- incorporating safeguards to actively detect pressure, and situations where people may be incapable of making an informed decision
- making assessments that are supported by robust clinical guidance, and including processes to ensure the competence of decision-makers and the rigor of decision-making processes
- providing good public information on the operation of the system (transparency)
- ensuring that all decisions to assist someone to die are subject to some form of review (accountability).

...provides **choice and control** to those seeking assisted dying, and supports their whānau to be involved as appropriate by:

- allowing people to access services and be assisted to die in a setting of their choice (where this is possible)
- allowing people to make decisions about how and when they want to be assisted to die
- allowing for families and whānau to be involved in the process where this is appropriate (and where the person seeking assisted dying agrees)
- allowing people to receive services that are culturally responsive to them, and those who are supporting them.

...supports and maintains the **wellbeing of those who provide assisted dying** by:

- providing good training and clinical support to health professionals
- ensuring they are aware of the practices they need to follow to keep themselves safe, and are well-trained to do so
- providing emotional, psychological and cultural support.

Some of these points are provided for through requirements in the Act, while others depended on how assisted dying services were to be provided.

After engaging with a range of stakeholders and considering the New Zealand context, it was determined that:

- assisted dying would be managed centrally by the Ministry of Health (and now Health New Zealand) as a national service – recognising that the volume of cases was likely to be small and there would be a need for central oversight to support effective and consistent service provision
- assisted dying would initially be funded on a fee-for-service basis, and include costs for travel – to support access to the service, enable people to receive assisted dying in their homes where this is appropriate, and enable suitable

practitioners from all parts of the health system who are willing to provide the service to be involved

- medications and equipment for assisted dying would be procured nationally and funded by the Ministry of Health (noting that this function now sits with Health New Zealand) – to address a number of technical issues related to organising and managing these.

Alongside these decisions, a programme of work took place to establish the Assisted Dying Service, including processes and policies to support a case management system for the Service. The principles of Te Tiriti o Waitangi were incorporated into the service design, taking into account the potential impact on the community of an assisted dying service, and in particular the impact for Māori.

In developing the service, the Ministry recognised the importance of an equitable, accessible, person-centred service that would not negatively impact a person's ability to access it, and which supported Māori self-determination and mana motuhake. The resulting service supports this approach by:

- enabling a person to exercise choice
- providing funding for practitioners to travel to provide services
- supporting the use of telehealth, where appropriate
- providing information in a variety of languages and formats, including supporting the use of interpreters
- incorporating Te Tiriti o Waitangi principles in assisted dying training and guidelines.

## Standard of Care and Clinical Guidelines

The Assisted Dying Service exists within the wider health system, and professional standards and frameworks are applied to the Assisted Dying Service.

Specific guidance for administering assisted dying is provided by the Standard of Care and Clinical Guidelines, which outlines the best practice in providing care and support to the person and their family or whānau when administering assisted dying. The Clinical Guidelines cover the considerations and recommendations for the attending medical practitioner when administering the assisted dying medication.



# What we know about who has received assisted dying

The Ministry, through Health New Zealand, collects data about the Assisted Dying Service as part of its role in overseeing and monitoring the service. Collecting this information helps support an understanding of who is accessing the service and how it is being provided. Data also gives information on how the process is being experienced by people, their family or whānau, and practitioners who provide the service. This drives continuous improvement of the service and results in better outcomes for those accessing the service.

Data on who is applying for and receiving assisted dying is published regularly, through Health New Zealand quarterly reports and an annual report produced by the Registrar. Health agencies have worked to report more information about assisted dying than the Act requires, as reporting such information is essential to:

- support transparent and accountable service delivery
- enable continual improvement of processes and practices around assisted dying
- support informed public discussion about what assisted dying means for New Zealand
- enable the development of research and knowledge about assisted dying that is specific to the New Zealand context.

The level of detail that can currently be reported in some areas is limited due to the need to protect confidentiality of individuals using the services when there are a low number of cases to date.

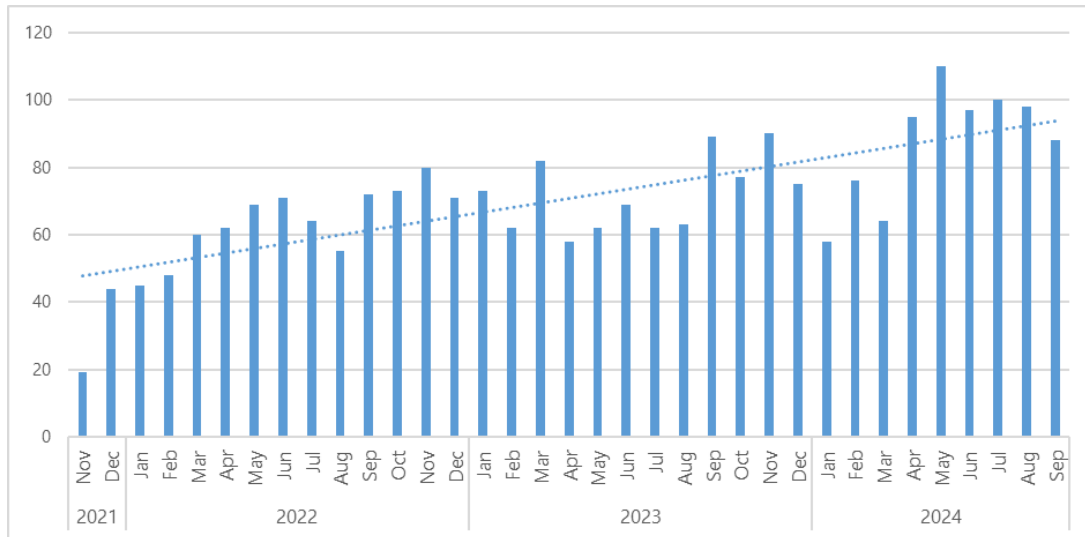
The collection and consolidation of data informing this report has been undertaken by Health New Zealand and provided to the Ministry of Health.

## Applications for assisted dying

Between 7 November 2021 and 30 September 2024, there were 2,482 requests (applications) for assisted dying.

**Figure 2** shows the number of applications received each month between 7 November 2021 and 30 September 2024, and indicates that these are increasing over time. Increases in the number of applications for assisted dying over this period may reflect a number of factors, including gradually increasing awareness of assisted dying as a relatively new service in the health system, changes in public attitudes towards assisted dying, and an ageing population.

**Figure 2: Applications for assisted dying between 7 November 2021 and 30 September 2024**



**Table 1** below summarises the demographic information related to these applications. Of the applications received during this period:

- the majority of applications for assisted dying came from people who identified as New Zealand European/Pākehā, with Māori, Pacific peoples, Asian and other ethnicities comprising a smaller proportion of applications – this may reflect differences in cultural views and beliefs about assisted dying among different groups, barriers to access for some groups, and demographic differences (for example, New Zealand Europeans/Pākehā have an older age structure than other groups)
- applications were split evenly between males and females
- the majority of applications for assisted dying came from people over 65 years of age
- most applications for assisted dying were from people suffering from cancer, with smaller numbers for those suffering from other conditions
- most of those who applied for assisted dying were receiving some form of palliative care
- most people who applied for assisted dying did not report a disability at the time of application.

**Table 1: Demographic summary of new applications**

Demographic summary: New applications (N=2,482) 7 November 2021 – 30 September 2024		Number of people <sup>3</sup>	% of applications
Ethnic group <sup>1</sup>	Māori	119	4.65
	Pacific peoples	13	0.51
	NZ European/Pākehā	2041	79.70
	Asian	60	2.34
	Other	328	12.81

<b>Demographic summary: New applications (N=2,482) 7 November 2021 – 30 September 2024</b>		<b>Number of people<sup>3</sup></b>	<b>% of applications</b>
Sex	Female/wāhine	1250	50.20
	Male/tāne	1232	49.80
	Gender diverse	0	0.00
Age group	18-44	50	1.99
	45-64	479	19.21
	65-84	1434	58.03
	85+	519	20.77
Diagnosis <sup>2</sup>	Cancer	1667	70.64
	Cardiovascular Condition	140	5.93
	Chronic Respiratory Disease	143	6.06
	Multiple Co-Morbidities	135	5.72
	Neurological Condition	212	8.98
	Other Organ Failure	63	2.67
Receiving palliative care at time of application?	Yes	1887	76.09
	No	595	23.91
Reported a disability at time of application? <sup>4</sup>	Yes	395	15.53
	No	2087	84.47

Notes:

1. Total ethnicity has been used. This means that individuals reporting more than one ethnicity are included within each category they identify with. In the current report, individuals identifying as 'European' have been included within the 'Other' category, distinct from New Zealand European/Pākehā.
2. Total diagnosis has been used. This means that individuals presenting with multiple diagnoses are included within each applicable diagnostic category. Note that this does not include diagnosis counts for people who were found to be ineligible.
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. Disability data collected is currently limited to a person's self-reported disability status at the point at which they apply for assisted dying. Note, however, that most people seeking and considered eligible for assisted dying could be considered disabled, given that the criteria to qualify include needing to be "in an advanced state of irreversible decline in physical capability", and suffering from "a terminal illness that is likely to end the person's life within six months". Health agencies are considering how to improve data collection in this area – for example, by collecting and reporting whether people seeking assisted dying identified as disabled before they developed a terminal illness.

## Outcomes of applications for assisted dying

Of the total applications (noting that this list does not include all possible outcomes as a small number of applications are currently open or lost eligibility for other reasons):

- 978 (39.4%) applications resulted in an assisted death

- 635 (25.6%) people died of their terminal illness/underlying condition during the process or before their scheduled assisted death
- 494 (19.9%) were found to be ineligible and their application did not progress
- 166 (6.7%) people lost competence during the process
- 123 (5%) people chose not to proceed and rescinded their application.

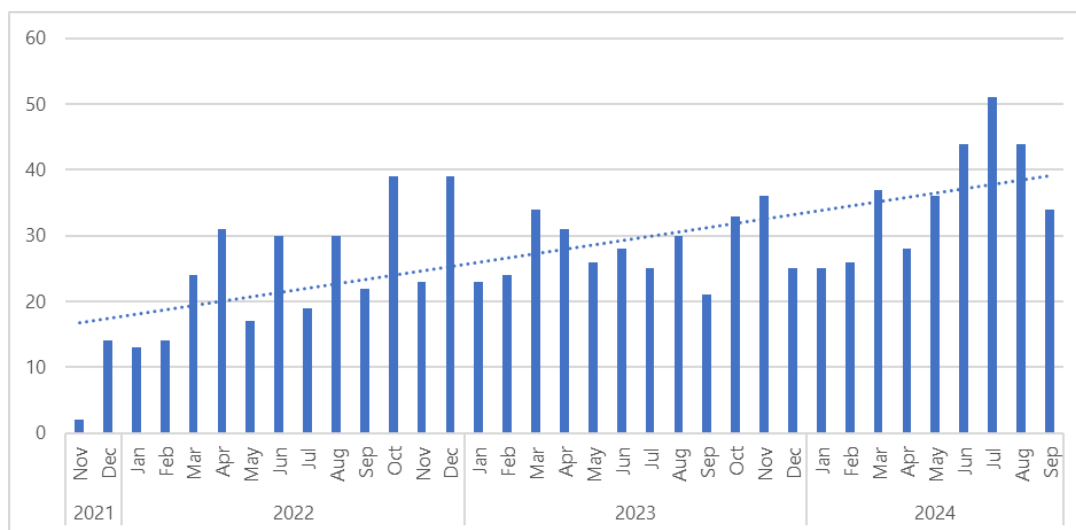
Further, among the total applications:

- there were 31 psychiatrist assessments – the attending or independent medical practitioner may request an opinion from a psychiatrist on whether the person is competent to make an informed decision about assisted dying
- the most common reason for being found ineligible was that the person was not experiencing unbearable suffering that cannot be relieved in a manner the person considered tolerable, and the next most common reason was that the person was not suffering from a terminal illness likely to end their life within six months
- most people applied once, though 31 people applied twice, and one person applied three times. Reapplications typically occur where someone is found to be ineligible when they apply the first time, and they apply again at another point.

## People who received an assisted death

Between 7 November 2021 and 30 September 2024, a total of 978 people received an assisted death. **Figure 3** shows the number of assisted deaths that took place during each month over the period. Like the number of applications, the number of assisted deaths has increased over time.

**Figure 3: Assisted deaths between 7 November 2021 and 30 September 2024**



Each application for assisted dying is different, and the time taken from application through to the assisted death varies based on the applicant's personal situation. On average, for those found eligible following assessment:

- the time between a person’s initial formal application and confirmation of their eligibility was 21 days<sup>9</sup>
- the time taken between initial formal application and the assisted death was 42 days.<sup>10</sup>

## Locations of assisted deaths

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

- 772 (78.9%) at a private residence or another private property
- 91 (9.3%) at a hospital
- 86 (8.8%) in an aged care facility
- 29 (3%) in a hospice facility.

## Method of administration

Under the Act, there are four options for administering the assisted dying medication. The attending medical practitioner provides the person with advice on each of the options, and the person then selects their preferred option. For the 978 assisted deaths that took place between 7 November 2021 and 30 September 2024:

- 50 people chose ingestion, triggered by the person
- 16 people chose intravenous delivery, triggered by the person
- 6 people chose ingestion through a tube, triggered by the attending medical practitioner or nurse practitioner
- 906 people chose injection, administered by the attending medical practitioner or nurse practitioner.

Each medication method has a standard administration protocol to ensure consistent, safe and quality services.

<sup>9</sup> This average was calculated using the time taken between a person’s first appointment with an attending medical practitioner, and the date at which the person’s eligibility was confirmed by the attending medical practitioner.

<sup>10</sup> This average was calculated using the time taken between a person’s first appointment with an attending medical practitioner, and the date that the person died. Note that this figure may include cases where a person reapplied.

## Assisted dying represents a small proportion of all deaths in New Zealand and other jurisdictions

**Table 2: Percentage of total deaths in each jurisdiction per year or reporting period**

	<b>Total</b>
Netherlands (2022)	5.1%
Canada (2022)	4.1%
Queensland, Australia (2023-24)	2.0%
Western Australia (2022-23)	1.4%
South Australia (2022-23)	0.3%
New South Wales, Australia (2023-24)	0.3%
<b>New Zealand (2023-24)</b>	<b>0.8%</b>
Oregon, USA (2023)	0.8%
Victoria, Australia (2023-24)	0.8%

Assisted deaths make up a small percentage of all deaths in the overall population each year. The above table shows the percentage of assisted deaths that represent all deaths for the reporting period specified. New Zealand's range is consistent with other countries where assisted dying is lawful. It is important to note that the rules to access assisted dying vary by jurisdiction, and this may influence the rate of deaths that occur as a result of assisted dying.

In New Zealand, based on a projected increase in those accessing the service, it is expected that there will be an approximately 23% growth in the number of applications for assisted dying in the 2024 – 2025 financial year, compared to the previous year.<sup>11</sup> Modelling indicates that the increase in applications will slow to a steady year-on-year growth rate of 11-13% in the following years.

<sup>11</sup> This analysis is based on service modelling completed by the Ministry using both linear regression and Autoregressive Integrated Moving Average (ARIMA) analysis to predict the ongoing demand, based on the actual weekly and monthly volume data and following international trends in applications for assisted dying.

# Review findings

## The End of Life Choice Act is achieving its primary purpose

The stated purposes of the End of Life Choice Act 2019 (the Act) have been achieved, which are to:

- give persons who have a terminal illness and who meet certain criteria the option of lawfully requesting medical assistance to end their lives
- establish a lawful process for assisting eligible persons who exercise that option.

The Act has also achieved its third implicit purpose, to provide for safeguards to ensure that assisted dying is only provided to those who are eligible, who actively seek and consent to it, and that this consent is provided without pressure from others.

As outlined in the previous section, more than 970 people have received an assisted death since the Act came into force on 7 November 2021. Targeted engagement as part of the review, and feedback received through the Assisted Dying Service over the last three years, indicates that the service is generally operating well (including regulatory, operational, and legal functions).

The core process set out in the Act for people to apply, be assessed for, and receive an assisted death is clear and robust, providing for:

- a person to make a request
- a first assessment of eligibility
- a second assessment of eligibility
- a third assessment to confirm competence if this is unclear
- a compliance check by the Registrar
- administration of medication for the assisted death.

The eligibility requirements to receive an assisted death are also reasonably clear, recognising that some of these criteria involve a level of subjectivity in the judgements that practitioners must make when they are assessing people.

The limitations on people seeking an assisted death are also clear in the wording of the legislation. These limitations include:

- that the decision to seek an assisted death must only be made by the person, and cannot be made on their behalf by any other person in any situation
- that someone cannot receive an assisted death if they do not meet the eligibility requirements
- that assisted dying cannot be approved in advance (through an advanced directive or similar mechanism).

There is also a clear understanding from those providing the service that someone receiving an assisted death must be competent to consent on the day of administration, though the legislation could be more explicit on this point.

The Act requires that the second assessment of eligibility must be undertaken by a practitioner who is not chosen by the person seeking assisted dying or their attending medical practitioner who provided the first assessment, and whose opinion is reached independently from the attending medical practitioner. This has made the second assessment an effective check to ensure that people meet the eligibility requirements.

The Act provides a role for the Registrar, who receives forms throughout the assisted dying process and has a role in ensuring that compliance requirements related to this are met before an assisted death can take place. This role has been an essential safeguard within the process.

The Act includes a requirement that, after the administration of the assisted dying medication, the attending medical practitioner or nurse practitioner must be available to the person receiving assisted dying until they die. The effect of this provision is that an assisted death cannot take place without a practitioner being present. This has been positive for a number of reasons, including that:

- assisted dying medication can be provided to the practitioner to manage, which avoids a number of potential safety risks associated with giving this type of medication directly to people seeking an assisted death
- people have the option of choosing to self-trigger IV medication, which would not be possible without the presence of a practitioner
- where people choose to self-administer medication, the practitioner who is present can monitor this and respond to any issues that may arise
- people can change their mind about the method of administration on the day (e.g., change from oral medication to IV medication) because practitioners are provided with medication to support different methods
- having a practitioner present provides reassurance to family or whānau members and others who may be present when a person receives an assisted death.

However, there is a trade-off with this requirement as it means that people wishing to receive an assisted death must wait until the practitioner is available, which in some circumstances may prolong the suffering they experience beyond what might otherwise have been the case. On balance, this limitation is outweighed by the safety and wider welfare benefits of having a practitioner present when an assisted death takes place.

In terms of the practical provision of assisted dying, there is a supportive and responsive workforce that has stepped forward to provide the service, with practitioners working hard to provide timely and responsive care, in spite of capacity and workforce pressures.

Providing funding for assisted dying has supported access. In particular, funding for practitioners to travel to people has supported people to be seen in their home or care



settings, and supported a degree of choice for some people in terms of where they receive an assisted death.

The Assisted Dying Service has been working well to support people and practitioners. The small team of clinical advisors who provide the service is well regarded by practitioners that were spoken to during targeted engagement.

Practitioners have been able to make use of telehealth to provide a timely and responsive service. This tends to be used for conversations with people (such as those that involve discussing methods or the chosen date). In some cases, assessments done by the independent medical practitioner are performed via telehealth, though standard practice is that this assessment happens in person. All first assessments by the attending medical practitioner must take place in person.

## Compliance with the Act is high, though there have been some potential breaches

The level of compliance with requirements in the Act has been very high. However, there have been a small number of potential breaches relating to the assisted dying process from health practitioners, and media coverage.

Some of these have resulted from a tension between what is a relatively prescriptive process and the way that medical practitioners are accustomed to working in the wider health system, where they are given significant discretion and autonomy to make decisions, and flexibility to take different courses of action if required.

The Ministry and Health New Zealand have taken a proportionate approach in responding to potential breaches, informing and educating practitioners in most instances, while referring others to the Health and Disability Commissioner and/or the Medical Council of New Zealand for a response.

There have been a small number of instances where media coverage has been potentially in breach of restrictions in the Act on information that can be published about individual cases. In these instances, this has been resolved with the media outlet removing or amending the information.

There have been no potential breaches in relation to the methods for administration of assisted dying medication. The medications that have been approved for assisted dying are effective in bringing about a timely assisted death. There have been no supply issues in regard to the medication.

At the time of publication, one potential breach has been referred to Police to investigate.

The Ministry is confident that everyone who has received an assisted death met the eligibility requirements set out in the Act and had chosen an assisted death.

# There is scope for improvement to the Act across a number of areas

The End of Life Choice Act is a new piece of legislation, seeking to regulate a complex and sensitive health service that is new to the health system and New Zealand society.

As a result of the review, the Ministry has identified a range of areas where improvements to the Act can be made within scope of this review. These have been organised into five areas:

- Supporting access and safety.
- Improving the process to receive assisted dying.
- Aligning the Act with the wider health system.
- Ensuring a capable and effective workforce for assisted dying.
- Clarifying organisational roles and responsibilities in the Act.

The next part of this report is organised into sections that canvass each of these areas. Each section provides background information on that area, discusses key issues that have been identified during the review, and makes recommendations to address them.

Alternative options are also briefly discussed where these were considered.

# Supporting access and safety in the Act

A central objective of all international systems that provide for assisted dying is the need to balance timely and equitable access to assisted dying with safeguards to protect those who are involved. While there can sometimes be tension between measures intended to support access and those intended to provide safeguards, all international systems that enable assisted dying recognise that both have a role.

## Approach to reviewing access and safety in the Act

The Ministry has sought to examine how well measures in the Act intended to support access and provide safeguards are operating. The intent of this analysis was to consider whether changes are needed to retain or strengthen the overall effectiveness of safeguards in the Act, and to improve access.

This has involved drawing on:

- the experience of those involved in managing and regulating the assisted dying process over the past three years, including the current Registrar, the Quality Assurance and Safety group in the Ministry, and Health New Zealand
- feedback from organisations involved in the provision of palliative and end-of-life care, the SCENZ Group, and from some practitioners who have been providing the service
- the experiences of people who have been through the process, and feedback shared by the family members and friends of those who have received an assisted death
- initial findings from research looking at assisted dying in New Zealand
- a clause-by-clause legal analysis of the Act
- current operating processes, guidance and data related to the provision of safeguards under the Act.

In examining how well measures in the Act intended to support access and provide safeguards are operating, and where changes might need to be made, the Ministry considered the following objectives, noting there is sometimes a balance to be struck between them:

- **The safety of the service that people seeking assisted dying and those supporting them receive** – this means ensuring that assisted dying is only available to those who are eligible, who actively seek and consent to it, are competent to consent to it, and that consent is provided free from pressure from others.
- **The quality of the service that people seeking assisted dying and those supporting them receive** – for the assisted dying service, quality depends on things like effective communication, empathy, cultural competence, and support for continuity of care.

- **Access to assisted dying, and timeliness of services** – including ensuring that people have the right information about assisted dying, that there are no inequitable barriers to accessing the service, and the process is responsive to applicants’ differing needs.
- **Accountability and transparency** – ensuring that the provision of assisted dying is transparent and accountable to the public and other stakeholders, while also protecting sensitive information and the privacy of those involved with assisted dying.

## Background information

### Key safeguards in the Act

For the purposes of this report, safeguards are legal provisions, professional requirements, and other mechanisms intended to protect people, practitioners, and the public in the delivery of assisted dying.

Safeguards seek to protect **those seeking assisted dying** by ensuring that:

- the service is only provided to those who meet eligibility criteria and are making their decision free from pressure
- assisted dying is only provided by suitably skilled and competent practitioners
- robust processes are in place to ensure services are high quality and include appropriate support for people and practitioners
- people are not subject to negative consequences as a result of seeking assisted dying (e.g., criminal prosecution, financial penalties, etc.).

Safeguards also protect **those providing assisted dying** (practitioners) by ensuring that:

- practitioners are not subject to criminal or civil prosecution as a result of providing assisted dying
- practitioners are not required to provide assisted dying services where they lack the skills, experience, or knowledge to do this safely, or have a conscientious objection.

Safeguards can also seek to address the **interests of the public** by ensuring that the provision of assisted dying is transparent and accountable, while also protecting sensitive information and the privacy of those involved with assisted dying.

It is important to note that in addition to safeguards that are specific to assisted dying, the health system also includes a wider set of measures that can be viewed as safeguards intended to protect anyone receiving any health service.

These include:

- the Health Practitioners Competence Assurance Act 2003 (HPCAA)

- the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights
- professional standards and guidelines for health practitioners that are developed by the relevant responsible authorities (e.g., the Medical Council of New Zealand).

The Act includes a number of key procedural steps and other safeguards (including strict eligibility criteria) to ensure that assisted dying is only available to those who are eligible and who:

- actively seek and consent to it
- are competent to consent to it
- provide consent free from pressure from others.

To ensure that a person actively seeks and consents to assisted dying, the Act requires that a person must raise assisted dying with a health practitioner first. Further, before an assessment of a person's eligibility is made, the person must be provided with information by the attending medical practitioner to enable them to make an informed decision and provide informed consent. This includes the prognosis for the person's terminal illness, the irreversible nature of assisted dying and anticipated impacts of assisted dying, and other options for end-of-life care.

A person is only eligible for assisted dying if they are competent to make an informed decision about assisted dying. Section 6 of the Act specifies that a person is competent to make an informed decision about assisted dying if they are able to:

- understand information about the nature of assisted dying that is relevant to the decision
- retain that information to the extent necessary to make the decision
- use or weigh that information as part of the process of making the decision
- communicate the decision in some way.

To ensure that a person provides consent free from pressure from others, the Act includes a number of requirements intended to detect and prevent a person's decision being made under pressure:

- A decision to seek assisted dying can only be made by the person. The use of advanced directives and decisions by welfare guardians related to assisted dying are prohibited.
- Health practitioners cannot, in the course of providing any health service, initiate discussion with a person about assisted dying or make any suggestion that the person exercise the option of receiving assisted dying.
- The attending medical practitioner must do their best to ensure that a person seeking assisted dying is doing so free from pressure from any other person. This includes conferring with other health practitioners who are in regular contact with the person (with or without their consent) and with members of the person's family (if the person approves). Any actions taken must be recorded.

- An attending medical or nurse practitioner must cease all action to assist a person to receive assisted dying if at any time during the process they suspect, on reasonable grounds, that a person is not expressing their wish for assisted dying free from pressure from any other person. This must also be reported to the Registrar.
- Those providing the service must confirm a person's decision to receive assisted dying throughout the process. This includes advising the person that at any time they may decide not to receive the medication, or decide to receive the medication at a later time within the period specified in the Act. The person has the right to rescind their decision at any time, and no further action can be taken if this occurs.

## Key issues identified

### The requirement that a health practitioner cannot raise assisted dying until a person does is contrary to health consumer rights, and is creating a significant barrier to access for some people

Section 10 of the Act states that a discussion about assisted dying must not be initiated by a health practitioner. The section states that a health practitioner who provides any health service to a person must not "initiate any discussion with the person that, in substance, is about assisted dying" or "make any suggestion to the person that, in substance, is a suggestion that the person exercise the option of receiving assisted dying under this Act".<sup>12</sup>

The intent of this provision is to address a concern that people may feel pressured to consider or seek assisted dying if this was suggested to them by a health practitioner, because health practitioners are viewed as experts on matters related to individuals' health.

A range of views on this provision were received during targeted engagement. Some groups commented that the provision helps to address the power imbalance between practitioners and patients, and acts as a safeguard for disabled people.

However, the majority of submissions held that the provision:

- does not effectively safeguard health consumers, as other people who are not health practitioners (who may have a closer relationship with the person) are able to raise assisted dying with them

*The prohibition on initiation of assisted dying as an option should be maintained. Once raised, full information about that option, alongside all other options, should be provided in accordance with the right to health. However, care should be taken to ensure it is provided in a neutral way, to avoid any perception of pressure or coercion to choose one of the options over others.*

– Disability Rights Commissioner

<sup>12</sup> A health practitioner who contravenes this section is not treated as having committed an offence under the Act, but may be found to have acted in breach of the Code of Health and Disability Services Consumers' Rights by the Health and Disability Commissioner, or the Human Rights Review Tribunal. They may also be subject to professional disciplinary sanction.

