Submitted to Public consultation for the review of the End of Life Choice Act (2019) on 2024-09-21

1. What is your name?

   Ann David

2. I am or I represent.

   President, End-of-Life Choice Society NZ Inc

3. Is this submission on behalf of an organisation?

   Yes. End-of-Life Choice Society NZ Inc

4. Do you live in New Zealand?

   Yes.

5. Official Information Act responses.

   Include my personal details in response to Official Information Act requests.

6. Do you think changes are needed to the eligibility requirements for a person to receive assisted dying?

   Yes. We wish to see Eligibility clause (5) (1) (c) changed and have no time to death specified.

   Prognostication (in this instance the ability to accurately predict time-to-death), is often extremely difficult and is openly acknowledged by doctors to be so. A raft of international and New Zealand research points to the unreliability of prognosis of death. This research has been particularly conducted within a palliative care framework where it is important to know how much time a person has left before death. Even doctors specifically trained to predict time-to-death within a 12-month period predict minimally better than those completely untrained.

   Clause 5 (1) (c) excludes people who experience years of unbearable suffering that cannot be relieved. They are rejected for assisted dying on grounds of a dubious prognosis that does not improve safety but that causes great distress to the slowly dying.

   These restrictions and exclusions result in significant and unreasonable unfairness and discrimination. For example, unbearable suffering in a cancer patient usually permits access to assisted dying, but unbearable suffering in a Parkinson’s disease or dementia sufferer does not.

   Quotes from our Members

   > *I have multiple health issues, including hypertension, familial hypercholesterolemia, Dupuytren's Contracture, LADA diabetes, ME/CFS, Fibromyalgia, and Bipolar 2. My kidneys are damaged from years of undiagnosed diabetes. My right hand is permanently numb and very sensitive due to my fingers beginning to distort and bend in the wrong direction. I am in mental and physical pain 24/7. My prognosis is a life of constant pain. I emailed the assisted dying service to apply for help. I was called the next day. Within 5 minutes the call was over and I had been rejected outright.*

My neurological illness has robbed me of any quality of life. It has isolated me from friends and family. Communication is limited because of partial voice loss, extreme light and sound sensitivity. Being housebound and in near darkness and silence, reliant on carers for everything and only able to take liquid food, has sapped the joy from my life. Living with this illness for the last 30 years has shown me how I will deteriorate. It will be a long, slow, painful road of physical decline which will be mentally distressing for me to experience and for my loved ones to witness.

7. Do you think changes are needed to the eligibility requirements for a person to receive assisted dying?

Yes. Clause 10 (1) (a) should be removed.

Prohibiting a medical practitioner from initiating a discussion about assisted dying eliminates all but confident, well-informed people with good health-literacy and (mostly with) the ability to navigate online services. It excludes applicants including some from socio-economically disadvantaged backgrounds or those too timid to ask their doctor for assisted dying. It is therefore inequitable and unjust, a breach of our nation's commitment under the Health and Disability Consumers' Code to the right to effective communication, the right to be fully informed and the right to make an informed choice and give informed consent.

There is no public education about assisted dying and none intended due to this "gag" clause. As shown by Heath NZ/Te Whatu Ora's own published data, applications from Māori (5.5%) and Pasifika (0.6%) applicants are small or negligible by comparison with their relative population importance in our multi-cultural landscape. Māori and Pasifika who may wish assisted dying are therefore disadvantaged. By comparison, Pākehā are over-represented in assisted dying application statistics (81%).

There is no "gag" clause in Canada, Western Australia, Tasmania or Queensland. There is no evidence there of people being unwittingly led into assisted dying. This barrier causes inequity and socio-economic disadvantage for no gain in safeguard.

8. Do you think the Act provides sufficient safeguards to ensure that people only receive assisted dying if:

Yes. The Society believes that the safeguards are plentiful and sufficient through Clauses 5, 13, 14, 15, 16 and 17 of the Act. Specific comment below.