- limits a health consumer's ability to make an informed choice or give informed consent under Right 7 of the Code of Health and Disability Services Consumers' Rights (the Code), as a person must have access to all information a reasonable person would expect to receive in order to give informed consent, and the Act overrides a person's right to information in the Code<sup>13</sup>
- is out of step with how health services are usually provided in New Zealand and how New Zealanders expect health services to be provided to them, which involves health practitioners proactively telling people about the options they have for care and treatment that are clinically appropriate for them
- perpetuates the view that assisted dying is taboo or should not be discussed.

Practitioners engaged with during the review felt the provision implied that health practitioners are not trustworthy or capable enough to discuss assisted dying with a person. Some practitioners said they felt 'stilted' or unable to properly carry out their role as a health professional, and that health practitioners routinely have conversations with people about their care options, including about sensitive matters involving life and death.

Practitioners and the Health and Disability Commissioner further raised that the Act is unclear about how specific a person's request for assisted dying must be. Some practitioners noted that people often use metaphorical language to bring up assisted dying, rather than talk about it directly – for example, 'I've had enough', or 'I want to chuck in the towel'. The requirement in the Act can lead to practitioners expecting very specific language to be used before engaging in a discussion about assisted dying, and a person feeling ignored if their practitioner erred on the side of caution and did not follow up with their request.

An additional effect of the provision that may not have been intended is that it has resulted in very limited information being available on assisted dying throughout the

*We consider ensuring that the request is initiated by the patient, helps to address the potential power imbalance between a health care professional and patient. It reduces any perception of medical led coercion to consider and pursue Assisted Dying.*

- Australia and New Zealand Society of Palliative Medicine

*Informing people of options does not equal coercion.*

- Australian and New Zealand College of Anaesthetists

*I cannot get my head around why your GP who's in charge of palliative care, or oncologist – why no one is able to bring up or give information about this. Giving information is very different to recommending it. It seems so strange and weird it's not allowed. It adds to something being taboo that is absolutely not taboo.*

- Family member of someone who received an assisted death

<sup>13</sup> The Act overrides:

- right 6(1)(b) and (c), where every consumer has the right to the information that a reasonable consumer would expect to receive, including an explanation of the options available, and advice of the estimated time within which the services will be provided
- right 6(2), where every consumer has the right to the information that a reasonable consumer needs to make an informed choice or give informed consent before making a choice or giving consent.



health system, which is at odds with other healthcare options. Ordinarily, information about health services is provided in health settings and other community settings using posters, pamphlets, and other printed material to educate people about their health and the options available to them. However, health agencies and providers have been reluctant to publish and provide information about assisted dying (outside of information provided on the Ministry and Health New Zealand websites) due to concerns that this may be seen as breaching section 10 requirements.

This effect extends to care facilities<sup>14</sup> being reluctant to put up information about assisted dying, including whether they allow assisted dying services on site. This can prevent people from knowing whether a provider objects to assisted dying services, which may inform a person's choice about whether to move into a particular hospice or aged care facility.

There is a balance to be struck between upholding health consumers' rights to informed consent, and ensuring that people are not pressured to make a particular decision. While the provision is achieving its intent to ensure that people are protected from pressure, it is also limiting access to the service. The combination of a lack of available information about assisted dying and the inability of health practitioners to raise assisted dying means that it is difficult for people who do not already know about assisted dying (or that it could apply to their situation) to become aware of it or access it. This in turn:

- creates a significant and inequitable barrier to access for some people, e.g., those who are less health literate, who have English as a second language, or different cultural relationships to healthcare providers
- may delay people finding out about and requesting assisted dying until they have very little time left – research on assisted dying in New Zealand has noted cases of people who would like to have received an assisted death, but only learned about it once they had progressed too far along in their illness to complete the process in time.

*I understand from the medical perspective about practitioners not raising it – we understood what was needed. So that the GP would understand this was his choice and nobody was pressuring him in any way. But I do think a bit more publicity around it is needed, a whole lot more publicity.*

- Family member of someone who received an assisted death

*People entering care homes and hospices have also been unaware of the care home or hospice's refusal to allow assisted dying on its premises until the death is imminent, because a practitioner has not been able to provide them with that information before they enter that service.*

- Health and Disability Commissioner

<sup>14</sup> In this report, 'care facilities' means public hospitals, private hospitals, hospices, residential aged care facilities, disability residential care facilities, and rest homes or other similar facilities where care is provided to a person (e.g., due to illness, disease, incapacity, or disability).

## The requirement on practitioners to 'do their best' to detect pressure is unusual and unclear

One of the implied purposes of the Act is that assisted dying should only be accessible by those who provide consent free from pressure from others. Section 24 of the Act sets out that if at any time the practitioner "suspects on reasonable grounds that a person who has expressed the wish to exercise the option of receiving assisted dying is not expressing their wish free from pressure from any other person", the practitioner must take no further action to assist the person in exercising the option of receiving assisted dying.

Section 11(2)(h) of the Act sets out what practitioners must do to detect pressure. It specifies that when a person has made a request for assisted dying, the attending medical practitioner must "do their best to ensure that the person expresses their wish free from pressure from any other person" by conferring with other health practitioners who are in regular contact with the person, and conferring with members of the person's family approved by the person.

The intent of this provision, and section 24, is to ensure that a person is making their own decision about assisted dying and acting on their own wishes at all stages of the process. The wording that practitioners must 'do their best' was likely intended to recognise that every assessment of pressure will inevitably involve some level of subjectivity, and that actions required for each assessment will vary depending on different peoples' circumstances.

A number of submitters raised that the current provisions around detecting pressure and how suspected pressure should be managed are not clear, and that further steps should be required to clarify what practitioners must do to meet their obligations to protect people. Practitioners engaged with as part of the review commented that it was not clear what it meant to 'do their best', however, noted that they most often came across families pressuring a person *not* to receive an assisted death.

As submitters have noted, the provision is not clear and may not be effectively meeting its intent. This is because the phrasing that practitioners must 'do their best' to detect pressure is not a recognised legal threshold and links the determination of whether or not this requirement has been met to the capabilities of the particular practitioner, rather than an independent legal threshold. Different practitioners will have different interpretations of what it means to 'do their best', and practitioners are left to decide what they consider pressure to be according to their skills, experience, and personal

*Practitioners must do their best to ensure the person is not under pressure – that went fine, we were in the background in the interviews but also the attending physician spoke to dad alone. It worked fine in practice. It was his choice.*

- Family member of someone who received an assisted death

*[the requirement to 'do their best'] is wholly unsatisfactory and open to broad interpretation.*

- Disability Rights Commissioner

*Association members have told us about their discomfort that some residents who have chosen an assisted death may have wanted to opt-out but didn't due to a perceived shame or embarrassment about changing their mind, or the pressure of "putting people out".*

- Aged Care Association

judgement. While there is guidance on how practitioners should assess this, there is no consistent standard applied to detect pressure according to the requirement in the legislation.

Further, section 24 implies that a practitioner has an ongoing obligation to assess whether a person is making their decision free from pressure, as it sets out that the assisted dying process must stop if *at any time* a person's practitioner suspects that the person is not expressing their wish free from pressure. However, because the requirement in section 11 is tied to a process step, it could be interpreted to mean that a practitioner must only look for signs of pressure once, during the assessment process.

It should be noted that pressure can also be placed on a person to not seek out assisted dying, or to withdraw from the assisted dying process. However, these are not covered in the current legislation or in this report, as this relates to people not taking up assisted dying rather than ensuring the safety of people who wish to proceed through the process to receive an assisted death.

## Beyond the eligibility assessment, the Act is not explicit about whether and how a person's competence is to be determined throughout the rest of the process

The eligibility criteria to access assisted dying include that a person must be competent to make an informed decision about assisted dying. The Act sets out that a person is competent to make an informed decision about assisted dying if they are able to:

- understand information about the nature of assisted dying that is relevant to the decision (comprehension)
- retain that information to the extent necessary to make the decision (recall/memory)
- use or weigh that information as part of the process of making the decision (reasoning)
- communicate that decision in some way.

Relatedly, the Act overrides right 7 of the Code<sup>15</sup> by requiring that a positive determination of the person's competence be made.

The Act requires that a person's competence is assessed by the person's attending medical practitioner, independent medical practitioner, and in

*We were concerned competence wouldn't be there. We already thought the competence wasn't there so it was quite a surprise when the practitioner called the day before, and the cousin put the phone by her ear and she was able to give consent, enough to say they would come on the day. They reduced her medications so on the day she wouldn't be sedated and able to give consent. ... We knew this is what she wished, so if it had been denied on the day that would have been really tough.*

- Friend of someone who received an assisted death

<sup>15</sup> Section 6 of the Act overrides right 7(2) to (4) of the Code of Health and Disability Services Consumers' Rights (the Code) (every consumer must be presumed competent to make an informed choice and give informed consent, consumers with diminished competence retain the right to make informed choices and give informed consent, and providers may provide services in some situations where a consumer is not competent to make an informed choice), as a person accessing assisted dying must be competent to make an informed decision about assisted dying. It also overrides right 7(5) of the Code (advanced directives or advance care plans may be used in accordance with common law), as a person may not use an advanced directive for assisted dying.

the case that either practitioner cannot determine the person's competence, by a psychiatrist.

The Act implies that the person must be competent on the day of the assisted death, to give consent to the administration of the assisted dying medication. The phrase "eligible person" is used when referring to the administration of medication, meaning the person must still be eligible at this point, which must include that they are competent to make an informed decision.

While it is implied, there is no explicit requirement in the Act for a practitioner to check that the person is competent on the day of the assisted death. The Act could be explicit that the person must be competent on the day of the assisted death (when final consent is sought), to support safety in the process by ensuring that people accessing assisted dying are eligible, and competent to consent to it.

### There is a lack of clarity about the core and ongoing duties on practitioners in the Act

The Act is prescriptive and drafted in a way that emphasises the completion of individual procedural requirements to achieve the purposes of the Act (demonstrated through the completion of forms), rather than directly specifying overarching duties on practitioners to be satisfied throughout the process, or at key points during it.

The requirements on practitioners that are set out in the Act should serve to:

- support the purposes of the Act, in particular that assisted dying is only available to those who are eligible, who actively seek and consent to it, are competent to consent to it, and that this consent is provided free from pressure from others
- protect practitioners and people accessing assisted dying by delineating assisted dying from offences under the Crimes Act 1961 (e.g., homicide and coerced suicide).

One effect of the current prescriptive approach to requirements in the Act is that some requirements are implied to be continuous obligations, but are expressed as actions at a point in time. For example, the requirement in section 11(2)(i) that the practitioner must check in with the person at regular intervals is implied to be ongoing, but is expressed as an action that needs to be recorded in a one-off form. This potentially limits the safety and quality of the service that people might receive.

There is a need for a set of clear expectations or duties that apply at key points in the process or in an ongoing way throughout the process, both to indicate those expectations to practitioners providing the service under the Act, and to clarify enforcement pathways to breaches of those duties or expectations (see the following issue identified).

## The legislation takes a one-size-fits-all approach to breaches of the requirements of the Act, and is not clear when an activity is criminal

Section 39 of the Act sets out the offences under the Act:

- A person who is a medical practitioner, nurse practitioner, or psychiatrist commits an offence if the medical practitioner, nurse practitioner, or psychiatrist wilfully fails to comply with any requirement of this Act.
- A person commits an offence if the person, without lawful excuse, completes or partially completes an approved form for any other person without that other person's consent; or alters or destroys a completed or partially completed approved form without the other person's consent.
- A person who commits an offence under section 39 is liable on conviction to imprisonment for a term not exceeding three months, and/or a fine not exceeding \$10,000.

Section 38(1) provides for immunity from criminal liability, where any person is immune from criminal liability if that person *in good faith and believing on reasonable grounds* that another person wishes to exercise the option of assisted dying under this Act:

- takes any action that causes, assists, or facilitates the death, in accordance with the requirements of the Act
- fails to take any action and that failure causes, assists, or facilitates the death, in accordance with the requirements of the Act.

As noted in the section above, the Act ties core duties that practitioners must fulfil to process steps at particular points in time. There are therefore a large number of requirements on practitioners, many of which are subjective, ill defined, and unclear regarding what a practitioner must do to fulfil them.

The offences in the Act take a one-size-fits-all approach: a practitioner commits an offence if that practitioner "wilfully fails to comply with any requirement of this Act". Given the large number of requirements in the Act, and that there is no distinction drawn between the severity of requirements in the Act, breaches of some of the requirements are likely not appropriate or proportionate to the offence – for example, it is unclear whether an error on a form would constitute an offence.

Immunity applies to protect practitioners from some of the most serious offences (e.g., homicide), so it is important that this immunity is lost only where this serious sanction is warranted and proportionate.

Currently, immunity only applies where the action that causes, assists, or facilitates the death was done "in accordance with the requirements of the Act". This means that a practitioner could arguably lose the benefit of criminal immunity where a technical breach of the process occurs (such as a failure to correctly fill in a required form or to send the form at the right point in time), whether or not this was wilful, intentional, or otherwise.

The Act should more clearly set out enforcement pathways for breaches of different types of requirements, in order to clarify which actions are appropriate to result in

criminal liability or an offence under the Act, and which other, less serious actions should result in other disciplinary proceedings.

## The Act could be more specific about what details cannot be published related to assisted deaths

Section 36 of the Act sets out restrictions that limit what information about individual assisted deaths can be made public, including:

- the method by which the medication was administered to the deceased
- the place where the medication was administered to the deceased
- the name of the person who administered the medication to the deceased, or the name of that person's employer.

These conditions apply regardless of whether the individuals involved with a particular assisted death are comfortable or give consent to the details of that assisted death being released.

Allowing the public to access published information about assisted deaths supports transparency and promotes public confidence in the service. However, this must be balanced with the need to protect the privacy of people who have received assisted deaths, their family and whānau, and practitioners involved in that process.

The current restrictions on what information about specific assisted deaths can be published may unnecessarily limit transparency by preventing the reporting of information that does not necessarily breach the privacy of individuals or the safety of the public.

For example, there have been a small number of minor breaches of the restriction on reporting the place where the medication was administered to a person. In practice, the Ministry has taken a proportionate approach to these breaches and issued a warning to outlets, as the details did not constitute a breach of privacy. Similarly, knowing that a person received medication via a particular method is unlikely to affect public safety, while the publication of the specific names of the medications used would raise concern.

## Recommendations

The Ministry makes the following recommendations to address the issues outlined in this section. For each recommendation, it is noted where alternative options were considered.

These recommendations are made as a package, noting that they (intentionally) overlap in places, and are mutually reinforcing.

### **Recommendation 1**

Amend section 10 of the Act so health practitioners cannot raise assisted dying, except as part of discussions about a person's treatment and end-of-life care options.

This change would mean that health practitioners are still prohibited from discussing assisted dying with people when it is not clinically relevant or appropriate. However, assisted dying could be proactively raised with a person as part of a discussion about their treatment or end-of-life care. Health practitioners with a conscientious objection to assisted dying would be expected to fulfil their obligations under the right 6 of the Code to provide all information that a reasonable health consumer would expect to receive, including an explanation of the options available.

This approach strikes a reasonable balance between enabling practitioners to make people aware of assisted dying as an option (in line with good clinical practice), while acknowledging that assisted dying is a sensitive subject that requires thoughtful and nuanced conversations to protect people and support patient choice. This approach would also better align assisted dying with the wider health system and health consumer rights.

### **Alternative options that were considered**

Another option considered was to remove the restriction on practitioners raising assisted dying from the Act entirely. This option would allow health practitioners to discuss assisted dying in the same way as other care options and treatments, and would support transparency and access to assisted dying. However, assisted dying is relatively new in New Zealand, and concerns were raised during engagement that health practitioners may discuss assisted dying with people in inappropriate ways or contexts. In particular, it was noted that disabled people may be at higher risk of pressure. It was determined that the approach recommended above strikes a more appropriate balance between safety and access.

### **Recommendation 2**

Add a provision to the Act stating that nothing in section 10 prevents the publication or provision of public information about assisted dying, or the assisted dying service.

The provision could state that the Ministry of Health and Health New Zealand may publish information related to assisted dying services, including requirements, safeguards, the time involved, as well as available supports and contact details.

While section 10 does not prohibit the publication of information about assisted dying, adding a provision of this nature would explicitly enable it. This would address concerns around section 10 limiting information being available on assisted dying



throughout the health system, as there is currently a reluctance to produce or disseminate information related to assisted dying in health settings.

This change would support the public to be better informed about assisted dying, and support the sharing of information about assisted dying in appropriate health settings or other settings – for example, in community groups that support people’s rights to make decisions, or ensure more vulnerable groups are protected and aware of their rights.

The publication of information about assisted dying would also more easily enable practitioners who have a conscientious objection to providing assisted dying to let people know how they may access the service (e.g., by providing a pamphlet or card with this information).

### **Recommendation 3**

Clarify the threshold for when the process must stop if the practitioner detects pressure. The Act could specify that:

- practitioners must ‘take reasonable steps’ to ensure that a person is expressing their wish free from pressure. This could include by conferring with other health practitioners who are in regular contact with the person and conferring with members of the person’s family or whānau approved by the person (as currently set out in the Act)
- the person’s practitioner must not provide or support an assisted death if they know that the person’s consent has been obtained due to another person citing, counselling, or procuring the person to access an assisted death.

Requiring practitioners to ‘take reasonable steps’ to ensure that a person is expressing their wish free from pressure would apply a more consistent standard for practitioners to detect pressure under the Act. Using this term, rather than requiring practitioners to ‘do their best’, connects this requirement to what is reasonable in the circumstances rather than the capability of individual practitioners.

A change to this effect would also provide a more objective basis for assessing a practitioner’s compliance with the requirement, as reasonableness tests are common in other legislation. Generally, terms such as ‘reasonable care’ or ‘due diligence’ are used to set a legal standard of what a competent practitioner would reasonably be expected to do in the circumstances. Some examples of what could be considered reasonable for the practitioner to do when detecting pressure include:

- talking to a person on their own (away from family, whānau, or friends)
- talking to family or whānau members separately (to discern their involvement in the process)
- engaging with other practitioners involved in the person’s care
- looking for known signs of pressure, for example in body language, comments made, or particular actions.



Note, however, that the above examples unavoidably involve a degree of subjectivity and will likely depend on each situation and context.

This recommendation would also clarify that a practitioner must not provide or support an assisted death where a person's consent has been obtained due to another person citing, counselling, or procuring the person to access an assisted death. This particular wording adds clarity to the current provision in the Act (section 24) by linking with current wording in the Crimes Act 1961 and existing case law. It also clarifies that a practitioner would breach this standard if they continued with an assisted death while *knowing* that a person had not consented freely, rather than if a practitioner had missed a sign of pressure.

#### **Recommendation 4**

Clarify in the Act that the person must be competent and informed to make a decision at key points in the process where the person is making a decision about assisted dying. This includes at the point of assessments, and on the day of the assisted death.

Also, specify some factors that by themselves are insufficient to find that a person is not competent to make an informed decision. These factors could include:

- the person's age
- the person's appearance
- any aspect of the person's behaviour or manner
- whether the person is disabled
- the person's methods of communication
- the person's cultural and linguistic circumstances.

This change would clarify that a person must be considered competent at key points in the process when they are required to make an informed choice or give informed consent. This recognises that a person's competence to give informed consent may fluctuate between decision points, due to the condition a person may have, or the effect of medications they might be taking.

Further, the Act would specify some factors that by themselves are insufficient to find that a person is not competent to make an informed decision. This would increase clarity in the Act about what is relevant to determining competence, and support equitable access, particularly for disabled people.

### **Recommendation 5**

More clearly set out in the Act the core duties that practitioners must fulfil to ensure that the person accessing assisted dying is eligible, actively seeking and consenting to it, is competent to consent to it, and that this consent is provided free from pressure from others.

More clearly define ongoing procedural requirements on practitioners that may constitute steps towards the practitioner's core duties.

Grouping the requirements on practitioners together into a set of core duties in the Act would achieve the purposes of Act in a simpler and more cohesive way than the current approach, which is based on the completion of forms.

These core duties could include the following examples:

- The practitioner has a genuine belief that the person accessing assisted dying is an eligible person, supported by:
  - a practitioner not knowingly providing the Registrar with false or misleading information, making a false or misleading statement, or falsifying documents
  - assisted deaths not proceeding without the practitioner receiving authorisation from the Registrar.
- As in recommendation 3 above, the person's practitioner must not provide or support an assisted death if they know that the person's consent has been obtained due to another person citing, counselling, or procuring the person to access an assisted death.
- In line with recommendation 4 above, a practitioner must not provide an assisted death if they know, or have reasonable grounds to believe, that the person is not competent or has not provided informed consent.

Practitioners' core requirements would be simpler to understand, and ensuring that practitioners have fulfilled these requirements could be used as a mechanism to ensure compliance with the underlying requirements of the Act. This would both support practitioners to understand and make sure that they meet these requirements, while also simplifying prosecution if necessary.

## Recommendation 6

Clarify the enforcement pathways for breaches of particular requirements in the Act, linked to the core duties and requirements as referenced in recommendation 5. There would be three enforcement pathways set out in the Act:

- Intentional breaches of core duties in the Act would be linked to new, specific offences in the Crimes Act 1961. These would apply when a practitioner had knowingly administered (or would have knowingly administered) an assisted death to someone who was not eligible or who did not consent to it.
- Breaches of certain procedural requirements that are necessary to maintain the integrity of the assisted dying process could be linked to specific lesser regulatory criminal penalties under the Act.
- Professional misconduct or where a practitioner has not complied with the requirements of the Code of Health and Disability Consumers Rights (where those actions are not linked to a practitioner intentionally not fulfilling their core duties under the Act) would result in referral to the Health and Disability Commissioner, or the practitioner's responsible authority, and possible disciplinary proceedings by the Health Practitioners Disciplinary Tribunal.

The current immunity provisions in the Act would be removed.

These changes, in combination with recommendation 5, would clarify the enforcement pathways for actions that are criminal and serious enough to be related to the Crimes Act 1961, and enforcement pathways for actions which are less serious and could be linked to breaches of the Code of Health and Disability Consumers Rights, or of other requirements under the Act. These changes would group the requirements on practitioners into categories based on a spectrum of harm, resulting in more intentional and proportionate responses to breaches of duties and requirements under the Act.

Enforcing breaches of core duties would be simplified, as breaches would be less linked to procedural errors. Creating new offences in the Crimes Act 1961 linked to these would improve alignment and integration with existing provisions in that Act, particularly for provisions around defences.

Failing to meet procedural requirements in the Act could also be evidence that contributes to the prosecution of a serious criminal offence under the Crimes Act 1961. For example, a health practitioner not ensuring that a person was expressing their wish free from pressure could be relevant evidence when determining whether the practitioner knew, or was wilfully blind, to the assisted death being carried out without free consent.

### Alternative options that were considered

Another option considered was to link breaches of core duties in the Act to existing offences under the Crimes Act 1961 (e.g., for homicide and coerced suicide). This option would maintain the current approach to immunity in the Act. This was

considered to be undesirable, as the immunity approach in the Act is complex and unclear, and does not adequately protect practitioners.

### **Recommendation 7**

Amend section 36 of the Act to be more specific about what details about an assisted death cannot be published, including:

- the name of assisted dying medications (rather than the method by which the medication was administered)
- the identity of the person who received an assisted death or any details that could reasonably be expected to identify the person (rather than the place where the medication was administered)
- the name of the person who administered the medication to the deceased, and the name of the facility where the person received an assisted death (rather than the name of that person's employer).

This change would improve clarity around what details of an assisted death can and cannot be published. This would more effectively protect the privacy of individuals who access and provide assisted dying services, while allowing for any details outside of these to be published to support transparency.

Specifically preventing the publication of the names of assisted dying medications would support public safety.

## Areas considered that do not require legislative change

### The use of supported decision-making in the context of assisted dying

A small number of submissions raised concern around whether disabled people are well supported enough to participate in assisted dying on an equal basis with others. Consideration was given to whether the Act should include a specific provision setting out how people can use supported decision-making in the context of assisted dying.

Some people may want or need support to make a decision about assisted dying, or to make decisions throughout the assisted dying process. Focus groups with practitioners and some people who had supported others through the process noted that supported decision-making is being used in some cases.

*Some key concerns for EOLCA include ... whether or not disabled people are supported to participate in the scheme on an equal basis with others. This includes ensuring accurate assessment of competency and not excluding disabled people (particularly those with intellectual/learning impairments) unless they cannot be supported to meet service criteria.*

– Whaikaha – Ministry of Disabled People

Current guidance provided to practitioners sets out information around supported decision-making in the context of assisted dying, including that supported decision-making can be used to support people to make an informed decision about assisted dying. Guidance also references additional information about supported decision-making that a person can access, and acknowledges that supported decision-making will look different for different people and at different times. For example, it could mean using talking mats or other visual aids, structuring the decision-making process in a way that the person can respond to, repeating information, using multimedia, and/or involving a trusted advocate.

Because the Act does not exclude the use of support decision-making, and there is existing guidance on how supported decision-making can be used throughout the process, it was considered that no change is required in this area. However, the use of supported decision-making could be strengthened and encouraged in training for practitioners (see recommendation 18).

## Introducing the requirement for an independent witness in the process

The review process involved scanning how assisted dying systems have been implemented in other jurisdictions (see **Appendix 3**), and considering whether any other additional safeguards should be introduced in New Zealand. One such feature present in some other systems is the requirement to have an independent witness present for a request to access assisted dying.

The assisted dying process across Australian states generally requires an independent witness to be present at a number of stages in the process, to confirm that the person consented to proceeding with an assisted death. While the approach varies by state, a witness is typically required when the person makes a first and second request, and when the person consents to receiving the medication. A witness must be someone who will not benefit from the death of the person.

Requiring an independent witness in the process could add an additional safeguard to ensure that a person who requests assisted dying has given their consent to proceed, as the witness would be able to provide an account of the request process if questions were raised about the conduct or actions of the practitioner or the person seeking assisted dying. This could be useful in situations where there may be a suggestion of untrustworthiness on the part of a practitioner, or if consent needs to be documented more clearly.

However, including this type of requirement may also impede access and cause delays in the process for some people, particularly if there were difficulties finding a willing and suitable witness. This would likely disproportionately affect those living in long-term care facilities, those living in more remote areas, and those who do not have family or whānau members to act as a witness. This challenge would be further exacerbated if only certain people were able to be eligible witnesses (such as medical staff, lawyers, etc.).

On balance, it was considered that requiring an independent witness to the process in New Zealand would not be desirable. This is because:

- the onus to locate a witness would be on the person seeking the assisted death, and this would place additional burden on that person at a time where they are likely to be very unwell (particularly if that person did not have family members available to act as a witness)
- there may be impacts on witnesses, depending on who could act as a witness and when in the process they would be required. It would not be appropriate, for example, for a layperson to act as a witness to the assisted death, as this could be highly distressing
- requiring a witness may create cost barriers for people accessing assisted dying if witnesses are required to be reimbursed for their time (e.g., if a health practitioner is required to act as a witness).

## Introducing a timeframe or 'cool-down' period for the assisted dying process

Another potential additional safeguard considered was whether a prescribed timeframe, or cool-down period, should be introduced to the process in New Zealand. This type of requirement would be intended to address concerns about people who are experiencing unbearable suffering making impulsive decisions about seeking an assisted death, by requiring that a certain period of time must pass after the person's request before an assisted death can take place. This time period would be to ensure that the person gives their decision full consideration and reflection.

Cool-down periods are included in a number of Australian states. However, states often allow for an override of the cool-down period in cases where a person's health is declining rapidly. This override highlights a key issue with the notion of cool-down periods – that they are inflexible, and in some cases create barriers to timely access to assisted dying for people. A prescribed waiting period could prolong unnecessary suffering for some people, especially if their condition is rapidly deteriorating, and may place additional pressure on practitioners to urgently complete applications for exceptions.

On balance, it was considered that a cool-down period should not be introduced in New Zealand. While safety might be marginally improved by such a requirement, it would create an additional barrier to access, particularly for those who are in a state of rapid decline or who may face other delays for any reason during the assessment process. To some extent, the request and assessment process under the Act naturally creates a cool-down period, over which a person can consider (and must sustain) their decision.

# Improving the process to receive assisted dying

Central to the availability of assisted dying under the Act is the process for people to seek, be assessed for, and receive an assisted death. The Act is prescriptive in the process that it sets out for this to happen.<sup>16</sup> The emphasis on prescribed processes in the Act reflects an understandable desire from Parliament to closely control and regulate the introduction and operation of what is a particularly sensitive new health service in New Zealand.

## Approach to reviewing the process to receive assisted dying

The review of the Act involved examining the adequacy and effectiveness of the prescribed process in the Act with a view to identifying where it can be improved, both in terms of supporting the administration of assisted dying, and improving the experience of those going through the process.

This has involved drawing on:

- the experience of those involved in managing and regulating the assisted dying process over the past three years, including the current Registrar, the Quality Assurance and Safety group in the Ministry, and Health New Zealand
- feedback from the SCENZ Group, and from practitioners who have been providing the service
- the experiences of people who have been through the process, and feedback shared by the family members and friends of those who have received an assisted death
- initial findings from research looking at assisted dying in New Zealand
- a clause-by-clause legal analysis of the Act compared to current operational practice.

In examining the adequacy and effectiveness of the process set out in the Act, the Ministry considered the following objectives, noting there is sometimes a balance to be struck between them:

- **Access to assisted dying, and timeliness of services** – ensuring there are not unreasonable barriers to completing the process, that the service is provided in a timely manner to limit uncertainty and suffering, and that the process after death is straightforward, respectful, and does not hinder normal grieving processes.
- **Clarity and consistency** – ensuring that the Act sets out clear requirements for the process, and in a way that maintains consistency throughout.

<sup>16</sup> Note that the level of prescription in the Act is similar to legislation in other jurisdictions that enables assisted dying, such as Australia and Canada.

- **Autonomy and control for people accessing the service** – ensuring that those seeking assisted dying access the service in a way that is appropriate for their wishes and needs.
- **The safety of the service that people seeking assisted dying and those supporting them receive, and safety of the workforce** – this means ensuring that that assisted dying is only available to those who are eligible, who actively seek and consent to it, are competent to consent to it, and that consent is provided free from pressure from others.
- **The quality of the service that people seeking assisted dying and those supporting them receive** – for assisted dying services, quality depends on things like effective communication, empathy, cultural competence, and support for continuity of care.

## Background information

The key process steps to access assisted dying are as follows:

- The person makes a request for assisted dying. They are referred to an attending medical practitioner through the Assisted Dying Service.
- The attending medical practitioner ensures that the person, and their family or whānau, have sufficient information to assist them to make an informed choice. The person signs a consent form.
- The attending medical practitioner assesses whether the person is eligible. If they form the opinion that the person is eligible, they contact the Assisted Dying Service for an independent medical practitioner.
- An independent medical practitioner is nominated by the Assisted Dying Service, and assesses if the person is eligible.
- If either practitioner has concerns about whether the person is competent to make an informed decision, a psychiatrist is asked to provide an assessment of the person's competence.
- If the person is confirmed as eligible, they choose the date when the medication will be administered and the method of administration. If the person is not eligible, the process stops.
- The attending medical practitioner writes the appropriate prescription and informs the Registrar.
- The Registrar checks the forms have been completed and notifies the attending medical practitioner if they are satisfied that they have met the requirements of the Act. A pharmacist then dispenses the medication to the attending medical practitioner or an attending nurse practitioner.
- The medication is administered to the person by the attending medical practitioner or an attending nurse practitioner.
- The assisted death is confirmed and reported to the Registrar. The Registrar provides the assisted death report to the Review Committee.

It is important to note that this is a simplified summary of the process set out in the Act, which includes a large amount of prescribed detail, including requirements for practitioners to complete forms at each step to demonstrate compliance with the



processes set out in the Act. There are currently 13 possible forms, noting that more forms may be completed where the date set for the assisted death needs to be moved. There are also additional forms for writing the prescription and the death certificate.

## Key issues identified

### The Act is not sufficiently clear on what should happen when a person is declined assisted dying in different circumstances

There are a number of reasons why a person might be declined assisted dying during the process, including:

1. not meeting the qualifying eligibility criteria – i.e., if a person was under 18 years of age, or not a citizen or permanent resident
2. not meeting the clinical eligibility criteria – for example, if the person had a terminal condition but did not meet prognostic timeframe, was not in an advanced state of irreversible decline in physical capability, or not experiencing unbearable suffering
3. not being found competent to make an informed decision
4. a practitioner suspecting that the person may be acting under pressure from another person and ending the process
5. a person outliving their prognosis.

A person might be declined assisted dying for any of reasons 2 – 5 at various points throughout the process.

The Act provides some direction on what a practitioner should do when a person has been found ineligible – section 16 sets out that if a practitioner reaches the opinion that the person is not eligible for assisted dying, the practitioner must “explain the reasons for their opinion to the person”. However, the Act only provides direction on what should happen as a next step in the process in two situations:

- When a person who has been found eligible rescinds their request: Under section 23, if at any time an eligible person rescinds their request, the practitioner must complete a form recording this decision, provide this to the Registrar, and take no further action in respect of the person’s request. If the person wishes to access assisted dying again, they must make a new request. This is the only section in the Act that explicitly references when a person needs to make a new request following a process in the Act.
- When a practitioner suspects pressure: Under section 24, if at any time an attending medical or nurse practitioner suspects on reasonable grounds that a person is not expressing their wish free from pressure, the practitioner must take no further action to assist the person. They must also tell the person that they are taking no further action, and record this in a form which is provided to the Registrar. This section implies that the process ends at this point and, though it is not stated, that the person would need to make a new request if they wanted to access assisted dying in the future.

Outside of these references, the Act is largely silent on when the process to seek an assisted death should cease and a person should be required to make a new request if they wish to reapply.

Operationally, the Act has been interpreted to require that where a person is found ineligible for assisted dying, the process ends, and that person is required to make a new request if they wish to seek assisted dying at a future date. An exception to this interpretation is when a practitioner has found that a person is not competent to make an informed decision. Some flexibility is required in these circumstances, noting that a person's competence to make an informed decision may fluctuate due to the nature of their condition, and the effect of medications that they may be receiving. The current process in this situation is to pause the process and reassess competence at a later date.

Given that the process in the rest of the Act is relatively prescriptive, and there is a process set out for when a person rescinds their request, the Act could more explicitly state what is required in other situations where a person is declined assisted dying to maintain clarity and consistency in the process.

### The Act does not provide sufficient direction for whether and how the responsibilities of an attending medical practitioner may be transferred to another attending medical practitioner during the process

The process to seek and receive an assisted death relies heavily on the role of the attending medical practitioner, who provides information, assesses eligibility, supports the person through the process, and administers the medication at the end of the process.

The Act is currently written in a way that implies the attending medical practitioner will provide end-to-end care throughout the process. The Act only enables a replacement attending medical practitioner to be appointed in situations where the practitioner initially approached does not wish to provide assisted dying due to a conscientious objection (section 9(3)).

There are a range of circumstances that may result in an attending medical practitioner not being able to continue in their role. For example, the practitioner may not be available for the person's chosen date for the assisted death, may become unwell, or may have other unavoidable commitments that mean they are unable to continue with the process. Further, a person accessing assisted dying may wish to be supported by a different practitioner.

The Act is silent on whether, or when, a different practitioner may take over the role of a person's current attending medical practitioner. It is important that the ability to appoint a replacement practitioner is enabled, to support accessibility and provide security for the person that the process can continue if the attending medical practitioner is no longer available.

Current operational practice is to allow for replacement attending medical and nurse practitioners to be appointed in situations where the original attending medical

practitioner is unable to continue. It would be preferable for the Act to provide a legal foundation for a replacement practitioner to be appointed, to ensure that accountabilities in the process are clear, and that the process is safe for people and practitioners.

## The time period during which a person can receive an assisted death after being found eligible for assisted dying is not sufficiently clear under the Act

Under section 17(2)(d), when a person is found eligible for assisted dying, they are given a form to complete which includes choosing the date and time for the administration of the assisted dying medication. This section does not specify a timeframe within which a person is able to set the date. However, this has been interpreted operationally to be within a six-month period, reflecting the eligibility criteria for assisted dying that the person must be suffering from a terminal illness that is likely to end their life within six months.

After setting an initial date for the administration of the medication, the person can change the date (or rescind their request) at any time. Sections 17, 19, and 20 of the Act state that the practitioner must ensure the person knows that they can decide, at any time before the administration of the medication, not to receive the medication or to receive the medication on a later date that is *not more than six months* after the date they initially chose.

Therefore, the Act is currently interpreted to indicate that a person seeking an assisted death can receive the assisted death within a period of up to 12 months after they are determined to be eligible.

This approach creates some inequity in the process, as some people will have a longer timeframe within which to set the date of their assisted death depending on when they set their initial date. For example, if a person is found eligible and sets the initial date six months into the future, they can then at a later point decide to move this date out by up to a further six months (resulting in the 12-month window). However, if a person sets the initial date three months into the future, they may only extend this date by up to a further six months, resulting in a possible nine-month window.

It is unclear whether this is what was intended by Parliament when the Act was passed, or whether Parliament expected that a person should be able to set and move the date of an assisted death within a fixed period.

While official data is unavailable on how many people have lived longer than their prognosis, early analysis indicates that the number of people approved for assisted dying who live beyond six months has been low.

## The requirements in the Act for setting and moving the date of an assisted death are unnecessary, and can prolong suffering for people who need to bring the date forward

The Act is prescriptive about the processes for managing the specific date where someone receives an assisted death. This includes requiring that:

- when a person is found eligible for assisted dying, they must immediately choose a date on which they wish to receive the medication (section 17(2))
- each time that a person wishes to move the date to a later point, the attending medical or nurse practitioner must complete a new form and provide this to the Registrar (section 18(3))
- the attending medical practitioner or attending nurse practitioner must advise the Registrar of the date, method, and time chosen for administration of the medication at least 48 hours before that time (this is often referred to as 'the 48-hour rule'). The Registrar must then undertake a compliance check and notify the practitioner (section 19(3-5)).

The Act does not specify a process for bringing the date of an assisted death forward. However, the Act can be interpreted as requiring that a new form be completed by the attending medical or nurse practitioner as a change of the date of the assisted death, which means that the requirement to advise the Registrar 48 hours before the new date applies.

Families and friends of people who had received an assisted death, and practitioners who provide assisted dying, provided very strong feedback questioning the necessity of the compliance requirements set out above related to setting and moving the date for an assisted death.

Their feedback indicated that some people and their families can find the need to choose a date when they are first found eligible confronting. Those who were close to the end of their life found it easier to set a date (and often set the date to be as soon as possible), and others for whom death appeared to be several months away often picked the furthest date out, on the basis that they would be able to bring the date

*Another thing that was strange is that you have to set a date when you're not ready to set a date or be using it yet. I would recommend a date range you're allowed to set a date in, but not needing to set the date that you know you're not going to use.*

*Having to nominate an actual date is quite daunting – we could see why, in terms of availability of doctors and need to order drugs, but it might be something that could be left more open?*

*We found the process quicker and more efficient than we expected. On the website it implied that it could take some time to get approval, so [x] applied well before he expected to need the process. That said, the disease progressed much more quickly than he anticipated, so the initial date he nominated (late April) was gradually moved forward to mid-March.*

- Family members of people who received an assisted death

forward later if they needed to. For these people, families noted that they found it odd to need to set an arbitrary date in advance, just to complete the compliance process.

Practitioners likewise noted that the end of life can be an unpredictable period, where a person's condition can fluctuate daily, requiring flexibility in how people and their pain are managed, and when an assisted death may be needed.

The '48-hour rule' in particular was strongly criticised. This rule means that, in some cases, the date of the assisted death cannot be brought forward quickly enough when a person's condition deteriorates faster than expected. This means that some people may pass away before their new date can be re-approved by the Registrar, and may suffer for longer while they wait for the 48-hour period to elapse. Practitioners described the 48-hour rule as 'cruel' and 'intrusive'. Many noted that while they understood the need for the Registrar to check compliance under the Act in the first instance, steps beyond that check should be between the person and their practitioner.

The level of prescription in the Act related to the process for a person to seek assisted dying reflects the need to ensure that the process is safe, and that only people who are eligible, competent, and acting free from pressure are able to receive an assisted death. However, this level of prescription in the process after a person has been found eligible does not add any additional safety benefits. New Zealand also appears to be the only country that requires a person to choose a date and time at the point when they are found eligible, with comparable jurisdictions providing more flexibility for setting and moving the date for an assisted death.

A number of these requirements could be removed to improve accessibility and the autonomy people are able to exercise in the process. Such a change would not impact on the safety of people receiving assisted dying, or the information that is recorded to ensure that there is a clear record of the process. For example, there is another process under the Act for the attending medical or nurse practitioner to record information about an assisted death after the person has died (an 'assisted death report' – see section 21 of the Act). This report captures details of the assisted death, including the date, location, method, and confirming that eligibility requirements were met.

*We were told there would be an issue if it would be within 48 hours. I can't understand that, who is it protecting? If someone suddenly takes a turn for the worse, and maybe they want to bring it forward by a day, why would that be a problem if you've already been assessed and approved?*

*Once you've been approved and gone through all the systems, maybe the doctor and the patient could have a little bit of responsibility and leeway on the timing. It's cruel, it's really cruel – you're begging for it to be brought forward, and in the end, we saved him one day.*

*It was not fast enough. The service was not nimble enough to cope with a faster than anticipated deterioration. It was only with a desperate plea to the attending medical practitioner and his incredible help that we were able to achieve an assisted death. I am a very proactive person and I struggled to get the help in time to meet my husband's needs / wishes. I hate to think how it would be for less assertive persons.*

- Family members of people who received an assisted death

*I had an assisted death scheduled for 10:30 am. An elderly and very pragmatic lovely man in the end stages of prostate cancer. ... His family phoned me approximately 24 hours ahead of the scheduled death saying that he had had a horrific 24 hours and was requesting that the death be brought forward – he would like it as soon as possible and did not want to go through another night like the last one.*

*Although I had the medication, the time and the desire to help, I had to tell him that I could not change the date without 48 hours notice to the Registrar. He then asked if I could attend at midnight and carry out the assisted death as shortly after midnight as possible – thus complying with the law. I double checked with the Assisted Dying Service and this was compliant with the law.*

*He was desperate in his request and I agreed. I went to bed and set my alarm for 11:10 pm, though I don't think I got much sleep as I was scared I might sleep through the alarm and let him down. I arrived at the location around 11:40pm, and obtained a very sincere and desperate consent for me to proceed. His lovely family and myself waited until midnight and then proceeded with the assisted death which was very peaceful.*

– Assisted Dying Practitioner

A related issue in the Act is that when a person is found eligible, in addition to choosing a date they must also select a method for the administration of the medication from one of the four methods referenced in the Act (section 19(2)). This provision was likely included to ensure that the attending medical practitioner would have time to arrange for medication and equipment to be available on the chosen date to support the method selected by the person.

However, the way that assisted dying has been implemented means that this provision serves little purpose in practice. Practitioners receive a kit that includes medication and equipment to allow for the chosen method, plus a back-up option that may be used if appropriate. For example, if the person chooses to receive the medication orally, this method is supplied with back-up IV medication and equipment. This is done to support patient choice, and to ensure that practitioners have a back-up option available in the event that the chosen method is no longer clinically appropriate.

This process means that it is unnecessary for the person to decide the method of administration when they are found eligible, particularly when it may be some months until the person's chosen date. In some cases, a person's condition may progress so that a method of administration chosen at that earlier point may no longer be appropriate on the day of the assisted death (for example, if the person chose to receive oral medication but they are no longer able to swallow, or if the person wishes to change their mind about how they receive the medication).

## The Act includes a level of operational prescription in places that is unnecessary in primary legislation, and could have unintended effects on how assisted dying is provided over time

There are several areas in the Act where requirements are set out at a level of operational detail that is unnecessary, and which may unintentionally limit or prevent improvements to the way assisted dying is provided over time. The level of prescription in the Act reflects a desire from Parliament to closely control and regulate assisted dying; however, this has had unintended effects.

One example of this is section 19(2)(a), which specifies the four methods that a person can choose for the administration of assisted dying medication. This is an unusual inclusion in the context of wider health legislation, as health legislation is usually focused on setting the legal framework for providing health services, the outcomes sought, and the mechanisms needed to achieve these. This recognises that clinical determinations are the domain of health experts. As such, clinical processes and procedures are usually set out in clinical guidance and regulated standards of care.

Similarly, references to practitioners writing or destroying prescriptions are not required in the Act, as these references duplicate existing processes that are well established around the management of medications in the wider health system.

Further, the ability to make regulations under the Act is limited. The Act currently includes a regulation-making power that enables making “regulations providing for any matters contemplated by this Act, necessary for its administration, or necessary for giving it full effect”. However, the scope of this power is limited given the combination of its framing (which is relatively vague), and the level of prescription in terms of detail that is already included in the Act.

## Recommendations

The Ministry makes the following recommendations to address the issues outlined in this section. For each recommendation, it is noted where alternative options were considered.

These recommendations are made as a package, noting that they (intentionally) overlap in places, and are mutually reinforcing.

### **Recommendation 8**

Add a provision stating that a person who is found ineligible for assisted dying, or who has rescinded their request to exercise the option of assisted dying, must submit a new request if they wish to reapply at a later date.

This recommendation would increase clarity about the procedure for when the assisted dying process ends, and a person must make a new request. This approach would ensure that where a person is found ineligible for any reason, it is clear that they are



required to go through the full process again for a new request, including assessments by an attending practitioner and independent medical practitioner.

### Alternative options that were considered

Another option considered was to include a requirement that when a person who was found ineligible makes another request, they must be assessed by the same attending practitioner who assessed them previously. This option would guard against situations where a person found ineligible by one attending practitioner may seek out a different attending practitioner to try and attain a different result.

In practice, where a person makes a request more than once, it can be desirable to have the same practitioner assess the person again because they are familiar with the person's situation and condition, and may have a better sense of whether or how their condition may have changed. However, this may not be practical or appropriate in every situation, and the ability to have someone be assessed by a different attending practitioner can also be beneficial in some situations. As such, and because of these factors, it was considered that this should be managed operationally.

#### **Recommendation 9**

Add a provision that enables the functions, responsibilities, and duties of an attending practitioner to be transferred to another attending practitioner, provided that the new attending practitioner agrees to take on the role.

When the new attending practitioner takes on the role, they must advise the Registrar.

The provision would state that the role of attending practitioner cannot be transferred to the independent medical practitioner.

This change would provide clarity around the ability for an attending practitioner to transfer their functions, responsibilities, and duties to another attending practitioner in situations where they are no longer willing or able to continue to act as a person's attending practitioner, or where the applicant does not want to continue with their current practitioner.

The responsibilities and ongoing duties of the original practitioner would be transferred to the new practitioner, which means they would need to be comfortable that the person still meets the requirements in the Act. The way this would likely work in practice would be as follows:

- The original attending practitioner would be unable or unwilling to exercise their functions, and communicate this to the person. Alternatively, the person would communicate a desire for a different practitioner.
- The original attending practitioner would ask the Assisted Dying Service to, as soon as practicable, provide the contact details of another attending practitioner willing to provide the service for that person.
- The replacement attending practitioner would confirm that they are willing to act as the person's attending practitioner, and notify the Registrar of the transfer.



- The original practitioner would provide a handover to the replacement attending practitioner, including sharing notes and introducing them to the person.
- Where the transfer has taken place after the person has been found eligible and the Registrar has determined that an assisted death can occur, the replacement attending practitioner would ensure they are comfortable that the person is eligible before proceeding.
- The original attending practitioner would return any medication to the pharmacy, and the replacement attending practitioner would be required to write a new prescription.

The attending practitioner would not be able to transfer their functions to the independent medical practitioner, as this could compromise the independence of that role. Further, some practitioners choose to become independent medical practitioners specifically because they do not wish to act in the role of an attending practitioner.

### Alternative options that were considered

Another option considered was to require that, where an attending practitioner is no longer willing or able to continue to act as a person's attending practitioner, the process must start again with the person making a new request to a new attending practitioner. The impact of this approach would vary depending on how far through the process the person is – for a person near the end of the process, the impact of starting again could be significant and potentially delay or prevent them from receiving an assisted death. This approach was therefore not recommended.

#### **Recommendation 10**

Add a provision that establishes a six-month period within which a person is able to set a date and receive an assisted death, following approval by the Registrar. This six-month period would commence from the date when the Registrar determines that compliance requirements have been met.

Further, add a provision providing that an additional six-month extension of this period may be granted by the Registrar if at the end of the initial six-month period:

- the attending practitioner is of the opinion that the person continues to be eligible for assisted dying, and
- the Registrar is satisfied that the attending practitioner has provided sufficient information demonstrating continued compliance with the requirements of the Act.

This provision would provide greater clarity about the time period during which a person can receive an assisted death under the Act. It would replace existing provisions that reference the ability for the person to change the date of the assisted death, which are unclear and can be applied inconsistently.

This approach is recommended because it most closely reflects what is currently provided for in the Act, but with greater clarity and consistency.

## Alternative options that were considered

Three alternative options were considered.

The first option would involve limiting the period within which a person can receive an assisted death to a fixed period of six months. People who had not passed away by this point would be required to make a new request and go through the process again. This approach would align more closely with the six-month prognosis requirement. However, given that the requirement in the Act is that a person has a terminal illness *likely* to end their life within six months, it is reasonable to expect that some people may live for longer than six months, but still be experiencing suffering and be expected to die within a slightly longer period.<sup>17</sup>

The second option would involve allowing a person to receive an assisted death during a fixed 12-month period after they have been determined to be eligible. This would reflect the maximum 12-month period operationalised under the current legislation. However, it was considered that this approach would enable a person to set an initial date more than six months into the future, and that this may run contrary to the six-month prognosis requirement.

The third option would involve removing the requirement for a time period within which a person can set a date entirely. This approach is common in other jurisdictions, including the Australian states, and acknowledges that:

- the nature and speed of a person's decline at the end of their life can vary
- the inclusion of an eligibility requirement linked to prognosis (i.e., being expected to die within six months) places a natural limit on how long a person has to receive an assisted death, with most people expected to die within this timeframe or just outside of it
- the requirement for a person to be eligible continues throughout the process, including on the day of their assisted death, which means that they still need to meet all of the requirements in the Act to receive an assisted death
- in the event that a person unexpectedly recovers, they are unlikely to want an assisted death.

However, it was considered that this would be a significant change to the current approach in the legislation.

<sup>17</sup> Note that the End of Life Choice Bill initially included a fixed six-month time period, before provisions were added later on in the parliamentary process allowing the person to move the date up to six months beyond the chosen initial date. There may have been a concern that a six month period would result in people choosing to have an earlier assisted death than planned, due to worry that they would need to make another application and risk losing competence to make an informed decision.

## **Recommendation 11**

Remove the requirement for the person to choose a date and time for administration of the medication after they have been found eligible (section 18).

Remove references in the Act to the "date initially chosen" (sections 17(2)(e)(ii), 19(2)(c) and 20(2)(b)).

Remove the requirement to choose a method for administration of the medication after a person has been found eligible (section 19(2)(a-c)).

Remove the 48-hour rule and related provisions requiring the Registrar to check compliance and confirm compliance with requirements in the Act (section 19(3), 19(4), and 19(5)).

*Note that the 'check' by the Registrar referenced in this recommendation is strengthened through recommendation 22.*

The requirement for a person to choose a date immediately after they have been found eligible, and the process requirements related to moving this date, do not provide tangible benefits to the process and can result in additional delays to the process, resulting in people experiencing prolonged pain and suffering.

Some of these provisions are currently required in the Act, as they establish the time period within which a person can receive an assisted death (for example, the additional six-month period is calculated from the date that a person initially chooses). However, if a provision is added specifically setting out this period (as per recommendation 10), these provisions are no longer required.

Further, the requirement in the Act for a person to choose a method for administration of the medication is prescriptive and inflexible, and there is no benefit to the Registrar being informed of this method. Removing this requirement would improve flexibility on the day of the assisted death if the method for administration needed to change, as it removes compliance on the practitioner to use the method that the person initially chose (e.g., if the initial method chosen became clinically unsuitable).

If the changes in this recommendation and recommendation 10 are made, the process would be as follows:

- A person must be determined to be eligible for assisted dying (as per the process in the Act).
- The Registrar would determine that compliance requirements in the Act have been met, and authorisation would be provided to the attending practitioner to proceed. The six-month timeframe would begin from this point.
- The person and the attending practitioner would then work together to decide a date within the six-month period, and an appropriate method for administration of the medication. This might happen right away, or the person might decide that they want to wait a while before deciding.

- The person would be able to change their mind at any point, and set a new date or choose a different method for administration in discussion with the attending practitioner.
- After the assisted death has taken place, the attending practitioner would complete an 'assisted death report', which provides details of the assisted death (see section 21 of the Act), which would then be provided to the Registrar (as per the current process).

While these changes might raise expectations from people seeking an assisted death about how quickly the process can progress, it was considered that this can be managed operationally by providing good information about the service and the processes required (e.g., noting that assisted dying is not an acute service, and that time will be required for medications to arrive), and encouraging the person and the attending practitioner to discuss what timeframe would be reasonable in each situation.

### **Recommendation 12**

Expand the regulation-making power in the Act to state that regulations must be made to specify:

- what a practitioner is required to do when they 'examine' a person as part of the assessment process
- the methods for administration of the medication
- requirements for the management of prescriptions made under the Act.

Remove the following provisions from the Act (on the basis that these will be covered by regulations instead):

- The list of methods for administration of the medication (section 19(2)).
- Provisions involving the way that prescriptions are managed (section 19(3)(a) – also removed by the recommendation above – and section 22).

While the Act currently includes a regulation-making power, the scope of this power is limited. Expanding the regulation-making power, and moving some of the prescribed operational details from the Act into regulation, would enable more flexibility in each of the areas to be set out while maintaining a level of regulatory oversight and control.

Having regulations specify what a practitioner would be required to do when they 'examine' a person would address an area where the Act is currently silent. There is value in setting minimum standards in regulations for how assessments should be carried out, as this would clarify expectations on practitioners for what should be included in an examination, and support consistency in the approach to the examination between practitioners.

## Minor recommended changes

In addition to the previous recommendations, the Ministry has also identified a number of smaller changes that would improve provisions in the Act related to the process to access assisted dying. The table below outlines each of these recommendations and a brief rationale for why each change is recommended.

**Table 3: Minor recommended changes to improve the process to receive assisted dying**

Recommendation	Rationale
Add a provision to require the attending practitioner to examine a person before forming an opinion on whether they are eligible.	This change would make requirements for attending practitioners consistent with the other practitioners referenced in the Act. Wording for the requirement to ‘examine’ the person is currently included for independent medical practitioners and psychiatrists, but not attending practitioners.
Make an amendment to specify that an Attorney acting under an Enduring Power of Attorney for personal care and welfare (EPOA) may not make decisions about assisted dying for another person.	This change would clarify that Attorneys acting under an EPOA are not able to make decisions about assisted dying for another person, reflecting the intent of the Act that no person should be able to make decisions about assisted dying for another person.
Make an amendment to specify that an independent medical practitioner must not confer with the attending practitioner when they are forming their opinion about the person’s eligibility.	<p>This change would provide increased clarity about how the independent practitioner is independent in the process (i.e., that they form their opinion about the person’s eligibility independently from the attending practitioner).</p> <p>It is important that this clarification is included in the Act, as this is different from the way that health practitioners operate in other parts of the health system where it is common practice for practitioners to discuss the care of a person as a team.</p> <p>This requirement, accompanied by the existing requirement for independent medical practitioners to be selected by the Assisted Dying Service, would ensure appropriate independence.</p>
Make amendments to reduce the level of prescription in the Act by changing the requirement for a practitioner to ‘send’ forms to the Registrar, to a requirement to ‘ensure that the required information is provided’ (see, for example, sections 12(5)(c), 13(3)(b), 14(4)(b-c), 15(4)(b-c), 16(5)(b), 17(3)(b), 20(3)(c), 22(2)(c), 23(2)(b), 24(d)).	This change would increase flexibility by enabling others who work with practitioners to provide information to the Registrar where this is required (e.g., a receptionist or other practitioners working in a practice), and provide some flexibility in the method to be used to send the form (such as the use of online systems).
Make an amendment to broaden section 35 so that it states that a person who dies as a result of assisted dying is, for the purposes of “any contract, deed or other financial instrument”, taken to have died as if assisted dying had not been provided.	This change would expand the protection provided in section 35, which is intended to prevent people (and their beneficiaries) from being financially penalised because they received an assisted death. The current wording may limit this protection to

Recommendation	Rationale
<p>Add a requirement to section 12 so that where the form requesting an assisted death is signed and dated by another person (a proxy), that person's contact information must be recorded.</p>	<p>contractual contexts, and exclude non-contractual situations such as wills and deeds.</p> <p>This change would enable the contact information of anyone who signs the request form on behalf of the person seeking assisted dying to be recorded as part of the process. These details may be needed in future if there is an investigation into a person's death.</p>

## Areas considered that do not require legislative change

### Adding an appeal process

The jurisdictional scan highlighted that some Australian states allow for decisions about a person's eligibility made by the first or second practitioner to be reviewed by a tribunal. This only includes decisions about the person's residency, whether they were competent to make a decision, or whether they were found to have been under pressure from others.