5. As per our response to Question 6 above, with the exception of clause 5 (1) (c) which is such an excessive safeguard as to become an unfair barrier, all other eligibility criteria in Clause 5 provide ample safeguards. Patients and doctors are well able to discern "unbearable suffering". The degree of suffering is accounted for by the nature of the medical condition itself. Doctors are also well able to discern "advanced state of irreversible decline in physical capability", which is an objective criterion relying upon medical knowledge.

13 & 14. The approved forms for the capture of uniform and sufficient information as devised by the SCENZ Group, are comprehensive. They enable the Registrar to discern any missing information prior to countersigning the prescription.

15. The requirement for the AMP and IMP to call in a psychiatrist if either medical practitioner doubts the competence of the person is important, though we understand it is

seldom needed. Feedback from assisted dying medical practitioners is that almost all applicants are clearly competent. It would therefore be an abuse of Right 7 (2) of the Code of Health and Disability Consumer's Rights to demand unnecessary competency testing or assessments by psychiatrists.

11. Clause 11 is particularly comprehensive, requiring uniform capture of sufficient information on a standardised form. The recommendation to the person to discuss their wish for assisted dying with significant others while also letting them know it is not compulsory to do this, signals respect for patient autonomy. If the "gag" were removed, this could have the effect of providing doctor and person more time for repeated discussions.

12, 18, 23. These clauses are rigorous to ensure that no interested third party can witness the signature of the person applying for assisted dying (if the doctor personally cannot witness it). And that a change of date of administration of the medication at the person's request is correctly re-recorded and re-filed. Also that there is a filed record of the person's withdrawal from the process and immediate destruction of the prescription (if applicable). In this last respect, we infinitely prefer the safety of the NZ process over that in the Australian States and Territory where the person is able to take the medication home for self-administration at a later time.

33. This clause is rigorous, making it easy for a person to withdraw from the process either by gesture, word or in writing. Withdrawal requires no specific formula of words; it is enough to indicate intent.

Clause 5 (1) (f) requires the person to be mentally competent for the purpose of making the decision to hasten their own death.

Clause 6 provides the definition of competence for this purpose, which is the standard medical definition of competence.

Clause 15 requires the action of referral to a psychiatrist if either AMP or IMP have grounds for suspecting that the person may not be competent. We have commented on this in our response at Question 8a.

11. This clause requires the medical practitioner first to undertake, record and file with the Registrar, the details of a lengthy consultation with the person. If/when the person wishes to proceed with a formal application, this must be signed in the presence of the doctor. The entire process gives the AMP more than enough time to observe the degree of willingness and independence the person brings to the formal application. If family/whānau are present, it also gives the AMP more than enough time to observe the interactions between person and whānau. If pressure is even suspected, both AMP and IMP must stop the process.

24. If, at any stage, the attending AMP or NP suspect pressure from a third party the process must stop and the person must be told the reason.

Assisted dying doctors tell the Society that they do not see evidence of any pressure to apply for assisted dying. They see only slight pressure in the reverse direction; i.e. pressure from some whānau to delay or withdraw from the process

9. Do you think any changes are needed to safeguards provided through the Act?

Yes 1. While the Society fully supports individual conscientious objection for all those working in the medical profession, it is unlawful to obstruct or frustrate the desire of a person within their care to access assisted dying. As the law currently stands, a conscientiously objecting medical professional or NP is required only to let the person know they can get information from the SCENZ Group. It does not require them by law to provide the 0800 223 852 phone number of the SCENZ Group, nor the assisted.dying@health.govt.nz email address. Unless this important and simple access information is included, a person who is not internet-enabled is disempowered by the conscientious objector. We see this as a lack of safeguard to protect the enquiring person. In addition to enhancing this safeguard, there will be a subsequent need to train/retain health professionals to understand their minimum lawful compliance obligations.

Yes 2. The Society does not support organisational conscientious objection by health care facilities such as hospices, residential aged care and hospitals for three reasons:

Firstly, an organisation is not a sentient being and therefore cannot have a “conscience”.