The Ministry considered whether there is a need for an appeal process to be set out in the Act where a person is found ineligible for assisted dying. It was determined that this is not required, on the basis that:

- there are already existing mechanisms to address concerns about the competence or conduct of a practitioner (e.g., via a complaint to the Health and Disability Commissioner)
- developing and operating an appeal process would have significant operational and financial implications, and could potentially reduce the capacity of what is an already limited workforce
- in practice, making a new request and going through the assessment process again would likely be quicker than awaiting a decision from an appeal process
- public law remedies are available in relation to the decisions of the oversight roles, such as the Registrar (for example, judicial review).

### Removing references to assisted dying from death documents

Under current settings, the attending medical or nurse practitioner is required to complete a Medical Certificate of Cause of Death (MCCD) when the person dies. The MCCD is a legal document which records the full details of the deceased, the circumstances, and the cause of death. The MCCD for an assisted death must include that an assisted death was the primary cause of death, and record the underlying health condition.

'Assisted Dying' must also be recorded in official records, including the certificate of cause of death (death certificate). The death certificate provides a record of the death and contains personal information about a deceased person. This certificate is different from a MCCD, and is used for various administrative and legal purposes, such as the administration of the person's estate or applying for a funeral grant.<sup>18</sup> During implementation of the Act, the Department of Internal Affairs made the decision to include 'assisted dying' on death certificates as a way to ensure that the Coroner did not need to investigate assisted deaths. Death certificates can be requested by any person, and will include references to an assisted death where this applies.

*Families are telling our members they have been embarrassed and upset and have had to justify their loved one's decisions – in some cases a decision they may not even have agreed with.*

– Funeral Directors Association of New Zealand

Feedback from a range of stakeholders during the review indicated that the current requirements for assisted dying to be recorded on the death certificate have posed challenges for people and their families, particularly in small communities, as some families may prefer to keep the nature of the family or whānau member's death private.

The Health and Disability Commissioner, Funeral Directors Association, and assisted dying researchers<sup>19</sup> have noted that family or whānau members may have a range of reasons for feeling uncomfortable with assisted dying being recorded on a death certificate. This includes concerns about social stigma, and not wanting other people to know about something they consider to be private. Researchers noted that whānau Māori were often unaware that assisted dying would be recorded on the death certificate, which caused distress when viewed by other people (e.g., funeral directors) as this was considered confidential information for whānau.

*When I collected the death certificate from the funeral directors it was a shock to see assisted dying on there. ... Due to the secrecy requested I hadn't discussed it with the funeral director, so was embarrassed that I hadn't. If it's not already in the process for people to know this when making the choice, I would recommend that it is added.*

– Family member of someone who received an assisted death

Suggestions raised during targeted engagement included:

- removing the requirement for assisted dying to be recorded on the death certificate, and/or requiring that the cause of death be the illness the person would have died from
- using an 'assisted dying' code to be more discreet
- making people who are going through the process aware in advance that assisted dying will be recorded on the death certificate, so that they can prepare themselves.

<sup>18</sup> The cause of death as recorded on the death certificate does not affect these purposes.

<sup>19</sup> Submission received from the 'Exploring Early Experiences of the Assisted Dying Service in Aotearoa' Research Group.

On the other hand, some practitioners and family members who had supported someone through the assisted dying process commented that they did not think assisted dying should be removed from death certificates, as they were concerned this might contribute to assisted dying being stigmatised, or 'something to be ashamed of'.

Whether to record assisted dying on death certificates was a point of contention when the Act was being considered by the Select Committee, with arguments made for and against. Some considered that recording the underlying terminal illness on the death certificate, and not assisted dying, would be 'fraud' and a 'falsification' of the death certificate that would lead to incorrect reporting of deaths and inadequate review processes. Further, some identified that it would be difficult or problematic to anticipate what the cause of death would be, had assisted dying not been provided.

Others considered that the recorded cause of death should be the underlying disease process or primary diagnosis that made the person eligible for an assisted death. One example given was that death certificates offer a genealogical record to families and descendants, and that the underlying cause of death may be important to descendants.

Approaches in other jurisdictions to recording assisted dying on death certificates vary. For example, Queensland, New South Wales, and Western Australia prohibit these documents from including references to assisted dying, while Tasmania and South Australia appear to be silent on whether assisted dying should be recorded. New South Wales and Victoria require assisted dying to be referred to on the death register as the 'manner' causing death, with a person's underlying condition noted as the cause.

On balance, it was considered that retaining that the person had an assisted death on death certificates captures that the death was caused by assisted dying, and serves to normalise assisted dying in the health system. The issues raised above can be mitigated by ensuring that families and whānau are aware that assisted dying will be listed as the cause of death on the death certificate.



# Aligning the Act with the wider health system

Assisted dying is a service under the Pae Ora (Healthy Futures) Act 2022. It is also provided by agencies and workforces within the wider health sector, and accessed through other health services. This means that assisted dying should be aligned with standards governing the wider health system, including wider workforce regulations, the Code of Health and Disability Services Consumers' Rights (the Code), and the expectations on health agencies and health entities in undertaking their roles.

However, assisted dying must also be recognised as a service that is particular and distinct from other services in the health system. It has very different processes and outcomes, and additional features to ensure the safety and autonomy of health consumers. This has been expressed, for example, where the Act overrides certain parts of the Code to provide for safeguards over and above what would normally be expected for a personal health service.<sup>20</sup>

As such, there is a careful balance to be struck between aligning assisted dying with the health system, while also maintaining some systems and processes that remain specific to assisted dying. Where separate systems have been created to support assisted dying, this has been to ensure safe and appropriate access to assisted dying without creating a full standalone system.

## Approach to reviewing the alignment of the Act with the wider health system

The Ministry has sought to examine how well the Act is aligned with the wider health system, and whether changes are needed to improve or strengthen this alignment. This part of the review has drawn on:

- the experience of those involved in managing and regulating the assisted dying process over the past three years, including the current Registrar, the Quality Assurance and Safety group in the Ministry, and Health New Zealand
- feedback from a number of organisations, including those involved in the provision of palliative and end-of-life care, those that regulate and monitor

<sup>20</sup> The following parts of the Code of Health and Disability Services Consumers' Rights are overridden by the Act:

- Right 6(1)(b and c) (the right to an explanation of options available) and right 6(2) (the right to information that a consumer needs to make an informed choice or give informed consent) are overridden by section 10(1) of the Act, which prevents practitioners from raising assisted dying with a person.
- Right 7(2) to (4) (every consumer must be presumed competent to make an informed choice and give informed consent, consumers with diminished competence retain the right to make informed choices and give informed consent, and providers may provide services in some situations where a consumer is not competent to make an informed choice) is overridden by section 6 of the Act as a person accessing assisted dying must be competent to make an informed decision about assisted dying.
- Right 7(5) (advanced directives or advance care plans may be used in accordance with common law) is similarly overridden by section 6 of the Act as a person may not use an advanced directive for assisted dying.

workforces that can be involved in assisted dying, and the Health and Disability Commissioner

- the experiences of practitioners who have been providing the service
- the experiences of people who have supported others through the assisted dying process
- initial findings from research looking at assisted dying in New Zealand
- a clause-by-clause legal analysis of the Act, and analysis of the Act and provision of assisted dying against the relevant rights set out in the Code
- a scan of how assisted dying is provided in comparable overseas jurisdictions.

In examining how well assisted dying is aligned with the wider health system, the Ministry considered the following objectives, noting there is sometimes a balance to be struck between them:

- **Upholding health consumer rights** – assisted dying is a health service, and as such, the provision of assisted dying must uphold health consumers' rights in a similar manner to other health services (where these are not overridden by the Act).
- **Upholding relevant rights and interests addressed through the Act** – the provision of assisted dying must also uphold relevant rights and interests addressed in the Act, such as the right of individuals to conscientiously object.
- **Access to assisted dying, and timeliness of services** – ensuring that the way assisted dying is provided and aligned with the health system supports equity of access, and timeliness of the service.
- **The quality of the service that people seeking assisted dying and those supporting them receive** – assisted dying services should draw on existing pathways for support as much as possible, and link in with the wider health system in a way that supports quality of services and continuity of care.

## Background information

### **Key points of interaction between assisted dying and the wider health system**

There are a number of points where assisted dying connects with the wider health system. For example:

- People may make a request for assisted dying, or for information about assisted dying, to any health practitioner in the wider health system.
- Practitioners in the wider health system are not required to be directly involved in assisted dying, but may be asked to provide information about a person to inform an assessment.
- People seeking assisted dying will likely be receiving care from other practitioners in the health system (for example, for pain or symptom management).

- People seeking assisted dying may be staying in facilities providing other health and care services – for example, hospitals, hospices, and residential care facilities.

## Conscientious objection in the Act

It is helpful to understand more about the role of conscientious objection in the Act, as this is a key concept that can influence interactions between the assisted dying process and the wider health system.

The right to conscientiously object is upheld under section 13 of the New Zealand Bill of Rights Act 1990, which provides that “everyone has the right to freedom of thought, conscience, religion, and belief, including the right to adopt and to hold opinions without interference”.

Sections 8 and 9 of the End of Life Choice Act enable practitioners to conscientiously object to providing assisted dying services:

- Section 8 enables any health practitioner to conscientiously object to “assisting any person who wishes to exercise the option of receiving assisted dying under this Act” (except in relation to the practitioner’s obligations outlined in section 9 – see below). This applies “despite any legal obligation to which the health practitioner is subject, regardless of how the legal obligation arises” – for example, a practitioner’s obligations under the Code.
- Section 8 also provides that an employer must not deny or provide an employee any employment, accommodation, goods, service, right, title, privilege, or benefit merely because the employee provides any assistance or objects to providing any assistance in relation to assisted dying.
- Section 9 requires an attending medical practitioner to tell the person requesting assisted dying of their conscientious objection, and of the person’s right to ask the SCENZ Group for the name and contact details of a replacement practitioner.

Practitioners with a conscientious objection may decline to provide or interact with the service on the basis of personal, moral, religious, or ethical beliefs. Health practitioners and people working in the health system in particular may conscientiously object to assisted dying for ethical reasons or obligations, including a health practitioners’ ethical commitment to ‘do no harm’.

The only other New Zealand health legislation that specifically enables conscientious objection is the Contraception, Sterilisation, and Abortion Act 1977.

## Conscientious objection and health consumer rights

Conscientious objection interacts with health consumer rights under the Code, where health practitioners’ rights to act according to their moral or ethical beliefs must be balanced with the health consumer’s right to receive appropriate care, continuity of care, and cooperation between providers.

There are some rights under the Code that are particularly relevant to how assisted dying is provided, which were considered during analysis as part of the review:

- **Right 2: Right to freedom from discrimination, coercion, harassment, and exploitation** – in the context of assisted dying, this means that people accessing assisted dying services have the right to be free from discrimination on the basis of that choice, including pressure to access or not access assisted dying.
- **Right 4: Right to services of an appropriate standard** – people accessing assisted dying services have the right to have services provided with reasonable care and skill, and the right to cooperation among providers to ensure quality and continuity of services. This is particularly relevant to how health practitioners and assisted dying practitioners work together to support a person’s end-of-life care.
- **Right 6: Right to be fully informed** – people accessing assisted dying have a right to information that a reasonable consumer, in that consumer’s circumstances, would expect to receive (including an explanation of their condition and the options available to them), and the right to information that a reasonable consumer would need to make an informed choice or give informed consent. This right is subject to some specific limitations under the Act.
- **Right 7: Right to make an informed choice and give informed consent** – services may only be provided if the consumer gives informed consent. This ties into the above right, where consumers must be fully informed in order to provide informed consent.

## Key issues identified

The framing of the Act assumes that all health practitioners will provide assisted dying services unless they have a conscientious objection, which is out of step with the health system and how the service operates

Section 8 of the Act provides that a health practitioner is not under any obligation to ‘assist any person’ who wishes to receive an assisted death if that health practitioner has a conscientious objection. Section 9 sets out that if an attending medical practitioner has a conscientious objection, and a person informs them that they wish to access assisted dying, then that practitioner must tell the person of their objection and their right to ask the SCENZ Group for a replacement medical practitioner.<sup>21</sup>

*This right to conscientiously object must always be protected. There should be accurate and easily understood public information on this right, as well as clear guidance for public and health professionals on the obligations of those who choose to conscientiously object.*

– Hospice New Zealand

<sup>21</sup> Section 10 of the Act is also relevant to the conscientious objection provisions. It prevents a health practitioner from raising assisted dying, which means that a person must always initiate discussions about assisted dying. This acts as a trigger point for practitioners to express their objection.

The Act conflates provisions around how people are able to access assisted dying with how practitioners are able to conscientiously object. This makes it unclear what a practitioner can conscientiously object to in the first instance, and leads to two further issues.

First, the Act is drafted from a perspective that assumes that all health practitioners will provide assisted dying, and that:

- a person seeking assisted dying will engage with their general practitioner (GP) or another practitioner involved in their care with a request to seek assisted dying
- the person's practitioner will then either agree and provide the service, or decline to provide the service because of their conscientious objection.

This approach does not align with the wider health system, where health practitioners normally 'opt in' to provide health services rather than being expected to provide them by default. It also does not align with how assisted dying is provided in practice. There is only a small group of practitioners throughout the country who have 'opted in' to provide assisted dying services and who receive requests for referrals through the Assisted Dying Service. As such, a person's initial conversation with a practitioner will almost always result in a referral.

Second, the Act assumes that a practitioner will only decline to provide assisted dying on the basis of a conscientious objection. In practice, practitioners may have a range of reasons for not providing this service, such as:

- practical reasons (e.g., lack of time or funding)
- competence (e.g., if they did not feel they had the right skills to provide the service)
- lack of knowledge (e.g., uncertainty about how the law works or the assisted dying process)
- reputational reasons (e.g., fear of impacting their relationships with other people or the reputation of their practice)
- personal reasons (e.g., the emotional impact that assisted dying might have on them).

These reasons are not provided for in the Act, and practitioners may be required to state that they have a conscientious objection in place of any of the reasons above.

During targeted engagement it was also raised that the requirement for a practitioner to inform a person of their conscientious objection can be uncomfortable, and lead to situations where someone seeking information is given a 'moralising lecture' or is made to feel that a judgement has been passed on them. Some stakeholders suggested that it would be sufficient for a practitioner to simply indicate that they do not provide assisted dying.

Finally, the Act requires that a practitioner who is an 'attending medical practitioner' must tell a person of their objection, and of their right to ask the SCENZ Group for a replacement medical practitioner. The Act is not clear on whether or when health practitioners who are *not* attending medical practitioners should make a referral to the SCENZ Group.

## The Act does not strike an appropriate balance between conscientious objection and health consumer rights

The Act is relatively broad in the way that it addresses how a person may conscientiously object. Section 8 enables a health practitioner to decline to do anything that they consider might assist a person in any way to access assisted dying. Setting out the ability for practitioners to conscientiously object in the Act is important to ensure that rights under the New Zealand Bill of Rights Act 1990 are upheld.

Practitioners may have different thresholds for what 'assisting a person' to access assisted dying means. Some may feel this means directly providing assisted dying services, and others may feel this includes providing a person's health information to inform an assessment, or even providing a person with the contact details of the SCENZ Group. Experience from the Assisted Dying Service over the past three years has shown that, in practice, conscientious objection is most likely to impact the provision of assisted dying at the following points in the process:

- when a person makes a request about assisted dying to a practitioner or person providing care that does not support assisted dying (particularly if the person making the request is in the care of a hospice, hospital, or aged care facility and has limited access to other practitioners)
- when an assisted dying practitioner requests information from another health practitioner to inform an assessment of eligibility (e.g., phoning the person's GP to assess whether the person is under pressure, or requesting information from an oncologist about a person's prognosis), and the health practitioner is reluctant to share the person's information.

The Act also sets out that a practitioner may conscientiously object 'despite any legal obligation to which the health practitioner is subject', which enables an objecting practitioner not to fulfil their duties under the Code.

Many submissions on the effects of conscientious objection were received as part of targeted

*It's very clear to me that people who are conscientious objectors won't put anything in any letter to mention prognosis, they're very careful not to.*

- Assisted Dying Practitioner

*Mum's oncologist didn't get [the prognosis] to mum until three weeks before she died. ... I strongly believe that people in the medical profession let their personal belief get in the way of the patient's wishes.*

- Family member of someone who received an assisted death

*I believe that their attempt at intervention was aimed at delaying [x]'s attempt at assisted dying, knowing that at some point he would not be able to communicate consent. The impact that it had... It ruined our final week with him and trust in medical professionals. He was anxious, we were anxious, and we're not any less upset than we were then.*

- Family member of someone who received an assisted death

*In one example a patient was begged not to go through with AD by their crying GP. This is a type of interference that breaches boundaries and intrudes on autonomy.*

- 'Exploring Early Experiences of the Assisted Dying Service in Aotearoa' Research Group

engagement from organisations, practitioners, New Zealand assisted dying researchers, and people who had supported a loved one through the assisted dying process.

These submissions, and the experience of those involved in managing and regulating the assisted dying process over the past three years, highlighted that the provisions in the Act enable practitioners to prioritise their right to conscientious objection over the rights of health consumers. It was raised that some practitioners (e.g., GPs), specialists (e.g., oncologists), or other people in the health system are:

- not informing a person of their right to contact the SCENZ Group after they have made a request for assisted dying
- withholding or delaying the provision of information to inform a person's eligibility assessment for assisted dying
- in the most extreme cases, actively attempting to dissuade people from seeking an assisted death – there has also been a small number of situations where practitioners not directly involved in the assisted dying process have sought to challenge or delay assessments made by the attending medical practitioner during the process.

Research exploring experiences of whānau Māori found that some whānau “experienced coercion to not seek [assisted dying] from palliative care professionals instead of a referral upon requesting information regarding [assisted dying]”, and that health professionals also did not always provide whānau with information about assisted dying in a timely and supportive way.<sup>22</sup>

People seeking assisted dying who live in care facilities<sup>23</sup> face particular barriers to access, as people in these facilities rely on staff for information and continuity of care, and are limited in their ability to seek information elsewhere.

These actions (or inactions) can lead to people feeling discriminated against or judged for their choice, and time delays in the process that prolong a person's suffering and may lead to the person passing away before exercising their choice to access assisted dying.

## The Act is silent on the obligations of care facilities in relation to assisted dying, particularly the ability of people to receive assisted dying in these locations

Just over one in five assisted deaths have taken place in a care facility. Between 7 November 2021 and 30 September 2024, 9.3% of assisted deaths took place at a hospital, 8.8% took place in an aged care facility, and 3% took place in a hospice facility. The remaining 78.9% took place in a private residence.

Some facilities that provide care for people who may seek assisted dying services have expressed an objection to participating in assisted dying, including allowing

<sup>22</sup> T. Moeke-Maxwell, L. Nikora and J. Robinson. 'Waerea – Māori whānau experiences of assisted dying in Aotearoa New Zealand'. Publication forthcoming.

<sup>23</sup> In this report, 'care facilities' means public hospitals, private hospitals, hospices, residential aged care facilities, disability residential care facilities, and rest homes or other similar facilities where care is provided to a person (e.g., due to illness, disease, incapacity, or disability).



assessments or other parts of the process (particularly assisted deaths) to take place in their facilities.<sup>24</sup> Reasons for this may include:

- a belief that assisted dying and palliative care are distinct or incompatible, noting the ethos of palliative care to 'neither to hasten nor postpone death'<sup>25</sup>
- in some cases, a strong religious ethos with values that conflict with assisted dying
- preserving a reputation for providing end-of-life care, or wanting to avoid a reputation as a location for assisted deaths
- to avoid discomfort for other residents living in the same facility
- to avoid tension with staff who may hold a range of perspectives on assisted dying.

The Act is silent on the obligations on care facilities to support health consumers' rights – particularly health consumers' rights to information and cooperation among providers. It therefore does not give direction on where the balance lies between the rights of organisations to refuse to allow assisted dying on site, and the rights of individuals in these facilities to access assisted dying as a health service.

This results in a range of ways that assisted dying is permitted in care facilities, including some facilities:

- allowing all assisted dying activities on site, including the assisted death (although targeted engagement indicated this is not often the case)
- allowing assessments for assisted dying to happen on site, but not the assisted death
- not allowing any activity related to assisted dying to happen on site, except for obligations to provide information on how to contact the SCENZ Group (noting, however, that there have been some complaints received about hospice staff not fulfilling this obligation).

*We would like to see the right to organisational conscientious objection included in the Act to ensure clarity for all and legislative protection for organisations.*

...

*It is important that the Act and any associated training, information and guidance is very clear that assisted dying is a separate and distinct service from palliative care and end of life care.*

– Hospice New Zealand

*It is essential in our view that vulnerable patients can see these institutions as places of safety and are not afraid to enter them. It also allows these institutions to focus on the care they have been designed to provide.*

– Australian and New Zealand Society of Palliative Medicine

*The silence of the End of Life Choice Act on the responsibilities of organisations who have a conscientious objection to assisted dying is unhelpful for those consumers who reside in certain health settings and can have a significant impact on people's dignity and mana at the end of their lives.*

– Health and Disability Commissioner

<sup>24</sup> In 2020, Hospice New Zealand challenged the End of Life Choice Act, specifically focusing on the obligations on healthcare providers who object to participating in assisted dying and whether the Act compelled hospices and practitioners to facilitate or participate in the process, even if they held an objection. The High Court ruled that organisations like hospice services, aged care facilities, or GP practices can object to assisted dying taking place on their premises or with the assistance of their staff.

<sup>25</sup> <https://www.who.int/health-topics/palliative-care>.



Targeted engagement, including the experiences of those who supported people through the assisted dying process and the experiences of those involved in managing and regulating the assisted dying process, raised that this lack of clarity impacts both people seeking assisted dying and assisted dying practitioners. In particular, it results in barriers where people:

- may have difficulty accessing information about assisted dying, particularly where they may not have their own support to obtain the information required and are dependent on the care facility responsible for their overall care and wellbeing
- may not be referred to the SCENZ Group, or have difficulty contacting the SCENZ Group
- may have difficulty accessing assisted dying assessments – likewise, some practitioners may feel the need to be covert about visiting care facilities for assisted dying assessments
- may be actively dissuaded from choosing assisted dying
- may feel fearful of raising assisted dying or feel the need to conceal that they are accessing assisted dying to continue to receive palliative care
- may be forced to choose between receiving palliative care in a facility, or receiving care elsewhere so that they can have an assisted death
- may be forced to move locations for the assisted death, which can cause pain and trauma – particularly as people may not be able to take some medications and equipment for pain management with them outside of certain facilities.

The lack of clarity in the Act also impacts care facilities that do not support assisted dying, as there is uncertainty about their rights and obligations, and how they balance those with their reputation and responsibilities to support other residents.

*Conscientious objection remains a significant issue amongst the complaints that we have received. For example, a consumer who already had a date set for their Assisted Death was initially accepted into a care home by the manager. Unfortunately, once they had been admitted, the Head Office became aware of the consumer's plans to have an Assisted Death and the care home was asked to exit the consumer, despite their very advanced decline.*

*We have also received several complaints about care homes and hospices where families have raised concerns about being treated in a disrespectful or discriminatory manner once staff became aware that their loved one was pursuing an Assisted Death.*

- Health and Disability Commissioner

*I was concerned he would end up in hospice if I couldn't keep him at home, and he wouldn't be able to do what he wanted, and have the assisted death. It added an awful layer to things at that time in life.*

- Family member of someone who received an assisted death

*We just didn't tell [the hospice] anything about it. Once I started taking over, I felt like I was having an affair, and felt dishonest with them about timeframes because I didn't want his care to be impacted. I felt very uncomfortable about it.*

- Family member of someone who received an assisted death

A range of views were expressed through targeted engagement on how health consumer rights should be balanced with an organisation's right to object. A number of submissions raised that there should be no restriction on people accessing assisted dying within their own home, whether this is a care facility or elsewhere, and a death in a person's own home (including in a care facility) should be a person's right. On the other hand, some submissions supported palliative care inpatient units and hospices being able to opt out of allowing assisted dying to take place in their facilities on the grounds of conscience.

## Some people accessing assisted dying in hospitals can face barriers to care

Public hospitals are not able to opt out of providing a location for assisted deaths to take place and are considered a 'facility of last resort' in Crown funding agreements.<sup>26</sup> Hospitals are not expected to provide staff to directly provide assisted dying services, but assisted deaths may take place in hospitals when:

- a person is not able to be discharged from the hospital for medical or practical reasons
- the assisted death cannot take place in the person's regular residence – for example, if they live in a residential facility that does not allow assisted deaths to take place on its premises, or if they do not want to pass away in their family home.

As part of targeted engagement on the review, the Health and Disability Commissioner, some assisted dying practitioners, and people who had supported loved ones through the assisted dying process commented that seeking care from hospitals can be difficult due to limited beds and individual staff within a hospital who may have a conscientious objection.

Submitters also raised that the language around hospitals being the place of 'last resort' is not appropriate as it creates a perception that a hospital is not a good place to die.

<sup>26</sup> A Crown funding agreement is an agreement between the Crown and a particular entity (in this case, hospitals or previously District Health Boards), where the Crown agrees to provide funding for particular services specified in the agreement.

*Dad was in hospital immobile, on fentanyl pumps, and they said, 'You can't have assisted dying in hospital, and you can't take the fentanyl pump with you out of hospital.' And we said, 'Ok, well... where can we go?' They said we could go home. But dad was 50 minutes away from home and every movement was agony for him, so I said that's not an option.*

*The prospect I had was my dad being delivered to my house without fentanyl, lying on my couch in my living room, no pain meds, dying, and the hospital not taking him back so me arranging for a funeral director to come and get him. ... In the end, the assisted dying doctor pulled some strings, and they allowed him to go in his room at the hospital.*

*Once they agreed to allow it the hospital were fantastic – it just felt like some somewhat arbitrary rules had been put in place that were really impacting on the pragmatism we wanted to bring. Dad controlled his own process, he booked in his death, he was always on the phone. And the clinical staff were fantastic. But the relief we got when we knew he could just go where he was and not have to be moved was really profound.*

– Family member of someone who received an assisted death

## People accessing assisted dying and their family or whānau, particularly people who have been found ineligible, need more support

A person found ineligible for assisted dying may have met some but not all of the eligibility criteria (e.g., having a terminal illness but without a six-month prognosis, or experiencing unbearable suffering but without a terminal illness), and may be in distress.

Targeted engagement highlighted that people who have been declined assisted dying may be at increased risk of suicide. Research further indicated that health practitioners who are not assisted dying practitioners telling a person that they will not be eligible for assisted dying can contribute to the person's distress.<sup>27</sup> The Chief Coroner shared information for the review indicating that a small number of suicides and suspected suicides have occurred in New Zealand where someone was recorded as having considered assisted dying, or had been found ineligible to receive an assisted death.

A number of organisations, and some people who had supported a loved one through the assisted dying process, raised concerns that there is no specific holistic care provision or bereavement support for friends, families, and whānau throughout the process or

*I think there needs to be some counselling available to people – those choosing the option, and those supporting them. To help people consider what it means to confront the issue, and think about what they feel about it, how they want to manage it themselves, or on behalf of their friend. Counselling should be in place for people making these decisions ... factual discussions for some people so they can make informed choices about administration.*

– Family member of someone who received an assisted death

<sup>27</sup> Submission: Adam Sims and Gary Cheung, "Unintended consequences of the End of Life Choice Act," *New Zealand Medical Journal* 136, no. 1578 (7 July 2023): 123–125. <https://nzmj.org.nz/media/pages/journal/vol-136-no-1578/unintended-consequences-of-the-end-of-life-choice-act/a4c4bda784-1696477072/unintended-consequences-of-the-end-of-life-choice-act.pdf>.

following an assisted death. Those who had supported someone through the process commented that the process on the day of the assisted death came as a shock, particularly for those who had not been as involved in earlier appointments, and recommended that support is offered to family or whānau after the assisted death to provide closure. Submitters also noted that normal grief counselling services may not be equipped or resourced to deal with this different grief experience.

There are currently no obligations on practitioners in the legislation to provide or facilitate support to a person who has been found ineligible for assisted dying, or for the friends, family, or whānau of a person accessing assisted dying. However, guidance for practitioners sets out that:

- the practitioner should inform the person's primary healthcare provider if the person has been found ineligible and the practitioner is not the person's primary healthcare provider
- the Assisted Dying Secretariat may follow up with the family or whānau (if agreed) to check in and recommend ongoing support options if required.

## The protections for employees who decide to provide or not provide assisted dying could be made clearer

Section 8 of the Act provides that an employer must not:

- deny to an employee any employment, accommodation, goods, service, right, title, privilege, or benefit because the employee conscientiously objects to providing any assistance related to assisted dying
- provide or grant to an employee any employment, accommodation, goods, service, right, title, privilege, or benefit conditional on the employee providing any assistance related to assisted dying.

However, this provision leaves gaps where an employer could deny an employee rights or benefits if they provide assisted dying services, or provide rights or benefits to an employee that does not provide the service. The Act could more clearly articulate that there must be no benefits or losses resulting from a health practitioner providing or not providing assisted dying.

## Recommendations

The Ministry makes the following recommendations to address the issues outlined in this section. For each recommendation it is noted where alternative options were considered.

These recommendations are made as a package, noting that they (intentionally) overlap in places, and are mutually reinforcing.

### **Recommendation 13**

Amend the Act to separate conscientious objection provisions from how a person accesses the Assisted Dying Service, and clarify obligations on all health practitioners to provide details of the Assisted Dying Service if a person makes a request.

Section 11(1)<sup>28</sup> would be replaced with wording to the effect of:

*If a person informs a health practitioner that they would like to exercise the option of receiving assisted dying, that health practitioner must provide the contact details for the Assisted Dying Service or contact the service on their behalf.*

This change would provide clarity for people applying for assisted dying, and for practitioners and other people working in the health system, about the process to access assisted dying services and what practitioners must do in response to a request. It would also simplify provisions about conscientious objection, as these would be separated from provisions relating to access to the service (see recommendation 14).

### **Recommendation 14**

Amend the Act to set out what practitioners are able to conscientiously object to, that conscientious objection does not override a practitioner's duty to act in accordance with the Code of Health and Disability Services Consumers' Rights, and specific actions that health practitioners must take to facilitate continuity of care.

Section 9 would be removed.<sup>29</sup> Section 8(1)<sup>30</sup> and section 8(2)<sup>31</sup> would be replaced with wording to the effect of:

*A health practitioner that conscientiously objects to assisted dying, or who is not able or willing to provide assisted dying services, is not required to:*

- *perform any of the functions or duties of an attending practitioner, independent medical practitioner or third assessor*
- *supply, prescribe, or administer an assisted dying medication*
- *be present at the time of administration.*

<sup>28</sup> Section 11(1): "A person who wishes to exercise the option of receiving assisted dying must inform the attending medical practitioner of their wish."

<sup>29</sup> Section 9 sets out that if a person informs the attending medical practitioner that they wish to access assisted dying, and the practitioner has a conscientious objection to providing that option, the practitioner must tell the person of their conscientious objection and of their right to ask the SCENZ Group for the contact details of a replacement practitioner.

<sup>30</sup> Section 8(1): "A health practitioner is not under any obligation to assist any person who wishes to exercise the option of receiving assisted dying under this Act if the health practitioner has a conscientious objection to providing that assistance to the person."

<sup>31</sup> Section 8(2): "Subsection (1)— (a) applies despite any legal obligation to which the health practitioner is subject, regardless of how the legal obligation arises; but (b) does not apply to the obligation in section 9(2)."

The Act would include that:

- conscientious objection does not override a health practitioner's duty to act in accordance with the Code of Health and Disability Services Consumers' Rights
- in response to a request for information about assisted dying, all health practitioners must provide the person with the contact details of the Assisted Dying Service
- a health practitioner who holds relevant health information about a person must, upon request from any practitioner operating under the Act for the purposes of an assessment under the Act, provide that information as soon as practicable.

This change would clarify how conscientious objection interacts with health consumer rights, what practitioners are able to object to, and what actions a practitioner must take to fulfil their duties under the Code of Health and Disability Services Consumers' Rights (the Code). This would clearly indicate expectations for health practitioners that may interact with assisted dying services, which in turn would improve the timeliness and ease of access to assisted dying for people seeking the service.

Breaches of this requirement would be linked to a breach of the Code, and may be subject to investigation by the Health and Disability Commissioner.

This change would also remove the requirement for a practitioner to inform a person of their conscientious objection, as targeted engagement highlighted that this requirement could be uncomfortable for practitioners and implies a judgement on the person's decision.

### Alternative options that were considered

Another option considered was to only set out in the Act that conscientious objection does not override a health practitioner's duty to act in accordance with the Code (rather than specific actions that practitioners must take to comply with their duties under the Code).

However, setting out key actions that all practitioners must take provides greater clarity on where the balance lies between the right to conscientiously object and the rights of health consumers, including duties on practitioners to facilitate continuity of care. The recommendation above better ensures that there are no undue barriers to progressing a person's request for an assisted death.

### **Recommendation 15**

Require care facilities to provide reasonable access to assisted dying to those who request it, particularly for those where the facility is the person's home.

'Care facilities' means public hospitals, private hospitals, hospices, residential aged care facilities, disability residential care facilities, rest homes, and other similar facilities where care is provided to a person (e.g., due to illness, disease, incapacity, or disability).

Care facilities would be required to do the following:

- Provide the contact details of the Assisted Dying Service to a person if they request it.
- Allow assisted dying practitioners access to a person on site for assisted dying appointments and assessments, or facilitate transfer of the person to the practitioner.
- Allow assisted dying practitioners access to the person on site for administration of the assisted dying medication **if they are a permanent resident or inpatient** (i.e., the care facility is their home).
- If transfer of a person who is not a permanent resident or inpatient to another suitable location would not be reasonable in the circumstances (e.g., where the transfer would cause harm to the person, undue delay, or prolonged suffering), allow the practitioner reasonable access to the person on site for any part of the service.
- Have a policy for how the care facility will give effect to the above requirements (noting that Health New Zealand facilities would have a single national policy).

Non-compliance could be addressed through existing certification policies (i.e., required certification to the Ngā Paerewa Health and Disability Service Standard).

The Ministry of Health New Zealand would publish information and provide education and guidance about the obligations of care facilities to support those wishing to access assisted dying.

This provision would make the obligations of care facilities and related organisations to comply with the Code of Health and Disability Services Consumers' Rights (the Code) explicit, and clarify where the balance sits between the rights of health consumers and care facilities. The Ministry considers that the balance of rights should favour the rights of consumers accessing healthcare, including assisted dying services.

While adding these requirements to the Act would have implications for care facilities that do not currently support or allow assisted dying to take place on site, it is important to note that this change would not require staff from these facilities to be directly involved in the assisted dying process, as the Act already provides for assisted dying practitioners through other mechanisms.

This change would:

- promote equitable access for people in care facilities for whom the facility is their home, and for people who need to access palliative care in addition to exercising their wish to receive an assisted death
- support people to be aware of and access all options for end-of-life care available to them, regardless of where they are living
- remove the use of transfers in situations where transfers would not be appropriate (for example, if the person was in a lot of pain and transfer to another location would worsen that pain)
- create consistency of practice across the range of care facilities
- support integration of assisted dying as a recognised health service.

Care facilities would also be required to demonstrate how they are giving effect to this change. If progressed, the Ministry and Health New Zealand would work with and support relevant stakeholders and sectors with facilities to enact this change.

### Alternative options that were considered

Two alternative options were considered.

The first was to make explicit that Code requirements (particularly those related to continuity of care) apply to care facilities. This option would be similar to the recommendation made above; however, it would not require care facilities to enable the administration of assisted dying to occur on site. Instead, care facilities would be required to assist people to find an alternative residence if they made a request for assisted dying. It was considered that this option would not go far enough to address the key problems that:

- some people in care facilities are not able to be transferred, and this option would prevent those people from exercising their choice
- some people may not have alternative places available where they can access assisted dying (particularly if they do not want to receive an assisted death at a hospital)
- some people may feel unfairly treated because of their choice.

The second option considered was to include a 'right to refuse' in the Act. This would enable care facilities to refuse to permit any part of the assisted dying process to be carried out at the facility. The care facility would be required to ensure that the person is advised of their refusal to permit assisted dying on site before the person accesses care, and facilitate transfer of a person to another location if they wanted to access assisted dying. This option was not preferred, as it would favour the rights of objecting organisations over health consumers' rights, and in doing so infringe on those rights.<sup>32</sup> This would entrench inequity of access for those living in care facilities, and particularly for those living in rural areas who may have fewer options for facilities available to them.

<sup>32</sup> For example, right 1(3) – every provider to take action to enable consumers to exercise their rights; right 4(4) – to have services provided in a manner that minimises the potential harm; right 4(5) – continuity of care between providers.



### **Recommendation 16**

Amend the Act to more clearly articulate that a practitioner should not be treated any more or less favourably than any other similarly qualified health provider by an employer, regardless of whether they provide assisted dying services or not.

This change would more clearly articulate the continuation of rights for practitioners who conscientiously object, and practitioners who provide the service, than the current provision (section 8(3-4)).

## Areas considered that do not require legislative change

### Requiring Health New Zealand to identify a suitable and appropriate location for assisted deaths to occur

Targeted engagement, and the experience of those involved in managing and regulating the assisted dying process, raised that:

- some hospitals do not have capacity to facilitate assisted deaths
- some people do not want to receive assisted dying in hospitals
- the language of hospitals being a 'facility of last resort' is inappropriate.

Consideration was given to adding a provision in the Act requiring Health New Zealand to identify appropriate locations for assisted deaths to take place. This would replace obligations in Crown funding agreements setting out that hospitals are a 'facility of last resort'. The locations identified would not need to be within hospitals, and could for example be other facilities in communities.

However, this change is not required as the recommendations outlined in this section would increase the availability of locations for assisted dying to occur. Further changes to resolve these issues should be operational responses, to enable flexibility in how the service is provided in future (for example, developing a national policy for hospitals).

### Requiring practitioners to support a person after being found ineligible for assisted dying

Operationally, and under the Code, an assisted dying practitioner should be in contact with the person's usual health provider if the person is found ineligible for assisted dying. Consideration was given to whether there may be a need for stronger requirements in the Act to facilitate support to a person after being assessed as ineligible for assisted dying – for example, a legislative requirement that practitioners refer a person back to their primary care provider.

However, it was considered more appropriate for this requirement to be part of strengthened operational guidance, to enable flexibility and responsiveness to a person's circumstances and needs and avoid duplication of existing processes in the

health system. Training could also be strengthened to encourage practitioners to refer a person back to their regular health provider or ensure that they are aware of resources available in their area for support.

## Establishing additional support for friends, families, and whānau throughout the assisted dying process and after an assisted death

Some submitters recommended that consideration be given to including funded specialist holistic care and bereavement support as part of the Assisted Dying Service, or creating 'Assisted Dying Navigator' roles to support people through the process.

As above, while it may be beneficial to provide specific support to families and whānau throughout or after the assisted dying process, legislation is not an effective mechanism to address this as it is inflexible and unable to adapt to different circumstances, needs, and available supports. Operational changes would be more effective and adaptable.

Further, additional support functions would not need to be separate to those provided in the rest of the health system. It would be undesirable to duplicate existing supports in the wider health system by creating separate systems for assisted dying in bereavement support, which would distance assisted dying from other types of death.

Existing bereavement and mental health supports include:

- hospice bereavement support (for those whose loved one was cared for by a hospice service)
- funded counselling in communities, accessed by referral via a GP or healthcare provider
- self-funded or employer-funded grief counselling services<sup>33</sup>
- resources available online about grief and support at the end of life<sup>34</sup>
- telehealth support services.<sup>35</sup>

<sup>33</sup> Some organisations may provide grief and loss counselling services responsive to individuals' financial situations, such as <https://www.griefcentre.org.nz/>.

<sup>34</sup> Such as <https://endoflife.services.govt.nz/> and <https://www.skylight.org.nz/>.

<sup>35</sup> Such as <https://1737.org.nz/> or Lifeline (0800 534 354, <https://www.lifeline.org.nz/>).

# Ensuring a capable and effective workforce for assisted dying

As for the health system as a whole, the provision of assisted dying relies on a skilled and capable workforce that can meet the needs of those who are seeking the service. The availability and accessibility of the workforce is critical to assisted dying as the process relies on the involvement of, and decisions by, assisted dying practitioners.

The Act sets out provisions governing which parts of the health workforce can be involved in the assisted dying process, and the requirements that practitioners must meet to be considered suitable to provide assisted dying services.

## Approach to reviewing the capability and effectiveness of the workforce

The review of the Act involved examining the adequacy and effectiveness of provisions specifying who can provide assisted dying, and what parts of the process can be performed by particular workforces.

This part of the review has drawn on:

- the experience of those involved in managing and regulating the assisted dying process over the past three years, including the current Registrar, the Quality Assurance and Safety group in the Ministry, and Health New Zealand
- the views of some practitioners who have been providing the service
- feedback from organisations that regulate and monitor workforces that can be involved in assisted dying, including the Medical Council of New Zealand, the Nursing Council of New Zealand, a number of medical colleges, and the Health and Disability Commissioner
- feedback from organisations that represent workforces that can be involved in assisted dying
- information about workforce standards and regulation from other jurisdictions where assisted dying is lawful.

In examining the adequacy and effectiveness of provisions related to the assisted dying workforce, the Ministry considered the following objectives, noting there is sometimes a balance to be struck between them:

- **The safety of the service that people seeking assisted dying and those supporting them receive** – this is critical to assisted dying and involves a high threshold given the consequential nature of this service.
- **The safety of the workforce providing assisted dying** – measures to regulate the health workforce seek to protect people, but can also protect practitioners, noting that practitioners acting outside of the requirements in the Act can potentially face serious consequences.

- **The quality of the service that people seeking assisted dying and those supporting them receive** – for assisted dying, service quality depends on factors such as effective communication, empathy, cultural competence and safety, and support for continuity of care.
- **Access to assisted dying, and timeliness of services** – limits on who can provide assisted dying can impact the size of this workforce, and as a result impact the availability and timeliness of assisted dying services.

## Background information

### Who can provide assisted dying services?

The **attending medical practitioner** is central to the assisted dying process. Their role includes ensuring that the person seeking assisted dying understands the necessary information about assisted dying and their options for end-of-life care, confirming that the person wishes to apply for an assisted death, and performing the first assessment to determine whether the person is eligible for an assisted death.

If the person is found to be eligible, the attending medical practitioner arranges for and administers the medication, or may be assisted by an attending nurse practitioner.

An attending medical practitioner can be any medical practitioner who is registered with the Medical Council of New Zealand as a practitioner of the profession of medicine, and holds a current practising certificate.

The **independent medical practitioner** performs the second assessment to determine whether the person is eligible for an assisted death. They must be independent of the person and the person's attending medical practitioner.

An independent medical practitioner is required to meet the same requirements as an attending medical practitioner, but must have held their practising certificate, or the equivalent certification, for at least five consecutive years.

An **attending nurse practitioner** can arrange for and administer the medication for a person receiving an assisted death at the end of the process. Under the Act they are required to act under the instruction of the attending medical practitioner.

Under the Act, an attending nurse practitioner is a nurse practitioner who is registered with the Nursing Council of New Zealand, whose scope of practice permits the performance of nurse practitioner functions, and holds a current practising certificate.

A **psychiatrist** may perform a third assessment of the person's competence to make an informed decision if needed. Under the Act, a psychiatrist means a medical practitioner whose scope of practice includes psychiatry.

In addition to the requirements set out in the Act, practitioners are also subject to the standards set by their responsible authority, as assisted dying and activities related to it are health services. For example, this includes standards issued by the Medical

Council of New Zealand related to good medical practice including continuity of care, informed consent, managing patient records, and good prescribing practice.

## What is required to provide assisted dying?

At a general level, practitioners providing assisted dying need to practise in a way that is clinically and culturally safe. This includes meeting the same standards of safety, professionalism, and person-centred and culturally responsive care that apply to services across the wider health system. It is also essential that practitioners have the skills and competencies required to deliver assisted dying specifically.

Based on feedback from those who have been involved in the provision of assisted dying over the past three years, along with the Medical Council of New Zealand and other workforce organisations, a practitioner providing assisted dying requires:

- prognostic capability – the ability to determine a person’s prognosis through the gathering and interpretation of relevant clinical information
- the ability to assess a person’s competence
- knowledge and skills related to the administration and management of medications (e.g., analgesia or sedation, cannulation skills)
- prescribing skills
- empathetic communication skills and the ability to have difficult conversations
- cultural competence and safety – including an understanding of different cultural views around assisted dying, and the tikanga and kawa of local facilities or marae within their area (or a willingness to draw on others who can support with this)
- the ability to provide information on and discuss other options for end-of-life care
- the ability to support family or whānau, including linking them in with relevant support services
- the ability to provide and support holistic care.

The Ministry and Health New Zealand’s experience managing assisted dying has also highlighted the importance of practitioners being willing to maintain professional objectivity when it comes to providing assisted dying. While practitioners generally work to advocate for and support people to access care and have their health needs met, this is not appropriate in the context of assisted dying, where being able to objectively determine eligibility and meet the requirements of the Act is essential to ensuring a safe and effective service.

Practitioners providing assisted dying must also be willing to accept a greater degree of prescription over how they provide care than for other health services. This includes limitations on the level of discretion that they can apply when following processes.

Finally, the safety and effectiveness of the assisted dying process is heavily dependent on information and evidence documented by the practitioner. As such, the integrity of practitioners and their truthful disclosure of information is important to ensure that

people seeking assisted dying and the public can have confidence in the Assisted Dying Service.

## Key issues identified

### The threshold at which practitioners can provide assisted dying services is too low given the consequential nature of assisted dying

The requirements for medical practitioners to act as an attending medical practitioner under the Act are relatively permissive and require only that a medical practitioner is registered with the Medical Council of New Zealand and holds a current practising certificate. For medical practitioners acting as independent medical practitioners, there is a further requirement that they have held their practising certificate for five years consecutively.

The profession of medicine covers a range of vocations, including some that are more relevant to the skills required for assisted dying (e.g., generalist roles in areas such as anaesthesia, oncology, intensive care medicine, general practice, and psychiatry), and some areas that do not routinely involve the general competencies required for assisted dying.

Parliament may have expected the Medical Council of New Zealand to develop a specific vocational scope of practice or standards to regulate who can provide assisted dying services following the passage of the Act. The Medical Council has chosen not to do this, on the basis that it considers the provision of health services under the Act to require a general set of skills and fall within the wider practice of medicine. The Medical Council has issued guidance referencing existing standards related to good medical practice that correspond to certain aspects of the Act.<sup>36</sup>

In practice, this means that medical practitioners operating in a wide range of different situations and with a wide range of specialisations and experience can decide to provide assisted dying services under the Act, without restriction. This includes:

- doctors who have recently graduated from medical school and are operating with provisional registration

*Practitioners must have adequate experience in general medical conditions, older people's health, the interaction of comorbidities and oncology to be able to determine life expectancy, and they must be aware of reversibility and treatable issues. They need good training in cognitive and capacity assessment. Many health practitioners work in fields where these skills have not been obtained (e.g. pathology, paediatrics and radiology).*

- The Australian and New Zealand Society for Geriatric Medicine

*I don't think anyone with less than 10 years' experience should do this job. I don't think people should be PGY3 because it is some of the most difficult, challenging, and moral, ethical, and clinical situations I've been in.*

- Assisted Dying Practitioner

<sup>36</sup> <https://www.mcnz.org.nz/assets/standards/d58930a18b/EOLCA-Council-statements-and-standards.pdf>.

- doctors wanting to come out of retirement for the purpose of providing assisted dying
- doctors operating in vocationally specialist areas that do not ordinarily involve general medical skills
- overseas trained doctors, including those who have arrived recently and are operating with provisional registration
- doctors who are required to practice under supervision due to previous concerns about their practice or behaviour.

Concerns have been expressed about this by the Health and Disability Commissioner and the Medical Council of New Zealand, who have described situations where they have sought to discourage certain practitioners from providing assisted dying services. Current assisted dying practitioners have also expressed concern that junior doctors would not have the skills or clinical maturity required to provide assisted dying.

While there is a professional expectation in the health system that practitioners only practise medicine to the extent that they are competent, the relative newness of assisted dying in New Zealand and the permissiveness of the requirements to be an attending medical practitioner mean that some practitioners who may not be sufficiently skilled and experienced to provide these services may still seek to provide them.

Further, some of the levers that exist in the rest of the health system that ensure a capable workforce are limited for practitioners providing assisted dying. For example, while professional colleges are usually a key mechanism in the health system that confirm competence and provide development and training for practitioners, there is no professional college with responsibility for assisted dying.

Finally, while the Act does require that the SCENZ Group maintain a list of practitioners who provide assisted dying (the SCENZ list), the Act frames this as a purely administrative tool to be used to help people seeking assisted dying to find a practitioner, rather than as a tool to regulate and manage the assisted dying workforce. The SCENZ list does not capture all practitioners who provide assisted dying services, as practitioners are not required to be on the list to provide these services.

## There is no legislative requirement to complete training as a condition of providing assisted dying

Practitioners providing assisted dying services should have particular knowledge of the process to assess a person for and provide an assisted death, and the legislative requirements that they need to fulfil to ensure a safe process.

These matters would ordinarily be addressed through training. However, the Act does not include a requirement for practitioners to complete specified training as a condition of providing assisted dying services. This is out of step with how assisted dying is provided internationally, noting that all Australian states with assisted dying regimes include legislative provisions requiring practitioners to complete training before providing assisted dying services.

This issue was noted when the Ministry was implementing assisted dying. An interim solution was developed where completing training was made a condition for practitioners to receive funding for delivering assisted dying services. However, this is an imperfect solution as practitioners are able to provide assisted dying without seeking funding from Health New Zealand for their services, meaning these practitioners would not be required to complete training.

A number of submissions received through targeted engagement commented that training should be required, and that training should be more robust. Some groups considered that training should be mandated and renewed annually, particularly on the legal standards that practitioners are required to meet.

## The workforce to provide assisted dying is insufficient

The availability of willing practitioners is critical to providing assisted dying services. As at 4 September 2024, there were 154 practitioners recorded on the SCENZ list, including:

- 109 willing to serve as an attending medical practitioner (with an additional 40 practitioners who provide the service but who have chosen not to be included on the SCENZ list)
- 94 willing to serve as an independent medical practitioner
- 75 willing to serve either as an attending medical practitioner or an independent medical practitioner as needed
- 15 attending nurse practitioners
- 11 psychiatrists.

The number of practitioners on the SCENZ list has remained relatively stable over the last three years, with similar numbers of practitioners moving on and off the list over time. The number of those who have acted as an attending medical practitioner but chosen not to be included on the SCENZ list has slowly grown – these practitioners only provide services to their own patients and do not want to receive referrals for other patients.<sup>37</sup>

Targeted engagement – including the experience of practitioners, those who have supported others through the process, and those involved in managing and regulating the assisted dying process – highlighted that the small network of practitioners who provide assisted dying is working hard to deliver responsive assisted dying services to those that request them.

However, targeted engagement also raised that the small size and uneven distribution of the workforce has impacted on the ability of people to access assisted dying, the time it takes to be seen and move through the process, and the extent to which people have a choice about who they receive assisted dying from. This also impacts practitioners who provide the service, who may need to travel long distances to see people, and may feel they need to provide assisted dying services in areas where there are limited or no other practitioners available. Practitioners providing the service noted

<sup>37</sup> Note that all applications for an assisted death are still required to be checked by the Registrar before proceeding.



that while providing assisted dying can be immensely rewarding, it can also be isolating and draining.

The relatively small workforce providing assisted dying may be a product of:

- limitations on who can provide assisted dying, and what parts of the process different parts of the health workforce can deliver
- practitioners objecting to providing assisted dying as a matter of conscience
- practitioners choosing not to provide assisted dying for other reasons – for example, they may have no interest in providing assisted dying services, consider that they do not have the relevant skills or experience, or may have concerns about:
  - hostility from members of the community
  - indirect hostility and stigma (e.g. being viewed negatively by people accessing services or colleagues)
  - the psychological and emotional impacts involved in providing assisted dying
  - the additional scrutiny of their clinical practice associated with providing assisted dying.

There are particularly low numbers of psychiatrists to complete additional competence assessments. While there are 11 psychiatrists on the SCENZ list who may be willing to provide a third assessment of competence where this is needed, in practice the availability of these practitioners is very limited. In a recent case where a psychiatrist was required, 10 of the psychiatrists either declined or were not available for three to four weeks to provide the assessment. Further, a number of psychiatrists on the SCENZ list have yet to assess a case. The limited availability of psychiatrists reflects that this is a small and specialised workforce that is already significantly oversubscribed by demands in the wider health system.

Modelling predicts that the number of people seeking assisted dying will steadily increase in coming years. As the size of the workforce has remained stable, there is concern that the limited size of the workforce will not be sufficient to meet the need for the service. There are currently recognised gaps in mid-central, Gisborne, Palmerston North, West Coast, and Southland (however, the shortages in these areas may be attributed to wider challenges related to the health workforce in these areas). A lack of practitioners also increases the cost of providing the service, due to the need for practitioners to travel longer distances and the time involved.

*We didn't have the psychiatric assessment, but in terms of process, if that was needed there would have been quite a few delays because there aren't that many people qualified to do that. We were concerned because a delay in psychiatric assessment for someone with brain tumour would have been a big issue.*

*Also, dad was losing function daily. So even though he was clear about his wishes throughout... We were worried that a delay would mean that he wouldn't be able to communicate his wish at the date and time.*

- Family member of someone who received an assisted death

## The role of nurse practitioners under the Act places them in a difficult situation

The Act provides for the role of an attending nurse practitioner. This role is limited to the final parts of the assisted dying process and involves nurse practitioners being able to prescribe and administer the assisted dying medication, and care for the person and their family or whānau on the day of the assisted death. Under the Act, nurse practitioners must be “acting under the instruction of an attending medical practitioner”. These requirements raise a number of issues.

First, through targeted engagement, nursing organisations raised issues with the requirement for nurse practitioners to operate under the instruction of medical practitioners in this context, as this is out of step with the way that nurse practitioners deliver health services throughout the rest of the health system. It was noted that the role and capabilities of nurse practitioners are not well understood in New Zealand.

Some groups during targeted engagement commented that nurse practitioners would not be sufficiently skilled and trained to take on an expanded role in the assisted dying process. However, the majority of submissions considered that nurse practitioners are a highly skilled and underutilised workforce that undergo significant training to become registered, noting that in other settings nurse practitioners can be a person’s primary healthcare provider, particularly in rural areas.<sup>38</sup>

Further, the current requirements in the Act mean that an attending nurse practitioner is placed in the position of first meeting a person seeking assisted dying, and those who support them, on the day that they arrive to administer the medication to end the person’s life. This was highlighted during targeted engagement as unreasonable, and nurse practitioners who have been involved in assisted dying noted that this approach runs contrary to the way they provide care in other health settings, where building a relationship with people supports continuity of care. Some nurse practitioners noted that in addition to the steps set out in the Act, they usually contact the person seeking assisted dying before

*The requirement for the process to be led by an attending medical practitioner means that some people will be referred to a medical practitioner outside their locality. If the attending medical practitioner is intended to be the person’s primary health practitioner, it would make sense to allow the nurse practitioner holding the relationship with that person to be able to undertake the process.*

– Nursing Council of New Zealand

*With clinical experience a nurse practitioner can perfectly do the job. ... It’s not good, for continuity of care, to start and stop a process and hand it over to someone else who has two hours to build rapport with someone. It’s hard on patients, because they have rapport [with their practitioner] and then have to build it up with someone else.*

– Assisted Dying Practitioner

<sup>38</sup> Becoming a nurse practitioner requires a three-year nursing or health science degree, four years of work experience as a registered nurse, completing advanced training through a clinically focused two-year Master’s degree approved by the Nursing Council of New Zealand, and passing an approved assessment against a set of nurse practitioner competencies.

the day and may visit them in person to build a relationship with them, and ensure that the person is comfortable with the process.