Secondly, it amounts to a gag on employees within the organisation whose conscience may advise them that it is cruel to remove this option from those they are caring for and whose suffering clearly cannot be brought under control by conventional methods.

Thirdly, it amounts to obstruction of the person wishing to access assisted dying, which is unlawful.

Persons living permanently onsite or as patients at these facilities who wish to access assisted dying, need the law to better protect them against obstruction, obfuscation or delay.

The Society does not ask conscientiously objecting individuals to personally involve themselves in a service they do not want to provide, but to allow persons easy access to assisted dying doctors/nurse practitioners. The ugly practice of “transferring out” of hospices when an inpatient wishes to access assisted dying may cause emotional and physical harm to that person and considerable distress to their families. We have received stories from our members and members of the public attesting to barriers and delays put in place by organisations with conscientious objection to assisted dying. Delays have resulted in the dying patient no longer being able to consent to assisting dying on the planned date. Applicants need better safeguards from conscientious objection.

10. Do you think any changes are needed to the process to apply for and receive assisted dying?

Yes. The Society believes that Nurse Practitioners (NPs) should be able to fully participate in all aspects of assisted dying. Our understanding is that they have the academic qualifications and the experience do to this, including consultation, assessments, discussions about date and method of delivery of the medication and the actual delivery of the life-ending medication. The only aspect they are currently not able to undertake is the prescription of Schedule 29 medications.

There are many benefits to NP participation:

Firstly, the assisted dying workforce would be expanded, making burn-out of the current workforce less likely and the service more sustainable.

Secondly, NPs are increasingly finding employment in the aged care sector which is the sector from which many applicants come.

Thirdly, NPs are often closely involved in regular care and develop close relationships which supports high quality end of life care.

11. Do you think changes should be made to the requirements for medical practitioners and nurse practitioners to provide parts of the assisted dying process?

No. The current process works well. The step-by-step requirements allow plenty of time for discussions between the person and their AMP or IMP. The person is reminded on several occasions that they can change their mind at any time. Once the person has chosen their date, they are reminded that they can change postpone this for up to 6 months if not yet ready to accept it. These intervals of time leave abundant opportunity for deep reflection on the part of the person, for conversations with significant others and consideration of their viewpoint if different from that of the person.

There is, however, anxiety on the part of persons applying for assisted dying when the process moves too slowly for them. This could be remediated by the three following initiatives:

Firstly, better public education about assisted dying would enable people to apply in time to access the service.

Secondly, stronger requirement of medical and health practitioners with conscientious objection to refer an enquiring person immediately to the SCENZ Group and supply the 0800 223 852 and assisted.dying@health.govt.nz contact details.

Thirdly by allowing Nurse Practitioners (NPs) To participate in all aspects of assisted dying. NPs are increasingly taking up onsite roles in aged care facilities where 38% of people die.

12. Do you think changes are required to the roles and responsibilities of the entities established under the Act to oversee assisted dying?

No. We see no need for change to either the Registrar's responsibilities, or the SCENZ Group's responsibilities or the Review Committee's responsibilities. There have been a very limited number of applications that have not proceeded to conclusion because they have been found not to be compliant with the Act at the final review (two only during the second year of operation as per Health NZ's published report).

The Society considers the following responsibility of the Registrar to be of paramount importance:

Reviewing the assisted dying forms completed by practitioners, to ensure compliance with the Act prior to the prescription being released.

13. Do you think the assisted dying process aligns with other parts of the health system?

No. Only one hospice currently supports assisted dying onsite and provides seamless support and care.

There is considerable variation and little transparency about the availability of assisted dying assessment and provision in residential aged care.

There is no information in primary care settings about End of Life Choice and Assisted Dying – which would be remedied in part by the removal of the gag clause.

Increased funding for palliative care in hospices is critical to support improved alignment with other aspects of end-of-life care and choice.

14. Is there anything that could be improved?

Yes. Please see our submission under headings below:

1. Summary recommendations to make the law and access to it fairer without compromising safety.

(a) Amend the current legislation to ensure that it complies with all relevant domestic and international human rights standards and obligations to which our nation is committed.