Finally, while section 19(3) of the Act states that a nurse practitioner may prescribe assisted dying medications, this is not currently possible. Some assisted dying medications must be prescribed off-label, and nurse practitioners are currently prevented from prescribing off-label medications by the Medicines Act 1981.<sup>39</sup>

## There is insufficient support available for practitioners providing assisted dying services

Practitioners normally receive support in their practice through their professional college, including professional and peer-support. However, opportunities for this support are limited as there is no college with responsibility for assisted dying. Further, because practitioners are funded on a fee-for-service basis under the Assisted Dying Service Notice<sup>40</sup> for the parts of the service that they provide, there are limited opportunities for practitioners to seek or receive support from their employers or colleagues who are not involved in providing assisted dying services.

The Act is largely silent on who is responsible for providing support for practitioners that goes beyond managing the process of assisted dying itself.

*Medical associations and regulatory bodies play an important role in developing safeguards for providers, so they feel safe and supported to provide AD services. Without this professional support, the provision of AD services can become quite an isolating experience, particularly for those practising in rural or remote areas.*

– New Zealand Resident Doctors' Association

The Assisted Dying Service currently provides or supports:

- quarterly peer support network evenings, and optional local peer support groups
- follow up calls after a practitioner's first provision of an assisted death, if requested by the practitioner, or if the case was identified by the Service as complex
- support over the phone, and discussion and advice when practitioners raise concerns or request a debrief
- monthly drop in sessions
- case review workshops to improve practice
- support through a psychiatrist on request.

During targeted engagement, practitioners providing assisted dying raised that while the provision of these services can be personally fulfilling, it can also be isolating and emotionally draining, particularly for those practising in rural or remote areas. The types of support that practitioners indicated could be helpful include:

<sup>39</sup> See <https://www.medsafe.govt.nz/profs/Rlss/unapp.asp>.

<sup>40</sup> See <https://gazette.govt.nz/notice/id/2021-go4217>.

- debriefs after providing an assisted death, including emotional support and professional supervision
- in-person workshops and online forums for people providing assisted dying to support each other
- having the opportunity to observe an assisted death before providing one themselves, and having a peer observe and provide feedback on practice from time to time
- having a second person present when administering medication to provide moral support, or 'just to watch the door'.

A lack of support for practitioners could impact on the number of those who are willing and able to provide assisted dying services.

## Recommendations

The Ministry makes the following recommendations to address the issues outlined in this section. For each recommendation it is noted where alternative options were considered.

These recommendations are made as a package, noting that they (intentionally) overlap in places, and are mutually reinforcing.

### **Recommendation 17**

Require medical and nurse practitioners providing assisted dying services to have held a practising certificate for a minimum period of:

- five years for medical practitioners, following general registration
- five years for nurse practitioners, where they have practised as a nurse practitioner.

The five-year period would not be required to be consecutive, recognising that some practitioners may take breaks (e.g., for parental leave).

This change would remove the ability for relatively new doctors and nurse practitioners to provide assisted dying services. This recognises that providing assisted dying requires some skills and capabilities that develop through experience, including having difficult conversations with people, cultural competence, the ability to engage with and support family or whānau, and professional judgement.

This change would also provide some protections for new practitioners from offering assisted dying, which from a legal perspective is riskier for practitioners than other areas of medicine.

This change would replace and strengthen the current requirement in the Act for independent medical practitioners to have held a practising certificate for five years, by expanding this requirement to all practitioners providing assisted dying services.

## Alternative options that were considered

Three alternative options were considered.

The first would involve requiring the development of a specific scope of practice or extended scope of practice for assisted dying. Scopes of practice in medicine generally cover broad areas of practice. This option was not recommended as assisted dying requires general skills related to the wider practice of medicine, and it would be difficult to differentiate a scope of practice for assisted dying from existing scopes of practice.

The second would involve requiring vocational registration before practitioners can provide assisted dying. Doctors generally receive general registration after two years of practice, and can then go on to be vocationally registered. This means they have completed a specialist qualification, and practice under a college, where they are required to undergo periodic recertification. Limiting assisted dying to practitioners with vocational registration would mean that doctors with only general registration would not be able to provide assisted dying.

A requirement for vocational registration would also prevent some doctors working in general practice from providing assisted dying services, as many practitioners working in general practices are not vocationally registered. Given that these practitioners make up a key part of the assisted dying workforce, making this change could significantly reduce the number of practitioners available to provide assisted dying services.

The third would involve requiring that either the attending practitioner or independent medical practitioner must have expertise in, and experience of the disease, illness, or medical condition of the person being assessed. This would increase requirements for practitioners providing assisted dying. Similar provisions are in place in some Australian states.

This change was not recommended as it would create a significant barrier to access, given the relatively small workforce providing assisted dying and the limited number of practitioners who have expertise with different conditions within this workforce. This would be a particular barrier to access for those suffering from less common conditions. A requirement of this nature would also create duplication in the assisted dying process, as a person's prognosis will often have been determined by a specialist already and assisted dying practitioners seek out this information to inform their assessment of the person's eligibility.

### **Recommendation 18**

Add an explicit requirement that practitioners who provide assisted dying services must complete required training, including any refresher training, which must cover their duties under the Act.

Adding this requirement to the Act would address a notable gap in the current legislation. While an interim solution is currently in place linking training requirements to funding, it is important that the Act signals that practitioners must complete

required training to ensure the quality and safety of the service. The wording of this requirement connects into a duties approach to setting responsibilities for practitioners, which is described in recommendation 5.

Required training can change over time as practice evolves. The detail of the training could be set by agencies involved, such as Health New Zealand, and would not need to be included in the legislation. Training could include:

- legal obligations and requirements on practitioners in the Act
- identifying and assessing risk factors for pressure
- undertaking competence assessments
- methods for the administration of assisted dying medication
- communication skills and methods
- cultural competency and disability training (particularly around alternative communication methods and the use of supported decision-making)
- connecting families and whānau to bereavement support, and supporting people who have been found ineligible
- managing their personal wellbeing.

### Alternative options that were considered

Another option considered was to add a requirement in the Act that practitioners who provide assisted dying be certified by either the Ministry or Health New Zealand. This approach would involve setting requirements for practitioners to be certified (e.g., conditional on completing training, competence and character checks, etc.), and requiring the names of certified practitioners to be recorded on a list to be used when helping people to find an assisted dying practitioner. Certification could be suspended or withdrawn in certain situations. This approach is used in some Australian states with assisted dying legislation.

This approach would strengthen the requirements on individual practitioners, and protections for people seeking assisted dying, by enabling the Ministry or Health New Zealand to directly manage and actively prevent practitioners from providing assisted dying services where there are concerns about their competence or conduct.

However, the introduction of a certification requirement specifically for assisted dying would be out of step with how the health workforce is managed in the wider health system, and would involve significant additional costs and administration. This approach could also reduce the size of the workforce available to provide assisted dying, particularly if the certification process was seen as arduous or costly for practitioners.

On balance, it was considered that mandating training alongside existing processes for managing the health workforce would be sufficient for managing who is able to provide assisted dying.

### **Recommendation 19**

Allow the third assessment (to determine competence) to be provided by:

- a psychiatrist (as currently set out in the Act), or
- a health practitioner with specialist vocational registration in an area set out by the Director-General of Health.

This would be accompanied by a provision stating that the Director-General of Health may, by notice in the *New Zealand Gazette*, specify a person or class of person with a particular vocational registration as people authorised to provide competence assessments for assisted dying, if the Director-General is satisfied that the person or class of person has undergone training in, and is competent in, competence assessments.

This change would provide some additional flexibility in terms of the health practitioners who can provide an assessment of competence where either the attending practitioner or the independent medical practitioner are not satisfied that the person seeking assisted dying is competent to make an informed decision. This recognises that the current workforce of psychiatrists available to provide competence assessments is constrained, and that there are other individuals within the wider health workforce who have the skills and training to make these assessments.

The proposed wording would allow the Director-General of Health to identify additional individuals or groups of individuals with particular specialist registrations to provide these assessments, where they are deemed to be sufficiently competent and capable. This could include practitioners who work in settings where determinations frequently need to be made about a person's competence, and some health practitioners working in the wider health workforce (such as clinical psychologists, who regularly make assessments of competence in mental health settings).

### **Recommendation 20**

Allow nurse practitioners to fulfil all of the responsibilities that are currently undertaken by an attending practitioner, but not fulfil the role of the independent medical practitioner.

As part of this change, remove wording in the Act that refers to attending nurse practitioners operating under the instruction of attending medical practitioners.

This change would address current arrangements in the Act where nurse practitioners are able to provide the final and most significant part of the assisted dying process, but in a restricted way that does not support nurse practitioners to build a relationship with the person and those supporting them, or good continuity of care throughout the process.

This change would recognise the skills and capabilities of nurse practitioners by enabling them to provide the main role in the assisted dying process, and would help to address the insufficient size of the workforce. Nurse practitioners are a highly skilled

workforce that can be utilised to better support access to assisted dying, including in rural areas. Nurse practitioners undergo significant training to become registered, and in other settings, nurse practitioners can be a person's primary healthcare provider.

Nurse practitioners seeking to provide assisted dying services would also be subject to requirements related to experience and training set out in the previous recommendations.

### Alternative options that were considered

Another option considered was to allow nurse practitioners to act in the role of the independent medical practitioner as well. However, it was considered that requiring a medical practitioner to undertake one of the assessments provides for a balance of skills in the assessment process, and that enabling nurse practitioners to act in the attending practitioner role would be a sufficient shift to recognise their skills and grow the workforce.

This approach is also being taken by the Australian Capital Territory (ACT). When the ACT system comes into operation (from 3 November 2025), nurse practitioners will be able to act in the equivalent attending practitioner role, but not in the role of the second independent assessor.



# Clarifying organisational roles and responsibilities in the Act

In addition to processes and requirements that enable the provision of assisted dying, the Act establishes three entities to support and monitor the process: the Registrar, the SCENZ Group, and the Review Committee. It also refers to roles for other health entities, including the Health and Disability Commissioner and the Ministry of Health.

While not directly conflicting with what is set out in the Act, the way that assisted dying has been implemented is different from what may have been envisioned when the Act was passed. This is because the Act was developed with limited information about how assisted dying would operate in New Zealand, and because structural changes to the health system have been made since the Act was passed – most notably the establishment of Health New Zealand as the agency responsible for the provision of public health services in New Zealand.

## Approach to reviewing organisational roles and responsibilities in the Act

The review of the Act involved determining whether changes are needed to strengthen and clarify the roles of the three entities established under the Act, as well as the role of other health entities related to assisted dying.

This part of the review has drawn on:

- the experience of those involved in managing and regulating the assisted dying process over the past three years, including the Quality Assurance and Safety group in the Ministry, and Health New Zealand
- feedback from the current Registrar, the SCENZ Group, and the Review Committee (including former members of the Review Committee)
- feedback from the Health and Disability Commissioner
- the views of some practitioners who have been providing the service
- information about support and oversight entities from other jurisdictions where assisted dying is lawful.

In examining the provisions related to the roles of the three entities established under the Act, the Ministry considered the following objectives:

- **Clarity and consistency** – ensuring that each entity under the Act has clear and well-defined roles, and functions to enable them to fulfil those roles, so that there is an effective system of oversight, compliance, and support for assisted dying.
- **The safety of the service that people seeking assisted dying and those supporting them receive, and safety of the workforce** – ensuring that the entities established under the Act are able to effectively monitor and enforce compliance with the requirements of the Act, and address any non-compliance.

- **Accountability and transparency** – ensuring that each entity operates transparently and is accountable to the public and relevant stakeholders, to support trust in the assisted dying process.
- **Quality improvement** – ensuring that there are systems in place for quality and service improvement over time, and that these are supported by the entities in the Act.

## Background information

The Act establishes the following entities that support and monitor the assisted dying process:

- The **Registrar (assisted dying)** is a statutory role under the Act and must be a Ministry employee who is nominated by the Director-General of Health. They are responsible for: establishing and maintaining a register of approved forms for the assisted dying process; reviewing the assisted dying forms completed by practitioners to ensure compliance with the Act; receiving and managing complaints (including referring them to other appropriate authorities); reporting annually to the Minister of Health about the number of deaths occurring through assisted dying; and taking any action as directed by the End of Life Review Committee.
- The **Support and Consultation for End of Life in New Zealand (SCENZ) Group** is a statutory body under the Act. Members are appointed by the Director-General of Health for a period of two years. Under the Act, the SCENZ Group is responsible for maintaining the list of medical practitioners and psychiatrists involved in providing assisted dying services, and providing the contact details of replacement or independent medical practitioners and psychiatrists as part of the Assisted Dying Service. The Group also has oversight of the standards of care for the medicines used in assisted dying.
- 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. Operationally, membership is reviewed every two years. The Review Committee is responsible for considering reports about assisted deaths after they have taken place and whether they show compliance with the requirements of the Act. The Review Committee may direct the Registrar to follow up on any information contained in an assisted death report that the Review Committee considers does not show satisfactory compliance with the requirements of the Act.

Two other entities are also involved in the assisted dying process:

- The **Assisted Dying Secretariat** supports the SCENZ Group, the Review Committee, and the Office of the Registrar, and has a regulatory and monitoring function to ensure compliance with the Act. The Secretariat is part of the Regulatory Assurance function within the Ministry.
- The **Assisted Dying Service (operated by Health New Zealand)** fulfils a number of operational functions, including service provision, training, clinical support, and data collection.

## Key issues identified

### The SCENZ Group has service delivery functions that do not align with its structure, or with the way similar groups operate in the health system

The SCENZ Group is given a number of responsibilities under the Act that make it unclear what the intent of the Group is.

On one hand, the Act suggests that the SCENZ Group will fulfil a service delivery role. It requires the SCENZ Group to:

- provide the contact details of attending medical practitioners or independent medical practitioners to people seeking assisted dying (a consumer-facing role)
- maintain a list of willing replacement medical practitioners, independent medical practitioners, and psychiatrists to support this
- “provide practical assistance if assistance is requested”.

On the other hand, the Act suggests that the SCENZ Group will provide clinical and health system expertise, as it is also responsible for preparing standards of care in relation to the administration of medication and providing advice on medical and legal procedures.

The Act provides limited direction on the composition of the SCENZ Group, with circular wording stating that the Director-General of Health must “appoint members who the Director-General considers have, collectively, knowledge and understanding of matters relevant to the functions of the SCENZ Group”.

The SCENZ Group has been able to fulfil its functions related to providing clinical and health system expertise, and members have been appointed to the Group who can provide expertise in these areas.

However, it was identified during the implementation process that it would not be practical for an appointed committee to fulfil the day-to-day service delivery functions required by the Act. Because the Act includes a clause stating that the Ministry must “service the SCENZ Group”, the Ministry was able to establish the Assisted Dying Secretariat, which took on and fulfilled the service delivery functions outlined in the Act on behalf of the SCENZ Group. These functions were later transferred to Health New Zealand after it established the Assisted Dying Service. The Assisted Dying Service now provides a contact point for people seeking assisted dying, provides information about the service to people, and refers requests for assisted dying to assisted dying practitioners.

In practice, the SCENZ Group operates in a similar way to an expert advisory group. These types of groups are common in the health system, and usually provide clinical oversight and guidance in complex areas of practice. However, the ability of the SCENZ Group to take on an expert or advisory role is limited by its prescribed functions under the Act.

Some members of the SCENZ Group, and other submissions received through the targeted engagement process, commented that the current legislation restricts the functions they believe the SCENZ Group could have. Members of the SCENZ Group, for example, commented that the Group is not empowered to manage which practitioners can provide assisted dying services or intervene if a practitioner is not providing adequate care.

Feedback has also been received from people who have supported others through the assisted dying process that the name of the SCENZ Group is confusing, and it is unclear how this relates to the SCENZ Group's functions.

A related issue is that while Health New Zealand has taken on some of the roles ascribed to the SCENZ Group as part of delivering the Assisted Dying Service, the role of Health New Zealand in providing that service is not clear in the Act.

### The meaning of the requirement that the Registrar must 'check' whether processes have been complied with under the Act is unclear, and the Registrar lacks explicit powers to fulfil its safeguarding function

Under the Act, the role of the Registrar is to maintain a register of forms relating to the assisted dying process, and to "check that the processes in sections 11 to 18 have been complied with" before an assisted death can take place (section 19(4)). As noted earlier in the report, the practitioner must provide forms to the Registrar at each stage of the process to show what steps have been taken.

The forms provided to the Registrar throughout the process demonstrate the practitioner's reasoning for forming an opinion that a person is eligible to receive assisted dying, including that they are competent to make an informed decision and are making their decision free from pressure. As such, the Registrar's check of these forms provides a critical safeguard, both for people accessing assisted dying and for practitioners providing assisted dying services.

However, the meaning of the requirement in the Act that the Registrar must 'check' whether processes have been complied with is ambiguous. It is unclear whether this is intended to be:

- an administrative check to ensure that information has been provided, or
- a more critical check that involves considering whether the volume and content of the information shows sufficient evidence of compliance with the requirements in the Act, and following up where more information is needed.

The Act is currently interpreted as requiring the latter approach by the Registrar. The current Registrar noted that they see this role as ensuring that the right processes have been followed, and that there is adequate information to support practitioners'

*SCENZ should be empowered to do more to support practitioners above and beyond maintaining the list of practitioners and the clinical standards.*

- 'Exploring Early Experiences of the Assisted Dying Service in Aotearoa' Research Group

decisions. Further, while the Registrar considered that there is value in having a person with clinical knowledge review and evaluate the information that is recorded, the Registrar's role is not to form a further opinion of eligibility as clinical judgements should be left to assisted dying practitioners.

The role of the Registrar in this regard is an essential safeguard in the process that could be clarified and strengthened in the Act.

A further issue that was noted during the review is that the Act does not provide the Registrar with any powers to enable its function under the Act. In particular, the Act does not set out what powers the Registrar has in order to stop the assisted dying process if there are concerns about the adequacy of information provided by practitioners. As such:

- it is unclear whether the Registrar has the authority to intervene if they consider that an assessment does not comply with the requirements of the Act
- it is unclear how the Registrar may interact with practitioners to address concerns about the sufficiency of an assessment
- there are no prescribed reasons in the Act for the Registrar to approve or reject an assisted dying request, and the absence of explicit criteria for making such decisions creates legal uncertainty. Without clear legislative backing, the Registrar is left in a vulnerable position if they reject a claim, as they could face legal challenges or disputes over whether their decision was justified
- the Act does not explicitly allow the Registrar to request additional information from practitioners if they consider the information provided to be insufficient. It is also unclear what actions the Registrar can take when practitioners are uncooperative, beyond relying on the criminal offence provisions.

Finally, while the current immunity provisions in the Act apply to the role of the Registrar, it is unclear how these provisions interact with this and other statutory roles in the Act. Because the Registrar plays a key role in determining whether an assisted death should go ahead, there should be adequate protections for this role in the Act.

### With its current scope, the End of Life Review Committee is unable to be an effective oversight body

It is the Ministry's understanding that when the Act was being considered by Parliament, a Review Committee was included to ensure that there is an independent entity monitoring cases of assisted dying to provide assurance that these are being managed appropriately, identify where improvements can be made, and direct any concerning cases to the appropriate entity for investigation. This intent would be broadly consistent with equivalent types of review bodies in other systems; however, this intent is not reflected in the Act.

*It is an assessment of compliance, but this requires us to have enough information and evidence on how decisions are made to determine compliance has been met.*

...

*There isn't any other way I see this job could be done to ensure the right thing happened for people.*

– The current Registrar

Under section 26(2) of the Act, the Review Committee is limited to reviewing whether the 'assisted death report' provided by the attending medical or nurse practitioner demonstrates satisfactory compliance with the final stage of the assisted dying process. The assisted death report is the final document produced at the end of the assisted dying process, and captures details related to how the assisted death was provided on the day. It does not contain any information about the process leading up to the assisted death.

Per section 21(2), the information provided to the Review Committee is:

- the name of the attending medical practitioner or attending nurse practitioner
- the person's name
- the person's last known address
- the fact that the person has died
- which of the methods described in section 19(2)(a) was used
- a description of the administration of the medication
- whether any problem arose in the administration of the medication and, if so, how it was dealt with
- the place where the person died
- the date and time when the person died
- the name of the medical practitioner or nurse practitioner who was available to the person until the person died
- the names of any other health practitioners who were present when the person died.

Members of the Review Committee submitted that the current arrangement severely limits the information provided to the Review Committee, and means the Review Committee is ineffective in its oversight role. A number of other groups who submitted through the targeted engagement process also raised concerns that the information provided to the Review Committee is inadequate and does not support a robust review process, and that the restrictions around the membership of the Review Committee limits the effective operation of the Review Committee.

Current settings in the Act place the Review Committee in a difficult position, as the Act is silent on the purpose of the Review Committee, and the limitation on the information the Review Committee is able to review prevents the Review Committee from being an effective oversight body.

Additionally, and similarly to the role of the Registrar, it is unclear how the immunity provisions interact with the role of the Review Committee. While the Review

*The scope of the Committee was severely restricted by the legal opinion and at that point we became little more than a 'rubber stamp' ... To construe the role of the Committee in this way was to make a mockery of the intent of the legislature.*

*Our recommendations were almost trivial, minor in nature, and often self-evident reminders to comply with the Act.*

- Former member of the Review Committee

Committee takes on less direct accountability than the Registrar, the Review Committee should be afforded the same level of immunity.

## Recommendations

The Ministry makes the following recommendations to address the issues outlined in this section. For each recommendation it is noted where alternative options were considered.

These recommendations are made as a package, noting that they (intentionally) overlap in places, and are mutually reinforcing.

A summary is included at the end of this section to note how these recommendations fit together.

### **Recommendation 21**

Amend section 25 of the Act to make the SCENZ Group an expert advisory group which provides specialist advice and support for practitioners, the Ministry of Health, and Health New Zealand on the processes under the Act.

The SCENZ Group would be responsible for providing expert advice on:

- workforce skills and competence requirements
- guidance on specific areas of clinical practice and the administration of medications
- training and support provided to practitioners.

The name of the SCENZ Group would be changed to reflect its functions – for example, the Assisted Dying Expert Advisory Group.

This change would see the SCENZ Group become an expert advisory group that provides specialist advice and support to Health New Zealand and the Ministry. This would mean the SCENZ Group loses some of its administrative functions, noting that in practice these are already undertaken by the Ministry and Health New Zealand.

This change reflects the value of an expert advisory group which can support agencies to work through complex decisions related to the provision of assisted dying. Expert advisory groups are commonly used to inform a number of other complex areas of health practice.

## **Recommendation 22**

Amend section 27 of the Act to require the Registrar to make a determination of compliance based on whether the documentation and information provided by practitioners demonstrates compliance with the requirements under the Act.

Further work would need to be done to frame the Registrar's compliance review in the Act, but it is likely that the Registrar would look to apply a reasonableness standard to confirm, for example, that:

- the forms have been completed
- the information provided to inform an assessment is logical and supports the practitioner's opinion
- a factual basis is documented that the person meets the criteria
- the practitioner's assessment is documented adequately.

A provision would be added stating that the Registrar's authorisation is required before an assisted death can proceed.

Section 27 of the Act would also be amended to provide powers for Registrar to:

- seek additional information when reviewing the documentation
- pause the process until sufficient information has been provided, and
- stop the process if the additional information is not sufficient to demonstrate compliance with the Act, or if it becomes apparent that other aspects of the legislation have not been complied with.

This change would address the lack of clarity around the requirement that the Registrar must 'check' whether processes have been complied with. In summary, the Registrar would be required to:

- review all forms and documentation provided
- if required, pause the process to seek additional information from practitioners
- make a formal determination that the attending practitioner and independent medical practitioner have provided sufficient evidence that non-clinical eligibility criteria have been met, and a rationale to substantiate their opinion that clinical eligibility criteria have been met.

This would not be an assessment of whether a person is eligible for assisted dying, or an appraisal of the accuracy of the practitioners' assessments. Rather, the Registrar would assess the sufficiency of the information provided.

This change would also clarify and reinforce the role of the Registrar as a safeguard in the process, and ensure that the Registrar has powers to request further information and pause or stop the process if needed. This change would ensure that the requirements of the Act are complied with and better protect health consumers.



### **Recommendation 23**

Amend section 26 of the Act to clarify that the purpose of the Review Committee is to:

- consider all documentation produced during the course of individuals seeking and/or receiving an assisted death
- determine whether the information recorded shows satisfactory compliance with the requirements of the Act
- as necessary, make recommendations to the relevant organisations and entities to support quality or practice improvements, and indicate where information may be insufficient to demonstrate compliance with the requirements of the Act.

The relevant organisations and entities are:

- Health New Zealand (the Assisted Dying Service), as the agency responsible for the operation of the Act – this could include feedback to individual practitioners
- the SCENZ Group, as the expert body advising on the operation of the Act
- the Registrar, in their capacity to review information and make determinations on compliance under the Act
- the Ministry of Health, as the agency responsible for regulation of assisted dying and the End of Life Choice Act.

Where the Review Committee considers that a matter identified in relation to assisted dying may warrant formal investigation, it may refer the matter to the relevant entity, such as:

- the Health and Disability Commissioner
- the Medical Council of New Zealand or Nursing Council of New Zealand
- the New Zealand Police.

These changes would align the role and functions of the Review Committee with what the Ministry understands Parliament intended, and clarify and strengthen the role and functions of the Review Committee.

These changes would clarify that the primary purpose of the Review Committee is to provide an avenue for service and practitioner related improvements, and to raise any cases that cause concern with the relevant agencies that have investigative powers.

To support its role, the Review Committee would have access to all material (e.g., forms) produced throughout the process when a person seeks and receives an assisted death.

The Review Committee would not have powers to require the provision of further information from practitioners, beyond what is recorded as part of the process, noting that the Review Committee is not an investigative or fault-finding body.

The Review Committee's referral function would not exclude the possibility that a person may, at any time, make their own complaint to the entities listed above.

### **Recommendation 24**

Set out in the Act specific immunities for the Registrar and the Review Committee. The Act would also specify that judicial review is available as an accountability pathway.

This change would clarify the immunity protections for the Registrar and the Review Committee. This could be set out in a way that is tailored to the roles of the Registrar and Review Committee. Such a provision would enable these statutory bodies to operate more effectively, with clear accountability and without undue legal risk attached to their roles.

This would be particularly necessary if the existing immunity provisions were removed, as set out in recommendation 6.

This recommendation is aligned with immunity approaches in other New Zealand legislation – some examples are provided below.

#### **Example: Immunity provision in the Mental Health (Compulsory Assessment and Treatment) Act 1992**

Section 108A: No proceedings against members of Review Tribunals unless bad faith shown

- (1) No civil proceedings may be brought against any member of a Review Tribunal for any thing he or she may do or report or say in the course of the exercise or intended exercise of his or her powers, duties, or functions under this Act, unless it is shown that he or she acted in bad faith.
- (2) Nothing in this section affects the right of any person or organisation to apply, in accordance with law, for judicial review of a member of a Review Tribunal's powers, duties, or functions under this Act.

#### **Example: Exclusion of liability provision in the Health Practitioners Competence Assurance Act 2003**

Section 119: Exclusion of liability

- (1) Neither an authority nor a member, employee, agent, or committee of an authority nor a member of such a committee is under any criminal or civil liability in respect of—
  - a) any act done or omitted in the course of the performance or exercise or intended performance or exercise of any of its functions, duties, or powers under this Act; or

- b) any words spoken or written at, or for the purposes of, a meeting, conference, hearing, inquiry or proceeding under this Act; or
- c) anything contained in any notice given under this Act.

(2) No person is under any civil liability in respect of anything done or omitted, or for any words spoken or written, in the course of making an assessment or a report under section 23.

(3) No person is under any civil liability in respect of anything done or omitted, or for any words spoken or written, in the course of conducting or assisting in conducting any competence review, competence programme, or recertification programme.

(4) This section does not exclude the liability of any person for anything done or omitted in bad faith or without reasonable care.

### **Recommendation 25**

Add a provision setting out the role of Health New Zealand in the Act. This would see Health New Zealand undertake a number of functions to support the operation of assisted dying as a health service.

The provision would specify that Health New Zealand must provide an Assisted Dying Service which:

- provides a point of contact for people seeking to receive an assisted death, or wanting more information about assisted dying
- provides contact details for an attending practitioner
- identifies and assigns an independent medical practitioner
- identifies and assigns a psychiatrist or other approved practitioner to provide an opinion on competence, if required
- provides training for practitioners.

This change would support the sustainability of assisted dying as a service by setting out clear responsibilities for a centralised administration and support function that enables the provision of assisted dying.

This change also recognises that Health New Zealand is responsible for providing the front-end for the Assisted Dying Service (the point of contact) for people seeking assisted dying, and a number of administrative functions connected to this.

## **Summary of how these recommendations fit together**

Combining the proposed recommendations, the organisational roles in providing and overseeing assisted dying would be as follows:

- The SCENZ Group would become an expert advisory group that provides specialist advice and support to Health New Zealand and the Ministry related to assisted dying.
- Health New Zealand would have responsibility for providing the ‘front end’ of the Assisted Dying Service, including a number of administrative functions to support the assisted dying process such as assigning and providing contact details for replacement or independent practitioners, and providing training to the workforce.
- The Registrar would have a clearly defined role to make determinations about whether information provided by practitioners shows compliance with the requirements under the Act, and would continue to receive and direct complaints.
- The Review Committee would have a role to review individual cases of assisted dying and make recommendations to Health New Zealand, the SCENZ Group, the Registrar, and the Ministry as appropriate, with expanded access to information provided by practitioners throughout the process.
- The Ministry would maintain its current role as a monitor and advisor on the health system (including assisted dying), administer the Act, and provide policy advice to government and parliament as needed.

## Minor recommended changes

In addition to the previous recommendations, the Ministry has also identified a number of smaller changes that would improve provisions in the Act related to the Review Committee. The table below outlines these recommendations and a brief rationale for why each change is recommended.

**Table 4: Minor recommended changes to improve provisions in the Act related to the End of Life Review Committee**

Recommendation	Rationale
Amend section 26 of the Act to allow more than three members to be appointed to the Review Committee by the Minister of Health if needed. The provision could specify that the Minister must appoint a Review Committee consisting of a medical ethicist, and <u>at least</u> two health practitioners, one of whom must be a medical practitioner who practises in the area of end-of-life care.	This change would remove the existing requirement in the Act, which limits the membership of the Review Committee to three specialists or experts, and allow the Minister of Health to appoint additional members to the Review Committee if needed.  This change would align with the Review Committee’s broader scope by allowing for an increased membership in future if needed to manage the Review Committee’s workload.
Add a provision requiring the Review Committee to provide an annual report of its activities to the Minister of Health.	This change would recognise that, as an independent review body, the Review Committee should have a mechanism that supports public transparency and accountability, which would help to build public confidence in assisted dying services.

## Other matters that Parliament may wish to consider

During the course of the review, a number of other matters were identified that Parliament may wish to consider alongside any amendments to the Act. Recommendations on these points have not been made, as they are outside the scope of the review.

### Including providing safeguards as an explicit purpose of the End of Life Choice Act

Setting the terms of reference for the review included considering what the purposes of the End of Life Choice Act (the Act) are, in order to examine how well the Act is achieving them. The Act specifies that its purposes are:

- to give persons who have a terminal illness and who meet certain criteria the option of lawfully requesting medical assistance to end their lives
- to establish a lawful process for assisting eligible persons who exercise that option.

An additional, implied purpose of the Act is to provide for safeguards which seek to ensure that assisted dying is only provided to those who are eligible, who actively seek and consent to it, and that this consent is provided without pressure from others.

This purpose is clearly reflected in the body of the Act, but is absent in the purpose section. While the practical effect of this omission is negligible, it is something that Parliament may wish to consider amending, to make this clear.

### Adding principles to underpin the Act

Legislation in other jurisdictions (and Australia specifically) often includes guiding principles to provide some underlying context for those interpreting the legislation and performing roles under it. Consideration could be given to including such principles in the End of Life Choice Act.

Below is an example of principles in Western Australia's Voluntary Assisted Dying Act 2019.

#### **Principles in Western Australia's *Voluntary Assisted Dying Act 2019***

A person exercising a power or performing a function under this Act must have regard to the following principles:

- every human life has equal value

- a person's autonomy, including autonomy in respect of end of life choices, should be respected
- a person has the right to be supported in making informed decisions about the person's medical treatment, and should be given, in a manner the person understands, information about medical treatment options including comfort and palliative care and treatment
- a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life
- a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained
- a person should be encouraged to openly discuss death and dying, and the person's preferences and values regarding their care, treatment and end of life should be encouraged and promoted
- a person should be supported in conversations with the person's health practitioners, family and carers and community about treatment and care preferences
- a person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in Western Australia and having regard to the person's culture and language
- a person who is a regional resident is entitled to the same level of access to voluntary assisted dying as a person who lives in the metropolitan region
- there is a need to protect persons who may be subject to abuse or coercion
- all persons, including health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.

## Changes to how the eligibility criteria are specified

Changes to the eligibility criteria for a person to receive assisted dying are beyond the scope of this review. However, targeted engagement with practitioners and a legal analysis of the Act raised some questions about whether the way that eligibility is specified in the Act could be improved.

The eligibility criteria in the Act (section 5) mixes criteria that are objective and fixed, with criteria that are subject to judgements by practitioners. As such, requirements related to a person's age and immigration status are set out in the same section as a person's prognosis and the requirement that they must be experiencing unbearable pain and suffering.

The Act implies that all of the criteria apply throughout the process. However, given that the objective criteria involve a different type of assessment to the subjective criteria, the criteria could be split between:

- qualifying criteria related to age and immigration status – these can be checked once at the beginning of the process, potentially by the Assisted Dying Service rather than the attending practitioner
- eligibility criteria that are subject to clinical judgement by practitioners – these are assessed at points throughout the process, and include a person's prognosis, decline in physical capability, experience of unbearable suffering, and competence to make an informed decision.

Additionally, some practitioners have questioned whether the following three eligibility criteria must all apply to the same underlying health condition:

- The person is suffering from a terminal illness that is likely to end the person's life within six months.
- The person is in an advanced state of irreversible decline in physical capability.
- The person is experiencing unbearable suffering that cannot be relieved in a manner that they consider tolerable.

It is unclear in the Act whether the person's terminal illness likely to end their life must also be responsible for their advanced state of irreversible decline in physical capability and the cause of their unbearable suffering, or whether these could be related to another condition alongside the terminal illness.

In most cases where people would be found eligible, their terminal illness will be the cause of their decline in physical capability and unbearable suffering. However, there are some terminal conditions that at a particular point in time may not meet the other criteria. In these cases, if a person also suffers from other conditions that cause a decline in physical capability and suffering, they may meet the criteria as a result of those other conditions.

The current interpretation of the Act is that a person in this situation could be found to meet all the criteria, as the Act does not explicitly state that a single condition is needed to meet all the criteria. Consideration could be given to whether this should be clarified in the Act or whether the current wording and interpretation are sufficient.

## Adding a definition for terminal illness

Section 5(1)(c) of the Act requires that a person is “suffering from a terminal illness that is likely to end that person’s life within six months”. The term ‘terminal illness’ is not defined in the Act. This point was raised when the Act was being considered by Parliament, where some members noted that the purpose of the Act included ‘terminal illness’ as a key concept, while leaving it undefined.

There is some ambiguity in the Act about whether a terminal illness must be incurable. For example, it is unclear whether an individual has a ‘terminal illness’ if that illness is likely to end their life within six months without treatment, but there is a chance that the progression of the illness and death could be managed, slowed, or cured with treatment.

An example of how this point is addressed in other jurisdictions is Tasmania’s End-of-Life Choices (Voluntary Assisted Dying) Act (2021), which provides that a disease, illness, injury, or medical condition is deemed incurable, irreversible, and expected to cause the death of the person if “there is no reasonably available treatment that is acceptable to the person” that can “cure or reverse the disease, illness, injury or medical condition and prevent the expected death of the person from the disease, illness, injury or medical condition”.

Parliament may wish to consider amending section 5(1)(c) of the Act to define ‘terminal illness’. As in the example above, any definition should consider the reasonable availability of treatments for the person, noting that while some treatments may technically exist, there can be practical, funding, or other availability limitations that mean that not all possible treatments will necessarily be reasonably available to, or acceptable to, a person.

*The Act does not define the term ‘terminal illness’. The Member responsible for the Bill considered at the time that the provision was self-explanatory, because of the requirement that an illness must be likely to cause death within six months ... The lack of clarity in respect of whether a terminal illness must be incurable creates some ambiguity for section 5(1)(c) of the Act.*

– New Zealand Law Society

## Whether a specific criminal offence is needed for inducing a person to seek an assisted death

Under the Act, practitioners are required to do their best to determine that a person seeking an assisted death is doing so free from pressure from others. The Act places requirements on practitioners related to this, with consequences including the potential for criminal prosecution if this requirement is not met. However, it is not clear whether those who might seek to pressure others to seek an assisted death are committing a criminal offence.

Under section 179 of the Crimes Act 1961, it is a criminal offence to incite, counsel, or procure a person to commit suicide, or to aid or abet any person in the commission of a suicide. A similar provision could be considered in relation to assisted dying, to address situations where a person induces or tries to induce another person to seek an assisted death.



It is important to note that the context around assisted dying is different from suicide. The provision of an assisted death to someone who is not consenting freely may be more analogous to homicide than suicide, and inducing someone to seek assisted dying against their will may therefore require a different criminal recourse.

## Clarifying whether and how an Enduring Power of Attorney for personal care and welfare interacts with a person's competence to make an informed decision about assisted dying

This report recommends that an amendment be made to the Act to clarify that a person acting with an Enduring Power of Attorney (EPOA) for personal care and welfare for another person cannot make a decision about assisted dying for that person. This is to reflect the intent of the Act that no person should be able to make decisions about assisted dying for another person.

A related issue is whether a person who is the subject of an EPOA for personal care and welfare should be excluded from applying for or receiving an assisted death, on the basis that they may have been deemed mentally incapable and therefore not competent to make an informed decision about assisted dying.

Medical practitioners are often involved in the decision to activate an EPOA, including determining that a person is mentally incapable. This suggests that an activated EPOA might be a reasonable basis on which to determine that a person is not capable of making an informed decision about assisted dying.

However, it is important to note that there are a number of different types of EPOAs that a person might have, and that once EPOAs are activated they are rarely deactivated, even if a person's condition improves. This means that a person can have an activated EPOA and still potentially be competent to make decisions.

The current approach taken in the assisted dying process is for practitioners who are assessing a person's competence to take an active EPOA into account when making their assessment, but not to treat this as determinative.

This may be an area where additional clarity could be provided in the Act.

# Appendices

## Appendix 1: Experiences of people who have sought assisted dying, and those who have supported them

Between July and August 2024, the Ministry interviewed and received written feedback from 19 people who had supported others through the assisted dying process, including one person who had been found ineligible. Their experiences with the service are summarised below, noting that each story was different and reflected the unique circumstances and experiences of individuals and families. The person who passed away is referenced as [x].

Early research findings were also received for the review, which were informed by interviews with practitioners and people who had sought assisted dying, or supported others through the process. These research findings are captured at the end of this Appendix.

### Themes from interviews with people with experience of the service

#### How people found out about and accessed the service

Most people that were spoken to already knew the service existed, having followed the referendum, and had searched for it online. A small number had heard about it from friends with a terminal condition.

For some, it was not clear what the process to access the service was:

- *"We brought up with the GP twice and nothing happened. We didn't know if we needed to call the 0800 number. At the start you don't know what those terms mean, so don't know which doctor to bring it up with or who an assisted dying doctor is."*
- *"It took a bit of time, we weren't clear on what was going to happen next. You've been smacked with a diagnosis ... and my husband raised it, and we went to our lawyer and they said, 'no, no, go to your GP'. That took weeks to figure out."*

A few people directly called the 0800 number. This was an easy process for some people, but more challenging for others if their calls were not followed up on:

- *[From someone found ineligible]: "After plucking up a lot of courage I called 0800 number. At that stage it wasn't working properly. Nobody called me back. That happened twice, then I got put on to [a practitioner]. It takes a lot of courage to make that phone call, and you feel devastated when you don't hear anything."*

- *"We had to stand around waiting for a call, and that did take quite a bit of time. When the call came it was quite bizarre in that it was quite casual, and we weren't in an appropriate place ... He didn't save the number, didn't know who we were talking to, so we lost 10 days or two weeks. I think if I'd been more upset or didn't have my head together, we would have just left it there. It would have been very easy to walk away."*

Some discussed their experiences bringing assisted dying up with their general practitioner. There were varying experiences with the speed at which referrals were made:

- *"When my mother-in-law asked her GP about it, it took her asking three weeks in a row before a referral to hospice was made. She believed the medical professionals about how to get assisted dying, which wasted precious time. They didn't know. No one was able to help us learn how to get the ball rolling for her."*
- *"We did go to his GP and raised assisted dying as a future option. She was clearly very uncomfortable and said their practice 'didn't do it' but that she would find out what the process was. She later emailed the 0800 number."*
- *"From March, changes [to the person's condition] were happening every week. At the end of March she said, 'right, I'm going to see the GP'. She had a young locum and I think he got a bit freaked out. ... She was handed the phone number on a piece of paper."*

One person noted their hospice nurse had a sheet of paper with the 0800 number on it, which they were allowed to photograph but not keep.

There were a range of experiences between wanting to access assisted dying quickly (as the person was rapidly deteriorating), and wanting to have the option available if the person needed it:

- *[From someone found ineligible]: "It wasn't that I wanted to do it, I wanted to hold the card. And have choices. You don't get many choices."*
- *"Last year in April she got the news that there was nothing more they could do, and she would progressively become incapacitated. Her call in April was, 'I'm out of here and let's make it happen,' and we said, 'oh, well, it might not be that easy, there is a process...'"*

## The assisted dying process

Feedback on the assessment process was generally positive. Comments on the attending medical practitioners included that *"They all had a different technique, but they were very thorough and quite sensitive"*, *"they were professional, clear, well-informed, and compassionate"*, and another said their practitioner had outstanding communication and gave them all the time they needed. One person said their attending medical practitioner reached out to offer support to the family throughout the process.

One person said: *"I felt safe in the process"*, and another said *"It's quite rigorous and daunting in terms of all the steps required, though this was mitigated by the care and professionalism of our case manager and the doctors involved. We felt well informed by all of them."*

## Time the process took

Some commented that the process took the right amount of time for them:

- *"We found the process quicker and more efficient than we expected."*
- *"It was about 10 days – literally from getting the go ahead. She said if she was accepted, she wanted the first possible date. And that was about 9 or 10 days from when the OK came through. ... The 10 days was probably a good amount of time because the family came, and we all got together and had a bit of a laugh... but she was well ready to go."*
- *"SCENZ worked very hard to make the day and time happen. We got fast tracked. That was extremely helpful. Even though it felt like an age for us, it took a week and a half all up. The support we got was amazing."*

While the process generally took the right amount of time for people, some commented that the process was not responsive enough to the person if they declined rapidly:

- *"By the time permission was granted for an assisted death, my husband had been admitted to hospice, he was unable to swallow, his medication had to be changed to liquid IV and the new medication was not working. This was an incredibly distressing time and something my husband and I had hoped he would not need to experience. He suffered unnecessarily."*

Others noted their loved ones were concerned that they would lose competence to consent to assisted dying before the day of the assisted death. That caused some people to want to set the date for the assisted death not too far in advance:

- *"Mum worried that she would have a stroke, so she was worried on that last day she wouldn't be able to speak and give consent."*
- *"If [the psychiatric assessment] was needed, ... we were really worried because dad had days, weeks. ... We were worried that a delay would mean that he wouldn't be able to communicate his wish at the date and time."*
- *"He was afraid that at some point the drugs or the disease might make him so drowsy that he was no longer deemed 'competent' to give approval, so he didn't want to hold off for too long in case this happened."*
- *"If it had been a few months later, she would not have been able to talk."*

## Setting the date for the assisted death

Some people spoken to noted that it was strange to need to set a date in advance:

- *"When [x] did set that initial date, he just set a date about three months away, in late February. By 10 February he decided he wasn't going to use that date, so chose a date that was quite far out – in May – just to save continuously changing the date."*
- *"Having to nominate an actual date is quite daunting – we could see why, in terms of availability of doctors and need to order drugs, but it might be something that could be left more open?"*
- *"That was definitely a hard part of it to get our heads around, because we're not experts. That was difficult. We didn't know how he was going to deteriorate."*

Most people spoken to needed to bring the date of death forward:

- *"The disease progressed much more quickly than he anticipated, so the initial date he nominated (late April) was gradually moved forward to mid-March."*

Some commented on the requirement to inform the Registrar and give 48 hours' notice to move the date forward:

- *"We were told there would be an issue if it would be within 48 hours. I can't understand that, who is it protecting? If someone suddenly takes a turn for the worse, and maybe they want to bring it forward by a day, why would that be a problem if you've already been assessed and approved?"*
- *"[x] actually requested that we bring that date forward. We were told no, you couldn't because legislation wouldn't allow it, and then they said, 'actually you can, but you have to do it immediately.' So we were put under a hell of a lot of pressure to meet that legal criteria. ... It's cruel, it's really cruel – you're begging for it to be brought forward, and in the end, we saved him one day."*

Some set the date to coincide with family visiting. Otherwise, the time of death was arranged based on the availability of the practitioners: *"Both times it was at the convenience of the person ... it was when the terms were set as to when they could get the medication."*

One person recommended *"a date range you're allowed to set a date in, but not needing to set the date that you know you're not going to use."*

## Conscientious objection and finding a location for the assisted death

While the majority of people that were spoken to needed to find a location for the assisted death, some people were able to have the assisted death at home:

- *"[x] decided he wanted to die at home. And right at the end he decided he wanted to go upstairs to look out the window. The doctor who administered the medication was so kind, he helped [x] up the stairs. He could not have got there by himself."*

People who had the assisted death outside of their home discussed various challenges in finding a location:

- *"My biggest bugbear is hospice not allowing you to choose assisted dying on their premises. I find that appalling, really appalling. My emotional reaction is that hospice should be made to allow it, and aged care as well. Because, for goodness sake, who are you dealing with? People that are dying."*
- *"We have 7-year-old, so we decided not to do that at home. It felt like we're in a very new system where there are some gaps. Choosing the location to go through with the assisted death was one of those gaps. The only suggestions from the practitioner was home, or some awful room at the hospital. Aside from that it was up to us to figure that out. It was really hard for us, especially at that time. Ideally there would be more places available to people. Incidentally we found a funeral director who could offer a location, but if we hadn't found that it would have been stressful and hard. I don't know where you would go if home isn't an option."*

- *"He was in hospice care, and once a time was arranged for an assisted death the hospice staff were very supportive. However, it was not possible to have this on site and the process of arranging an ambulance was difficult, and the journey home was very physically very hard for my husband."*

Others commented on the difficulty of accessing palliative care at the same time as wanting to exercise the choice to receive assisted dying:

- *"The first visit from the hospice nurse was a bit awkward, because we had heard of the NZ hospice movement's vehement opposition to assisted dying, and knew of hospice supporters who referred to it as 'state sanctioned suicide'. We were a bit scared to mention it and were afraid it would affect [x]'s care, or that they might say he wasn't suffering enough to warrant assisted dying. ... [x] wanted to avoid declining to the point where he might need to actually go into the local hospice, knowing their negative position on assisted dying."*
- *"When he told that to the hospice nurse, the reactions were very obvious in that they were saying on the phone, 'we support any decision you make,' but it's very clear they don't support that decision. When we found out that if he ended up in hospice, he wouldn't be able to choose assisted dying in that premises, he would have to be put in a car... I found that totally disgusting. I was concerned he would end up in hospice if I couldn't keep him at home, and he wouldn't be able to do what he wanted, and have the assisted death. It added an awful layer to things at that time in life."*
- *"Public funding should be made contingent on at least not obstructing assisted dying. If an organisation receives public funding, while I think it's appropriate for people to not have to take part in a process that is ethically unsound - the organisation should be required to make facilitates available as funding is provided for that."*

One person noted that their partner's aged care facility changed their position over time. They went through the process twice: the first time, the facility did not agree to allow the death to happen on site. The second time, the board of the facility had reviewed their point of view and *"could see number of people who had availed themselves, and they changed their mind."*

Some commented on the process for having the assisted death in the hospital:

- *"We went out to a small community-based hospital just under an hour's drive away, they call it a 'room of last resort', which is an unfortunate name."*
- *"Dad was in hospital, immobile, on fentanyl pumps, and they said, 'You can't have assisted dying in hospital, and you can't take the fentanyl pump with you out of hospital.' And we said, 'Ok, well... where can we go?' They said you could go home. But dad was 50 minutes away from home and every movement was agony for him, so I said that's not an option. ... The prospect I had was my dad being delivered to my house without fentanyl, lying on my couch in my living room, no pain meds, dying. ... In the end, the assisted dying doctor pulled some strings, and they allowed him to go in his room at the hospital."*

## Conscientious objection and delays to assisted dying requests

Many of the people spoken to also talked about the impacts of individuals' conscientious objection on their experience. For one, their loved one passed away in the process because it was difficult to get a prognosis and the process took too long:

- *"The main problem with the assisted dying process is getting the doctor to say you're likely to die within six months. Nobody wants to put their head on the chopping block and say that. Mum's oncologist didn't get that to mum until three weeks before she died. ... The assisted death was scheduled for 2 June, and she died on 1 June. She lived through everything she didn't want to live through. The whole point of assisted dying is to prevent people from suffering, and because it's taking so long to get doctors to say you'll die in six months, then get the Ministry of Health to sign it off, everyone else to sign it off, get the drugs... it just took too long. I strongly believe people in the medical profession let their personal belief get in the way of the patient's wishes."*

Another family commented on a health practitioner that was obstructive in the process:

- *"I actually believe that their attempt at intervention was aimed at delaying [x]'s attempt at assisted dying, knowing that at some point he would not be able to communicate consent. The impact that it had... It ruined our final week with our dad and trust in medical professionals. He was anxious she might get an injunction. He was anxious, we were anxious, and we are not any less upset now than we were then."*

## The assisted death

Many people commented that the assisted death was peaceful, and a good death:

- *"It was a beautiful process in the sense that it was calm, it was very calm. She knew what she wanted, and for her, it was an end to a struggle of quite a few years."*
- *"It was very peaceful, and far beyond anything I could have imagined given the state of her body and brain. It was good in that we were able to see though what she wanted, which was for us to be there."*
- *"I'm so glad [assisted dying] was brought in before [x] needed to use it... it would have been awful without this. ... Things would have just gotten worse and worse, there were no long-term beds in the hospice. ... it would have been painful, being looked after by people he didn't know away from his home."*
- *"It was a really beautiful death. He had the people he loved there, his dogs were here, we were lucky and had a sunny morning ... as a way to die, it was beautiful."*
- *"The thing is, she'd just gone in her sleep and that's exactly what it was. She just dozed off, talked to the very last minute, dozed off, and for all of us it was incredibly peaceful and lovely. Couldn't have asked for a better way for her, because we all knew what the next couple of weeks were going to be like."*
- *"The process enabled [x] to have a 'good end' in his own home, and for family to gather and farewell him while he could interact with them. We were able to talk openly about his dying. His sons, who were there with us when the procedure occurred, were able to remember the very last interactions and his actual dying as positively as a death can be. It has helped my own mourning to have these memories of a kind and gentle death."*



- *"It was so quick, and he just went. He made several dreadful jokes, and he said, 'we better get on with it'. Dad was ready. Avoiding a horrific death is a reason people choose assisted dying. Having a good death is why people choose this."*

## Requirement to be competent to give informed consent

Many people commented on the anxiety around needing to be competent to make an informed decision at key points in the process:

- *"I'm all about informed consent for all medical procedures. However, in mum's situation, she was holding on so that she could give informed consent on the day, and that caused her even more anxiety. It wouldn't let her relax or give up to the process."*
- *"My father was quite anxious that he would go under or have some kind of event or be too drugged up to give consent."*

Some talked about their loved one reducing medications for pain management so that they could give consent:

- *"Mum refused all pain medication because she didn't want to be groggy. She didn't want to be in a situation where they felt she couldn't make the decision. She said, 'I just need to be totally clear in my mind'. She was incredibly brave, because she was in so much pain by this point."*
- *"The doctor at the care unit ... they reduced her medications so on the day she wouldn't be sedated and able to give consent. ... The biggest stress was on the morning was her ability to give consent. We knew this is what she wished, so if it had been denied on the day that would have been really tough. ... [X] was so determined that she formed two broken sentences that she knew why the doctor was there, and what he was there to do, and that's what she wanted. That gave me a lot of peace."*

Some people thought consent should not be needed on the day.

## Other safeguards in the process

Some people talked about the restriction on health practitioners to raise assisted dying. Some understood this requirement to be a safeguard, but others considered it to be unnecessary:

- *"Safeguards are excessive, if anything. It's ridiculous and patronising that health practitioners can't raise it first."*
- *"I cannot get my head around why your GP who's in charge of palliative care, or oncologist, why no one is able to bring up or give information about this. Giving information is very different to recommending it. It seems so strange and weird it's not allowed. It adds to something being taboo that is absolutely not taboo."*
- *"Health practitioners prohibited from raising assisted dying – I think that's a barrier to access for some people. Not everyone has the internet."*
- *"It really just should be part of palliative care, not a different thing people have to go and find out about themselves. We're not going to let our pets suffer, but we let people just suffer, suffer, suffer until they die."*

Not many people commented on the requirement for practitioners to do their best to detect pressure. Some worried that their support for their loved ones' decision would be



seen as pressure. One person commented that they thought their loved one's decision had been influenced by family members:

- *"My ma would have said she'd go ahead with it. My sister talked to her about it, and my ma is the kind of person who liked to please us all. I just think there was something not quite right there. People in that generation just want to please people, they don't want to make a fuss."*

## Interactions with the rest of the health system

Some commented that they felt they knew more about the assisted dying process than their regular health provider. For some people, their health provider's lack of knowledge about assisted dying caused delays in the process to access the service: *"Had the hospital given the right advice, had the GP known and contacted the right person, had the counsellor known the process, she could have started what was needed sooner."*

One person noted that relationships between people and their health providers are no longer as personal as they have been in the past: *"GPs no longer know their patients or have a relationship with them. Practice doctors don't have the time to provide 'caring' as doctors might have in the past. ... It's ironic that we felt we had far more of a relationship with the attending medical practitioner by the time [x] was ready to die than he did with his own GP."*

Some commented that assisted dying and health services in general felt disconnected from each other: *"You get a sense you're being shuttled from oncology to the GP, to palliative care, and you're having to navigate yourself, and advocate for your husband, and it's quite disjointed. ... It just felt like [x] is out by himself trying to organise this."*

A number of people noted that it made a difference having a great funeral director and being able to plan before the day of death. Others commented that the palliative care they received was excellent, and that assisted dying and palliative care should be more connected.

On the care that hospice provided, one person noted that *"there is no doubt that hospice help with pain relief and small, practical measures to maintain comfort did help him hold on for longer than he might have – it sort of helped – until it didn't."*

## Other areas for improvement

One person recommended making people aware that assisted dying will be on the death certificate: *"When I collected the death certificate from the Funeral Directors it was a shock to see assisted dying on there. ... Due to the secrecy requested I hadn't discussed it with the Funeral Director so was embarrassed that I hadn't. If it's not already in the process for people to know this when making the choice I would recommend that it is added."*

Some people commented that the process on the day came as a shock, particularly for those who had not been as involved in earlier appointments: *"When we came to be in that room, we weren't prepared. Perhaps the information given on the day...I'd like a system where I had a chance to receive an invitation to speak to someone beforehand."*

Some commented that there needs to be more information available for people:

- *"...the lack of knowledge is the big one. People think it's only for people with cancer, not realising it's a terminal illness."*
- *"There needs to be more education, more knowledge, more information available. Just knowing about the process or who to contact, and just that general information."*

Some mentioned that there was no support offered to family after the assisted death, and that this would be important. One person suggested making budget available in terms of counselling support during and after an assisted death.