(b) Replace the requirement for persons to be assessed as being "likely to die within 6 months" with a requirement for persons to have a "serious and incurable medical condition/disease/illness". All other eligibility criteria should remain as currently stated, including the need to be experiencing "unbearable suffering that cannot be relieved" and "in an advanced state of irreversible decline in physical capability".

(c) Remove the 'gag' clause by allowing doctors and nurse practitioners to raise the topic of assisted dying with a person who meets the criteria of "grievous and irremediable medical condition" plus "unbearable suffering that cannot be relieved" and "irreversible decline in physical capability", provided assisted dying is explained in context with all other end-stage care options, including palliative care.

(d) Introduce a "waiver of final consent" clause that would allow approved applicants at risk of losing mental capacity in the interval between being approved and the planned date of the assisted death, due to the need to take stronger symptom relief medication, disease progression or both, to receive assisted dying by signing a "waiver of final consent" form while still mentally competent.

(e) Enable persons diagnosed with dementia to access assisted dying by means of an advance assisted dying request. Evidence shows that even with the best of care many people die protracted, harrowing deaths with dementias.

(f) Allow nurse practitioners to undertake the full range of activities in respect of assisted dying that doctors are currently permitted to undertake.

(h) Require hospices and aged care facilities that receive funding by the taxpayer to any degree to allow patients to receive consultation, assessments and assisted dying on their premises if that is the wish of those patients.

(i) Require conscientiously objecting health practitioners to advise the patient they can seek help from SCENZ and also to provide the relevant contact details that would enable them to do so (i.e. the SCENZ email address and the SCENZ 0800 phone number).

2. Who we are and what we do.

The End-of-Life Choice Society of New Zealand Inc (the Society) is an advocacy group that was set up in 1979 in response to the need for an evidence-based solution to unbearable suffering caused by an incurable medical condition that even the best of medical care is unable to relieve. Our membership includes people from all walks of life, living in many different regions across New Zealand. We receive feedback, enquiries and pleas for help from our members and from the general public and we have taken into account that feedback in the content of this submission. We advocate for the right to die with dignity, which we consider to be the last human right to receive attention. We promote information about the End of Life Choice Act (2019) to our members and to the general public via our website, Facebook page and X account (formerly Twitter).

3. Key successes of the current End of Life Choice Act 2019.

The End of Life Choice Act (2019) came into force in November 2021 after a 2.5-year passage through Parliament and a public referendum. It has therefore been operating for 2.5 full years at the time of this submission in September 2024. Routine reporting by Te Whatu Ora/Heath NZ shows that the safeguards are working well. Significantly, no breaches have been substantiated. There have been a few minor complaints, mostly about unlawful obstruction of an applicant’s rights to access the law.

Applicants, whānau and assisted dying doctors report a smoothly running service that meets the needs of eligible applicants. In addition to researcher and media reports, the Society confirms the same feedback from members of the public and from its own members who have accessed the service.

Assisted dying providers find this to be one of the most rewarding aspects of their professional life, in that it brings release from suffering that cannot be otherwise relieved. Applicants and whānau express enormous gratitude to their assisted dying providers.

> *The doctors were amazing and made the whole process as smooth and calm as it could be. He was able to be at home with all the family present to say goodbye. My sons and I stayed with him while he died. It was a good death.*

> *Being involved with assisted dying and dealing with people and their extended families at the end of their lives has made me a more grounded practitioner and a better human being.*

We perceive that the safeguards are working well. They discriminate between eligible and ineligible applicants, as evidenced by the fact that approximately 20% of applicants are progressively eliminated. This is what the Society expected, given our knowledge of similar legislation in jurisdictions that legislated well ahead of New Zealand. Clearly, New Zealand is capable of safely managing chosen deaths.

4. What's not working: safe but unfair – argument for observance of human rights.

While the assisted dying service is safe, it is, however, perceived to be unfair. This is what the Society feared, given the narrowness of the eligibility criteria and the imposition of the 'gag' clause. This review is an opportunity to correct those inequities, injustices and inappropriate discriminations.

(a) About prognostication.

Prognostication (in this instance the ability to accurately predict time-to-death) is often extremely difficult and is openly acknowledged by doctors to be so. A raft of international and New Zealand research points to the unreliability of prognosis of death. This research has been particularly conducted within a palliative care framework where it is important to know how much time a person has left before death. Even doctors specifically trained to predict time-to-death within a 12-month period are marginally more accurate than those completely untrained. Yet a 6-month prognosis of death is the current primary eligibility criterion for access to assisted dying. The Society, therefore, submits that it is a nonsense criterion, serving no purpose other than to restrict numbers of applicants for ideological reasons rather than to open a service-of-last-resort to those who need it.

The requirement to receive a prognosis of 6 months or less to death excludes people who experience years of unbearable suffering that cannot be relieved. They are rejected for assisted dying on grounds of a dubious prognosis that does not improve safety but causes great distress to the slowly dying. This was surely not the intention of the original legislation as proposed in bill form and not what the public has for decades been clamouring for, as demonstrated by research on public attitudes from 2002 to 2017.

Several research papers showing the inaccuracy and difficulties of prognostication:

Chu, C., White, N., & Stone, P. (2019). Prognostication in palliative care. Clin Med (Lond), 19(4), 306-310. https://doi.org/10.7861/clinmedicine.19-4-306

White, N., Reid, F., Harris, A., Harries, P., & Stone, P. (2016). A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? PLOS ONE. https://doi.org/10.1371/journal.pone.0161407

Orlovic, M., Droney, J. et al. (2023). Accuracy of clinical predictions of prognosis at the end-of-life: Evidence from routinely collected data in urgent care records. BMC Palliative Care, 22(51). https://doi.org/10.1186/s12904-023-01155-y

O'Callaghan, A., Laking, G., Frey, R., Robinson, J., & Gott, M. (2014). Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting. Pall Med, 28(8), 1046-1052. https://doi.org/10.1177/0269216314536089

Research on degree of public desire for assisted dying in New Zealand 2002–2017:

Young, J., Egan, R., Walker, S., Graham-DeMello, A., & Jackson, C. (2018). The euthanasia debate: synthesising the evidence on New Zealander's attitudes. Kōtuitui: New Zealand Journal of Social Sciences Online, 14(1), 1-21. https://doi.org/10.1080/1177083X.2018.1532915

Clearly, suffering from an incurable disease or medical condition may not be confined to the last few months of life. Irremediable suffering may be severe, unmanageable, and increasing for several years prior to death. These restrictions and exclusions result in significant and unreasonable unfairness and discrimination. For example, unbearable suffering in a cancer patient usually permits access to assisted dying but unbearable suffering in a person with Parkinson's disease usually does not, and unbearable suffering in a person with a dementia excludes them entirely. There is clear evidence that when physical suffering occurs it causes concomitant emotional and psychological suffering. Being progressively "trapped inside one's own body" (e.g. MND, Parkinson's, dementia) is greatly feared because this will inevitably cause emotional and psychological distress.

> *She was effectively a prisoner in her bed. She was unrelentingly unhappy; no medication helped. Her dementia cruelly allowed her to be aware of her confusion and delusions. Repeatedly she asked me to help her to die. When I didn't, she starved herself to death. We were helpless as we watched her long suffering – in a hospital.*

> *On being returned to the dementia ward, he'd smash his head against the walls and on any concrete he could find in an attempt to end his life. His distress was obvious to anyone and everyone. He tried to escape. Towards the end, he was sedated to near-oblivion for weeks on end. Let's not pretend to call this 'care'!*

The result of the current 6-months-to-death eligibility criterion is reflected in the unnaturally distorted statistics. While cancer accounts for only 30% of deaths in the general population, it accounts for 67% of assisted deaths because its trajectory is slightly more predictable. Cardio-vascular disease is NZ's primary cause of death at 31%, but is the cause of only 6% of assisted deaths. Dementia was the cause of 10% of deaths in the general population in 2020, is rapidly on the increase, but has been the cause of 0% of assisted deaths to mid 2024.

b) The 'gag' clause.