## Changes to eligibility settings

A number of people recommended expanding eligibility to those who have longer than six months left:

- *"Those six months are irrelevant. The suffering became relevant in the last year or so. She couldn't drive, couldn't write anymore. A number of things were impossible. If there's anything I believe, it's that we should all be given the respect to determine our own time."*
- *"I would like to see it extended to 12 months, because [x] was given initially 'up to 12 months', and he died in probably less than six months after he finally got a diagnosis – took about five months to get a diagnosis."*

## Research findings

Early research findings that included interviews with people involved in or impacted by the introduction of the End of Life Choice Act 2019 (the Act) were also received to inform the review, including:

- preliminary results from research undertaken by the Aotearoa Ethics in Palliative Care (AEPC) research group, which involved interviews with 41 palliative care staff in four hospices in New Zealand, at the end of the first year that the Act was in force
- a submission from the 'Exploring Early Experiences of the Assisted Dying Service in Aotearoa' Research Group,<sup>41</sup> with findings informed by 96 online semi-structured interviews and face-to-face focus groups to explore the experiences of key stakeholders (service users, family members, providers and non-providers, health service leaders, and Māori community members).

Research received from AEPC noted observations from some palliative care staff that existential suffering had increased since the legislation came into force, some people felt distressed waiting for assisted dying, and that some whānau felt distress when they did not want their relative to proceed with an assisted death, which required support from palliative care staff.

<sup>41</sup> Authors: Dr Jessica Young (Principal Investigator), Dr Jeanne Snelling, Dr Aida Dehkhoda, Associate Professor Te Hurinui Karaka-Clarke, Associate Professor Jackie Robinson, Professor Ben White, Professor Kate Diesfeld, Dr Tess Moeke-Maxwell, Dr Janine Winters, Associate Professor Annabel Ahuriri-Driscoll, Associate Professor Gary Cheung. Advisors: Dr Jo Scott-Jones; Mr Philip Patston.

Research received from the 'Exploring Early Experiences of the Assisted Dying Service in Aotearoa' Research Group canvassed a wide range of issues related to the operation of the Act. In summary, the research highlighted the following findings for parts of the process that people thought were working well:

- Families and patients expressed deep gratitude for the compassionate, person and family-centred, dignified, and timely care that practitioners are offering. Many of the assisted deaths were described as beautiful, meaningful, and provided the control that people wanted.
- Once approved, people found eligible for assisted dying felt a huge relief. Participants were very pleased to be able to have the choice.
- Practitioners found the work profound and a privilege to be involved in this significant, intimate time of people's lives.
- People found ineligible because their estimated prognosis did not meet the eligibility criteria felt comfortable recommencing the process when their circumstances changed.
- The patients, families, practitioners, and non-providers interviewed considered that the process is working safely and is well safeguarded.
- For those who were not imminently dying, once the application was initiated, the process flowed smoothly most of the time.
- Since it first started the AD service is becoming more embedded within the health and social care system.
- Families were grateful the service was publicly funded, and practitioners said funding enabled them to offer this service, which results in a more equitable service for patients.

The research also discussed parts of the process that could be improved:

- People who were found ineligible due to not having a terminal illness expressed frustration. Many felt wronged and thought that the law should change to include their circumstances.
- For some, applying with enough time to complete their application was an issue. Other barriers to access referenced by participants included non-cooperating health practitioners, institutional objection, and a lack of information about the process.
- Some people were told they would not be eligible for assisted dying by their health practitioner, in situations where they may have been eligible. Some people were told by healthcare practitioners that they would likely die before being approved for assisted dying. There is a risk that health practitioners who are not expert prognosticators, and/or are not experts in the assisting dying criteria and have not undergone assisted dying training, and/or who have a moral objection to assisted dying, may misinform patients.
- Family members expected follow-up care from the clinical advisor (part of the Assisted Dying Service) or attending medical practitioner after the assisted death, though some provided it and not all family members felt they needed it. A phone call to see if any referrals to bereavement support, debriefing, or answering any questions they had would have been appreciated because there were often no opportunities to close the loop.

- There is scope to improve the accessibility of the service, e.g., for those with hearing impairments.
- Many participants (including patients, whānau, and practitioners) described a sense of stigma associated with assisted dying. Some were concerned about how to manage other people's reactions and emotions about assisted dying. At other times there were concerns about the possibility of interference, or unnecessary questioning from others if the nature of the death was disclosed. Some patients, families, and practitioners felt they had to keep the assisted death secret because of the restrictions on disclosing some details about assisted deaths in the Act. Due to privacy or secrecy, some people grieved alone.

## Appendix 2: Experiences of whānau Māori with the Assisted Dying Service

As part of the review process, the Ministry of Health – Manatū Hauora (the Ministry) sought to understand what the experiences of whānau Māori have been with assisted dying during the first three years. As assisted dying is relatively new in New Zealand, and the number of Māori who have sought an assisted death is relatively small, there is limited information available about Māori experiences with assisted dying.

As part of the review process, some early observations from two studies that are still to be published were shared with the Ministry to inform the review.<sup>42,43</sup> These were conducted by researchers who have interviewed Māori and whānau Māori about their views and experiences related to assisted dying.

The Ministry is grateful to these researchers for sharing some of their early findings to inform the review. Some of their key findings are shared here.

### Māori have cultural reasons to be supportive of, or opposed to, assisted dying

Some communities' tikanga (customary values) are not aligned with or supportive of assisted dying, while others reflected that "assisted dying is something we have always done", meaning Māori have always provided manaaki and aroha (care and compassion) at the end of a person's life.

For those against the concept of assisted dying, some held the view that the wairua (spirit) belongs to God, and the body should be allowed to perish naturally. Others did not support assisted dying because they believed it would distress their whānau, or they wanted to use their whānau support system.

Those in support of assisted dying referenced pūrākau (stories, legends) emphasising mana motuhake (autonomy, self-determination) over life and death. In this sense, assisted dying could be seen as normalised within te ao Māori (the Māori worldview). One participant, for example, cited that Hine Titama chose to leave the world of light and enlightenment to enter Rarohenga (the underworld), where she transformed herself into Hine-Nui-Te-Pō (the maiden of death).

Other whānau supported assisted dying as a way to support the wishes of the terminally ill person, who wanted to preserve their mana<sup>44</sup> over their physical appearance for as long as possible. Upholding the mana of the ill person and their ability to express their mana motuhake over their life and death preferences were paramount to whānau. Whānau also supported the person with planning and preparing for the dying day and the tangihanga

<sup>42</sup> T. Moeke-Maxwell; R. Frey; G. Cheung. 'Experiences of the End of Life Choice Act 2019 amongst families and whānau'. Publication forthcoming.

<sup>43</sup> T. Moeke-Maxwell, L. Nikora and J. Robinson. 'Waerea – Māori whānau experiences of assisted dying in Aotearoa New Zealand'. Publication forthcoming.

<sup>44</sup> See <https://maoridictionary.co.nz/word/3424>.

(funeral ceremony) proceedings – whānau wanted to assume their roles in cultural death customs and carry out tangihanga rituals to a high standard.

## Perspectives of whānau Māori accessing and using assisted dying

Māori individuals who had a life-limiting illness valued the freedom to seek assisted dying and have control over their end-of-life and death. These individuals were supported by whānau who had close relationships with them to seek out and navigate the service.

Whānau had mostly positive things to say about engaging with the assisted dying service. Whānau spoke very highly of assisted dying practitioners, and considered them to be “kind, relaxed, considerate, caring and supportive”.

Bereaved whānau believed that assisted dying is mana-enhancing for individuals using the service. Looking physically ‘normal’ influenced the desire for terminally ill people to choose to have an assisted death, to preserve the mana of their whānau and to ease the suffering of whānau. Participants commented that their whānau members wanted to shield and protect whānau (particularly mokopuna (children or grandchildren)) and friends from feeling distressed seeing them decline in physical health.

## Accessing information about assisted dying is difficult for whānau Māori

Both studies found that Māori communities are unaware of or not openly discussing assisted dying, and find it difficult to find information about the service.

Most participants were unaware of how to access assisted dying, and were unaware of safeguards, processes, and criteria for the service that prevent an assisted death from occurring straight away. There was also a lack of support to navigate the process. It was noted that this was linked to practitioners not being able to raise assisted dying with people.

This led to whānau Māori being unaware that they need to apply for an assessment early in the illness trajectory. Some were too advanced in their illness to access assisted dying, with researchers noting that when a whānau member could not fulfil the desire of a whānau member to have an assisted death they experienced confusion, disappointment, and a sense of inadequacy resulting in experiences of regret and grief.

The health and support workforce (including the health workforce, pastoral care workers, hospice Kaiāwhina and nurses, hospital Kaiwhakahaere, counsellors, rongoā practitioners, tohunga, kaumātua and funeral directors) can be unaware of assisted dying safeguards, process, and eligibility requirements. Participants often felt inadequately prepared to respond to whānau Māori who approached them for information, and they felt prohibited to share the information that they did have due to the restriction on raising assisted dying with people.

## There were barriers for Māori accessing and using assisted dying services related to conscientious objection

Research indicated that conscientious objection was a barrier for Māori accessing and using the service. Conscientious objection by health and palliative care services and by

individual health professionals can minimise the opportunities for Māori to access assisted dying, and to enact their mana motuhake over life and death. Researchers noted that people seeking assisted dying and their whānau need unbiased support from health professionals, with the following examples given:

- Some whānau encountered discrimination from practitioners with a conscientious objection, including one whānau who were told the hospital did not support assisted dying. This created fear of further obstruction by conscientious objectors.
- Knowing their local hospice service did not support assisted dying caused one person to decline specialist palliative care at home leading to unmet palliative care needs.
- One whānau member was too afraid to seek clinical support for the ill person's decline in mental health as they feared they would be no longer eligible for assisted dying if deemed mentally unwell.

Health professionals did not always provide whānau Māori with information about assisted dying in a timely and supportive manner. Some whānau found it difficult to communicate with hospices and hospital clinicians due to the prohibition on assisted dying being raised by practitioners, or a perception that the person may be a conscientious objector and associated fear of discrimination:

- Some hospices referred whānau to the Ministry website or provided a card with the 0800 number on it, rather than providing verbal information.
- Some whānau experienced health practitioners expressing their concerns about assisted dying due to a conscientious objection, including some who "experienced coercion to not seek assisted dying from palliative care professionals instead of a referral upon requesting information regarding assisted dying."

## Applying late

Some people who wanted an assisted death delayed their requests for assessment and the procedure date, leading to some people becoming too unwell or passing away before accessing assisted dying. Reasons for delay were cited as holding on to hope, including the use of rongoā (natural healing) to cure or slow down disease progression. Most participants thought that the six-month eligibility criteria should be lengthened to accommodate different illnesses and trajectories.

Most participants felt that the person should not have to give consent on the day of death. Whānau Māori interviewed believed that it was culturally appropriate for a nominated whānau member to become a proxy for the dying person and to confirm the terminally ill person's consent on their behalf, should they lack the capacity to speak or physically consent.

## Challenges during and following the assisted death

When whānau lacked in-depth information about the assisted dying process and procedure (e.g., those who had not been along to previous appointments), lack of preparation caused some people distress at the time of the death, and complicated grief as people felt traumatised by the assisted dying experience. Many did not feel formal counselling and social services could meet their cultural needs and they did not believe individual clinicians would have any experience of supporting someone who had gone

through an assisted death. Funeral Directors commented that they were tasked with supporting grieving whānau.

Whānau Māori were often unaware that the death certificate would record assisted dying as the cause of death, causing distress when viewed by other people (e.g., funeral directors) as this was considered confidential information for whānau. It was suggested to remove the inclusion of 'assisted death', or that assisted dying clinicians should ensure whānau understand that assisted dying will be recorded on the death certificate so that whānau can prepare.

Following an assisted death, normal tangihanga rituals prevailed although some whānau opted for smaller private rituals of farewell. However, the research noted that if assisted dying is viewed as a 'suicide' some tūpāpaku (deceased person's body) may not be allowed to lie in state on a marae or be buried in an urupā (burial ground). Researchers considered that this points to a lack of awareness and acceptability of assisted dying within Māori communities and an urgent need for assisted dying to become familiar, understood, and accepted.

Researchers suggested that Māori need access to information about assisted dying in an environment where they feel safe and culturally supported to express their perspectives and to debate the cultural, spiritual, physical, clinical, emotional, and familial issues associated with accessing and using assisted dying. The research noted that whānau would like to see local assisted dying information delivered at marae and provided by 'outsiders' to enable discussion that is culturally appropriate (tika), robust, and tikanga-driven.

Recommendations that have come out of this research have been considered by the Ministry as part of the review process.



## Appendix 3: How assisted dying in New Zealand compares with other countries

This table provides a brief comparison between the main provisions in legislation that enables the operation of assisted dying in New Zealand and selected overseas jurisdictions. Specifically, the table refers to the following legislation:

- Voluntary Assisted Dying Act 2017 (Victoria, Australia).
- Voluntary Assisted Dying Act 2019 (Western Australia).
- End-of-Life Choices (Voluntary Assisted Dying) Act 2021 (Tasmania, Australia).
- Voluntary Assisted Dying Act 2021 (South Australia).
- Voluntary Assisted Dying Act 2021 (Queensland, Australia).
- Voluntary Assisted Dying Act 2022 (New South Wales, Australia).
- Voluntary Assisted Dying Act 2024 (Australian Capital Territories (ACT)).
- End of Life Choice Act 2019 (New Zealand).
- Belgian Euthanasia Act 2002.
- The Netherlands Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.
- Canada Criminal Code, RSE 1985, c C-46.<sup>45</sup>
- Oregon Death with Dignity Act 1997, Or Rev Stat.<sup>46</sup>

This table should be read together with the discussion in the body of the report.

Note that the table is based on the requirements and settings in legislation and may not capture requirements that apply operationally through local guidance and standards that influence clinical practice.

<sup>45</sup> This table does not refer to the Quebec *Act respecting end-of-life care*, RSQ, c S-32.0001, which provides a framework for palliative care in order to ensure that everyone can have access to quality care that is appropriate for their needs throughout the course of their illness.

<sup>46</sup> Oregon is presented as an example of state legislation in the United States, as it was the first jurisdiction of the United States to enact physician assisted dying, in 1997. To date, similar legislation has been enacted in Washington, Vermont, California, Colorado, District of Columbia, Hawaii, New Jersey, and Maine. There are some differences between the legislation in each of those jurisdictions.

**Table 5: Jurisdictional scan of how assisted dying in New Zealand compares with other countries**

	New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
Guiding principles in legislation		✓	✓	✓	✓	✓	✓	✓			✓	
Person must be 18 years or over	✓	✓	✓	✓	✓	✓	✓	✓	The Act applies for patients aged 12 years and over (with certain requirements for parental involvement)	Includes terminally ill children under 18 years	✓	✓
Must be a citizen or permanent resident in jurisdiction	✓	✓ (must have been ordinarily resident for at least 12 months)	✓ (must have been ordinarily resident for at least 12 months)	✓ (must have been ordinarily resident for at least 12 months)	✓ (must have been ordinarily resident for at least 12 months or granted exemption)	✓ (must have been ordinarily resident for at least 12 months)	✓ (must have been ordinarily resident for at least 12 months or granted exemption)	✓ (must have been ordinarily resident for at least 12 months or granted exemption)			✓	✓
Person has decision-making capacity or competence in relation to assisted dying	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Person is acting voluntarily and without coercion or free from pressure	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Diagnosed with an eligible disease, illness or medical condition (e.g., advanced,	✓	✓	✓	✓	✓	✓	✓	✓	No reference to condition	✓ (must be the result of a serious and incurable	✓	✓

	New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
incurable, progressive, will cause death)										disease or accident-induced condition)		
Disease, illness or medical condition is expected to cause death within a specified timeframe	✓ (6 months)	✓ (6 months, 12 months for neuro-degenerative condition)	✓ (6 months, 12 months for neuro-degenerative condition)	✓ (6 months, 12 months for neuro-degenerative condition; unless exempted)	✓ (12 months)	✓ (6 months, 12 months for neuro-degenerative condition; unless exempted)	✓ (6 months, 12 months for neuro-degenerative condition; unless exempted)	✓ (12 months)			No timeframe specified but based on whether the person's natural death has become reasonably foreseeable or not	✓ (6 months)
Person is suffering	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Express provision that mental illness or disability alone is not an eligible disease, illness or medical condition	✓ (and advanced age)	✓	✓	✓	✓	✓	✓	✓			Exclusion from eligibility for persons suffering solely from a mental illness has been extended until March 17, 2027	✓ (age or disability)
<b>Request to access assisted dying</b>	✓	✓	✓ (unless a practitioner also informs the person of treatment and palliative care options available at the same time)	✓ (unless a practitioner also informs the person of treatment and palliative care options available at the same time)	✓ (unless a practitioner also informs the person of treatment and palliative care options available at the same time)	✓	✓ (unless a practitioner also informs the person of treatment and palliative care options available at the same time)	✓ (unless a practitioner also informs the person of treatment and palliative care options available at the same time)				

	New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
Person themselves must make request	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Person can make a request in an advanced directive or similar									✓	✓	Waiver of Final Consent – a person can waive the requirement to provide consent just before receiving medication if their natural death is reasonably foreseeable	
Person must make three requests	✓ (initial verbal request, request confirmed in writing, final consent on the day)	✓ (initial verbal request, written declaration, final verbal request)	✓ (initial verbal request, written declaration, final verbal request)	✓ (initial verbal request, written declaration, final verbal request)	✓ (initial verbal request, written declaration, final verbal request)	✓ (initial verbal request, written declaration, final verbal request)	✓ (initial verbal request, written declaration, final verbal request)	✓ (initial verbal request, written declaration, final verbal request)				✓ (initial verbal request, written declaration, final verbal request)
One request must be in writing	✓ (or signed by a proxy)	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
Two witnesses to written request		✓ (must certify the person appeared to act freely, voluntarily, and appeared to have decision-making capacity and understand	✓ (must confirm the person appeared to act freely, voluntarily, and appeared to have decision-making capacity and	✓ (must be at least 18 years of age and not a family member, knows or believes they are likely to benefit from the death of the person, or	✓ (must confirm the person appeared to act freely, voluntarily, and appeared to have decision-making capacity and	✓ (must confirm the person appeared to act freely, voluntarily, and appeared to have decision-making capacity and	✓ (must confirm the person appeared to act freely, voluntarily, and appeared to have decision-making capacity and	✓ (must confirm the person appeared to act voluntarily and without coercion. Must be at least 18 years of age and not an			✓ (one witness; must be at least 18 years of age, understands the nature of a request for medical assistance	✓ (must attest to the best of their knowledge and belief the person is capable, acting voluntarily and is not

		New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
			the nature and effect of their decision. Must be at least 18 years old and not an ineligible witness <sup>47)</sup>	understand the nature and effect of their decision. Must be at least 18 years old and not an ineligible witness)	the owner or responsible for providing health services or professional care services to the person)	understand the nature and effect of their decision. Must be at least 18 years old and not an ineligible witness)	understand the nature and effect of their decision. Must be at least 18 years old and not an ineligible witness, and not more than one witness may be a family member)	understand the nature and effect of their decision. Must be at least 18 years old and not an ineligible witness or family member)	ineligible witness)			in dying, and not an ineligible witness)	being coerced. Must be at least 18 years of age, not a relative of the person, or an ineligible witness)
	Prescribed waiting period between first and final requests ('cool down' period)		✓ (9 days, unless likely to die sooner)	✓ (9 days, unless likely to die sooner or lose capacity)	✓ (48 hours between each request; unless likely to die in 7 days or lose capacity in 48 hours)	✓ (9 days, unless likely to die sooner or lose capacity)	✓ (9 days, unless likely to die sooner)	✓ (5 days, unless likely to die sooner or lose capacity)	✓ (9 days, unless likely to die sooner or lose capacity)		Where death is not imminent, there is a one-month waiting period	Where natural death is not reasonably foreseeable, there is a 90-day minimum assessment period	✓ (15 days, unless likely to die sooner)
	Person may withdraw request at any time	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Assessment</b>	Assessment of criteria for eligibility is carried out by medical practitioners	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

<sup>47</sup> Knows or believes they are likely to benefit from the death of the person, or the owner or responsible for providing health services or professional care services to the person.

	New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
Nurse practitioners are able to carry out assessment of criteria for eligibility	Can only administer assisted dying medication under the instruction of a medical practitioner		Can administer the medication as the administering practitioner for a patient (but not assess eligibility) if they hold a nursing registration endorsed as a nurse practitioner and practised for at least two years but cannot carry out an assessment of the person	A registered nurse can administer the medication as an administering practitioner (but not assess eligibility)	Can administer the medication as an administering practitioner (but not assess eligibility) if they have practiced as a nurse practitioner for at least 1 year and hold registration endorsement as a nurse practitioner; a registered nurse must have practiced for at least 5 years and hold registration		Can administer the medication as an administering practitioner (but not assess eligibility) and must be registered and endorsed as a nurse practitioner	✓ (a nurse practitioner who has practiced for 1 year or more post nurse practitioner endorsement can assess eligibility and administer medication)	Can only make limited preparations for a procedure (cannot assess eligibility)	Where the person has regular contact with a nursing team, the physician must discuss the request with them but there is no further role provided (cannot assess eligibility)	✓ (Can conduct assessments and administer medication where provinces and territories allow)	
Two independent assessments by two practitioners	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Referral to another medical practitioner if eligibility cannot be determined (e.g., uncertainty about the person's competence)	✓ (psychiatrist for competence to make an informed decision about assisted dying)	✓ (specialist in the relevant area to determine diagnosis or decision-making capacity)	✓ (registered health practitioner who has appropriate skills and training to determine diagnosis or decision-making capacity)	✓ (medical practitioner, psychiatrist, or psychologist who has the skills and training that are appropriate to determine diagnosis or decision-making capacity)	✓ (registered health practitioner who has appropriate skills and training to determine diagnosis or decision-making capacity)	✓ (registered health practitioner who has appropriate skills and training to determine diagnosis or decision-making capacity)	✓ (psychiatrist or registered health practitioner who has appropriate skills and training to determine diagnosis or decision-making capacity)	✓ (another person who has the appropriate skills and training to provide advice about whether the person meets the eligibility requirement)		✓ (where the person's death is not imminent a second physician who is a psychiatrist or specialist in the disorder in question)		✓ (where the person may be suffering from a psychiatric disorder or depression causing impaired judgement, the patient is to be referred for counselling)

	New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
										must approve the person's request)		to determine the matter)
Person must be given particular information (e.g., about their diagnosis, and other end-of-life care options)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Assessing medical practitioners	Meet minimum requirements about qualifications and experience ✓ (independent medical practitioner must have held a practising certificate or equivalent certification from an overseas authority for at least the previous 5 years; a medical practitioner must be registered with the Medical Council of New Zealand)	✓ (coordinating and consulting medical practitioners must hold a fellowship with a specialist medical college or be a vocationally registered general practitioner; either practitioner must have practised as a registered medical practitioner for at least 5 years)	✓ (coordinating or consulting medical practitioner must hold specialist registration and practised for at least 1 year, or hold general registration and practised for at least 10 years, or an overseas-trained specialist who holds limited registration or provisional registration)	✓ (must have practised as a medical practitioner for at least 5 years after vocational registration as a general practitioner or after completing a fellowship with a specialist medical college)	✓ (coordinating, consulting and administering practitioners must hold specialist registration and have practised for at least 1 year, or hold a general registration and have practised for at least 5 years, or hold specialist registration and practised for at least 5 years as the holder of general	✓ (coordinating or consulting medical practitioner must hold a fellowship with a specialist medical college, or be a vocationally registered general practitioner; either practitioner must have practised as a registered medical practitioner for at least 5 years)	✓ (coordinating or consulting medical practitioner must hold specialist registration or general registration and has practised for at least 10 years as the general holder of registration; an administering practitioner must hold a specialist registration or general registration and has	✓ (coordinating, consulting and administering practitioners must hold specialist registration and have practised for at least 1 year)				

	New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
	and hold a current practising certificate)				registration. Overseas trained specialists without registration must meet separate requirements)		practised for at least 5 years)					
Complete mandatory training before assessing person		✓	✓	✓	✓	✓	✓	✓				
Conscientious objection	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Institutional objection					✓ (must not hinder access to information or a registered health practitioner or member of the care navigator service)	✓ (allow for the transfer of a person to another health service establishment or prescribed health facility)	✓ (must not hinder access to information or a registered health practitioner or member of the care navigator service)	✓ (allow for the transfer of a person to another health service establishment or prescribed health facility and must not hinder access to information or a registered health practitioner or member of the care navigator service)				
If conscientiously object, refer or	✓ (right to ask SCENZ Group for details of a	✓ (give person information)	✓ (give person information)	✓ (contact details of Voluntary Assisted	✓ (give person information)	✓ (give person information)	✓ (give person information)	✓ (contact details for the approved care		✓ (transfer file on request)		✓ (transfer file on request)



		New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
	provide information	replacement practitioner)			Dying Commission)				navigator service)				
	Self-administration is default method		✓	✓	✓	✓	✓	✓	✓				✓
	Practitioner administration permitted	✓	✓ (if self-administration inappropriate)	✓ (if self-administration inappropriate)	✓ (if self-administration inappropriate)	✓ (if self-administration inappropriate)	✓ (if self-administration inappropriate)	✓ (if self-administration inappropriate)	✓ (if self-administration inappropriate)	✓	✓	✓	
	Requirement for administration to be witnessed		✓ (practitioner administration)	✓ (practitioner administration)		✓ (practitioner administration)	✓ (practitioner administration)	✓ (practitioner administration)	✓ (practitioner administration)				
	Provisions governing the management of the assisted dying substance or prescription	✓ (prescribing, dispensing and disposal)	✓ (prescribing, dispensing and disposal)	✓ (prescribing, dispensing and disposal)	✓ (prescribing, dispensing and disposal)	✓ (prescribing, dispensing and disposal)	✓ (prescribing, dispensing and disposal)	✓ (prescribing, dispensing and disposal)	✓ (prescribing, dispensing and disposal)				✓ (prescribing and dispensing)
Offences and protections	Offence to induce a person through dishonesty or undue influence, to request assisted dying		✓	✓	✓	✓	✓	✓	✓				✓
	Offence to induce a person, through dishonesty or undue influence to self-administer the substance		✓	✓	✓	✓	✓	✓	✓	✓			
	Offence to falsify records	✓ (offence to alter, destroy	✓	✓	✓	✓	✓	✓	✓			✓	✓

	New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
or make misleading statement	or complete form without consent)											
Offence to fail to report on assisted dying		✓	✓	✓	✓	✓		✓			✓	
Offence to administer the substance when not authorised to do so		✓	✓	✓	✓	✓		✓				
Offence for practitioner to wilfully fail to comply with requirement of legislation	✓										✓	
Protection for a person who assists in or facilitates access to assisted dying	✓	✓	✓	✓	✓	✓	✓	✓				
Protection for health practitioners acting in good faith and without negligence	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓
Protection for health practitioners present at time of self-administration	✓	✓	✓	✓	✓		✓	✓			✓	✓

		New Zealand	Victoria	Western Australia	Tasmania	Queensland	South Australia	New South Wales	ACT	Netherlands	Belgium	Canada (Federal)	Oregon (USA)
Reporting	Death certificate identifies assisted dying as the cause of death	✓	Records the person's underlying illness, disease or medical condition	Records the person's underlying illness, disease or medical condition	Recorded as natural	Records the person's underlying illness, disease or medical condition	Records the person's underlying illness, disease or medical condition	Records the person's underlying illness, disease or medical condition	Records the person's underlying illness, disease or medical condition	✓	The manner of death is considered natural	Dependant on guidelines in the province or territory	Records the person's underlying terminal disease and the manner of death as natural
	Review by tribunal of some criteria for access (e.g., residency, decision-making capacity or voluntariness)		✓	✓	✓	✓	✓	✓	✓				
Oversight	Oversight by an independent body	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		
	Review of legislation	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	