The 'gag' clause eliminates all but well-informed people with good health literacy and (mostly with) the ability to navigate online services. It excludes applicants from socio-economically disadvantaged backgrounds or those too timid to ask their doctor for assisted dying. It is therefore inequitable and unjust and a breach of our nation's commitment under the Code of Health and Disability Consumers' Rights – namely the right to effective communication, the right to be fully informed and the right to make an informed choice and give informed consent.

Data from Health NZ/Te Whatu Ora show that the numbers of people applying for assisted dying are very small. There is no public education about assisted dying and none intended due to the 'gag' clause. Notably, applications from Māori (5.5%) and Pasifika (0.6%) applicants are small or negligible by comparison with their relative population importance in our multi-cultural landscape. Māori and Pasifika who may wish to request assisted dying are therefore disadvantaged. By comparison, Pākehā are over-represented in assisted dying statistics (82%).

Removal of the 'gag' clause would remove the barriers of inequity and socio-economic disadvantage with no loss of safeguard. There is no 'gag' clause in Canada, Western Australia, Tasmania, New South Wales or Queensland. There is no evidence from those regions of people being unwittingly led into assisted dying.

(c) Palliative care

The Society very strongly supports palliative care and urges an increase in taxpayer funding so that its services can be improved and more evenly distributed, including to rural and remote areas. Palliative care should also be made accessible earlier in the trajectory of a disease/illness/condition and for longer periods of time than current funding allows. We acknowledge that 90% of palliative care patients distinctly benefit from palliative care services, as do their whānau. However, we note that 75% - 77% of applicants for assisted dying are already receiving palliative care at the time of applying.

We also note that some overseas palliative care services (e.g. Palliative Care Australia) monitor their own effectiveness both in the community and within hospice. Regular Patient Outcomes Reports show some 6%–8% of people experience "severe" suffering in their terminal phase as assessed by their own palliative care clinicians. Although Hospice NZ does not monitor its own outcomes in the same way publicly, it is unlikely that our results would be any different from those in Australia where funding limitations are similarly restricted and service levels are of similarly high quality.

Refer to: Patient Outcomes in Palliative Care National Report (July to December 2020), PCOC Australia, pages 35-36.
https://documents.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow269015.pdf

Anecdotally, we know that several palliative care nurses and some palliative care doctors would like to support assisted dying as a choice but are forbidden by their hospice employers to engage. The choice is needed, they say, as a last resort for unbearable suffering that cannot be relieved and to honour the hospice promise of holistic and non-judgemental care.

(d) Palliative relief through control.

Those who have been assessed as eligible for assisted dying, and their whānau, express enormous relief simply from knowing they have this choice to end their suffering. This relief is palliative in itself and is reported in every jurisdiction where assisted dying is available. It is confirmed by the Society's own experience of participants in assisted dying (or their whānau) who have contacted us. The reverse is also true: people cruelly denied access to a means of control, who are trapped in their suffering until they die, experience heightened anxiety and distress in addition to their physical suffering.

> *Waves of relief swept over me when my doctor told me I'd been approved for assisted dying. I knew I could die as myself – still me. I am so grateful to my assisted dying doctor. This is a good death."*

(e) Conscientious objection

The Society fully supports individual conscientious objection for all those working in the health profession. It is an important principle that should never be eroded.

We do not, however, support organisational conscientious objection in hospices, aged care facilities and hospitals for three reasons:

- An organisation is not a sentient being and therefore cannot have a “conscience”.
- It amounts to a gag on employees within the organisation whose conscience may advise them that it is cruel to remove this option from those they are caring for and whose suffering clearly cannot be brought under control by conventional methods.
- It amounts to obstruction, which is unlawful. The Society does not ask conscientious objectors to personally involve themselves in a service they do not want to provide, but to allow applicants easy access to assisted dying doctors/nurse practitioners as third parties.

(f) In context

For context, approximately 80,000 assisted deaths have occurred in New Zealand over the 26 months since the End of Life Choice Act came into force in November 2021. Of these, 687 have been assisted deaths. Assisted dying therefore accounts for less than 1% of total deaths over the 26-month period.

(g) In conclusion

The concerns about assisted dying legalisation that were raised during the 2.5-year passage of the legislation through Parliament and during the following referendum year have not eventuated. The safeguards are working. There has been no ‘stampede’ for assisted dying. People have not lost trust in doctors. Palliative care has not been de-funded because of assisted dying, which has a separate funding stream. Medical research has not lost funding because of assisted dying.

5. Comparable jurisdictions with less restrictive law but equally safe outcomes.

The Benelux countries (The Netherlands, Belgium, Luxembourg) legislated assisted dying law in 2000, with legislation coming into effect around 2002. These countries have more liberal access to assisted dying when compared to New Zealand and is based on the simple concept of “hopeless suffering”. There is no ‘gag’ clause on assisted dying, no time-to-death requirement, and assisted dying may be accessed by means of an advance request for persons at risk of losing mental competence in future provided the advance request is made at the time the person is still mentally competent. Assisted dying is nevertheless strictly regulated. In the Netherlands, the outcomes of applications are reviewed by regional review committees, overseen by a national review committee with reports produced publicly. Even so, with such liberal legislation and after 22 years of assisted dying practice, assisted deaths account for 5.1% of total deaths in the Netherlands.

Netherlands Annual Report 2022 showing assisted deaths as 5.1% of total deaths: https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports

Canada first legalised assisted dying (Medical assistance in dying - MAiD) on a national basis in 2016 by means of Bill C-14. At that time, the requirement was for the applicant’s death to be “reasonably foreseeable”. But the legislation evolved in 2021 when human rights cases of unbearable suffering caused by medical conditions where death was not “reasonably foreseeable” were brought before the courts. Assisted dying is now possible for persons with a “grievous and irremediable medical condition” where death is not reasonably foreseeable.

The 2022 report on assisted dying outcomes after this relaxation of eligibility criteria shows that overall in Canada assisted deaths comprised 4.1% of total deaths, although this figure is higher in some provinces.

Canadian Annual Report 2022 showing assisted (MAiD) deaths as 4.1% of total deaths: https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2022.html

6. Public support for the Society's recommendations: Horizon Research Survey

Excerpts from the multi-page Horizon Research Report conducted for the End-of-Life Choice Society NZ in April 2024 are presented in this section. The Society is happy to provide the full Horizon Research report as an Excel document if requested.

These results are from an online survey of 1,038 respondents in New Zealand and aged 18 years and over.

The sample was weighted on age, gender, ethnicity, education, personal income and party vote at the 2023 election in order to reflect the New Zealand population. The survey has a maximum margin of error at +- 3% overall.

Notably, 56% of respondents to the Horizon Research survey voted "NO" to assisted dying at the general referendum in 2020, yet there is majority support for all of the Society's positions in 2024.

Q 6. "It's unfair that the law forbids doctors to talk about assisted dying unless the person asks, as the person might not know this and would therefore miss out on considering assisted dying." *(Answer options were Strongly Agree, Agree, Disagree, Strongly Disagree.)*

Overall (Strongly Agree + Agree)	63%.
Te Pati Māori voters agreed most	75%
NZ First voters agreed least	57%

Identify as Disabled? *(Answer options were Yes, No.)*

Disabled voters agreed most strongly	68%.
Non-disabled voters agreed least strongly	62%

Q 7. "Do you think it would be fairer to have no time-to-death specified at all?" *(Answer options were Yes, No, Don't Know.)*

Yes	52%.
No	20%
Don't Know	28%

ACT voters agreed most	62%
NZ First voters agreed least	42%

Identify as Disabled? *(Answer options were Yes, No.)*

Disabled and Non-disabled were identical at "Yes"	52%.

Q 10. “A person with dementia should be able to access assisted dying in the early to mid-stages of their illness, while still mentally competent.” *(Answer options were Strongly Agree, Agree, Disagree, Strongly Disagree.)*

Overall (Strongly Agree + Agree)	71%.
Labour voters agreed most	80%
NZ First voters agreed least	56%

Identify as Disabled? *(Answer options were Yes, No.)*

Non-disabled voters agreed most strongly	72%.
Disabled voters agreed least strongly	71%

Q 11. “Would you support or oppose allowing a dementia patient to sign an advance assisted dying request?” *(Answer options were Strongly support, Support, Neither support nor oppose, Oppose, Strongly oppose, I really don’t know.)*

Overall (Strongly Support + Support)	61%.
ACT voters agreed most	77%
NZ First voters agreed least	46%

Identify as Disabled? *(Answer options were Yes, No.)*

Non-disabled voters agreed most strongly	62%.
Disabled voters agreed least strongly	56%

Q 12. “Do you believe people with disabilities that have unbearable suffering and are mentally competent to choose for themselves should have access to assisted dying?” *(Answer options were Yes, No, Don’t Know)*

Yes	64%.
No	16%
Don’t Know	20%

Labour voters answered “yes” most strongly	74%.
NZ First voters answered “yes” least strongly	56%

Identify as Disabled? *(Answer options were Yes, No.)*

Non-disabled voters agreed most strongly	65%.
Disabled voters agreed least strongly	61%

Conclusion

There is a high level of support across all groups for the recommendations for improvements to the End of Life Choice Act 2019 made in this report by the Society. This is in spite of the fact that 58% of respondents to the Horizon Research survey voted “NO” to assisted dying at the general referendum in 2020.

7. Summary of human rights legislation and principles New Zealand is committed to but may be in breach of due to the End of Life Choice Act 2019 as it currently stands

The Human Rights Approach to Assisted Dying

The human rights approach, developed internationally and adapted for Aotearoa New Zealand by the New Zealand Human Rights Commission, and strongly supported by the Society, requires the linking of decision-making at every level (including legislation, policy and processes) to human rights standards set out in the relevant human rights Covenants and Conventions to which New Zealand is a party. This approach requires the identification of all relevant human rights involved, a balancing of rights where necessary, prioritising the rights of the most vulnerable people, to maximise respect for all rights and rights-holders. This includes an emphasis on the participation of individuals and groups in decision-making that affects them, and non-discrimination among individuals and groups through equal enjoyment of rights and obligations by all. Central to this approach is the empowerment of individuals and groups by their use of rights as leverage for action and to legitimise their voice in decision-making. It also emphasises accountability for actions and decisions, which enables groups to complain about decisions that affect them adversely. Internationally there is increasing emphasis on a human rights-based approach to health. The principles of equality and freedom from discrimination are considered fundamental to the development of health policy, along with the rights of vulnerable groups and universally accessible health systems.

The Society draws attention to key relevant elements of Aotearoa New Zealand's acknowledged human rights obligations:

[answer truncated to 25000 characters]

15. Do you have any other feedback related to the Act?

Yes. Thank you for the opportunity to submit to the first review of the End of Life Choice Act (2019), (the Act). We are the End-of-Life Choice Society NZ Inc (the Society).

This compassionate law was enacted in 2019 and came into force in November 2021 in response to decades of debate, research and mounting public pressure. The Act was endorsed in 2020 by a referendum which returned 65% support.

The Act allows New Zealanders suffering unbearably and irremediably from an incurable medical condition to choose to end their suffering by accessing medical intervention to end their life if their situation meets certain criteria.

The Act is extremely strict, with multiple access criteria. It is demonstrably very safe. It is also demonstrably very unfair, as it currently excludes some individuals who are suffering unbearably but who need it most.

The Society is suggesting some important updates to make the legislation fairer, more fit for purpose and more aligned with the human rights responsibilities that our nation is committed to and that the public expects to see expressed in all of our legislation.