

End of Life Choice Act 2019

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The conflicts

- Duty to preserve life
- Duty to relieve suffering
- Suicide prevention
- Religious and cultural beliefs

Why clinicians need to know

- The End of Life Choice Act 2019 gives people who experience unbearable suffering from a terminal illness the option of legally asking for medical assistance to end their lives
- Assisted dying will become lawful in New Zealand from 7 November 2021
- You may be asked about assisted dying

Outline

- Key aspects to the act
- Practice points
- Assessment of Competency
- Protecting against coercion
- Relational autonomy
- Clinical syndromes
- Comprehensive assessment
- Discussion

Eligibility Criteria

A person **must meet all** of the following criteria to be eligible for assisted dying:

- be aged 18 years or over
- be a citizen or permanent resident of New Zealand
- suffer from a **terminal illness** that is likely to end their life within **6 months**
- be in an **advanced** state of **irreversible decline** in physical capability
- experience **unbearable suffering** that cannot be relieved in a manner that the person considers tolerable
- be **competent** to make an informed decision about assisted dying
- A person cannot access assisted dying solely because they are suffering from a mental disorder or mental illness, have a disability, or are of advanced age.

Suffering

The request for assisted dying is

'usually motivated by multiple interactive factors in relation to progressive serious illness including both physical and psychological suffering, a desire to control the circumstances of one's death and to relieve distress over the loss of autonomy'

Cassell EJ; The nature of suffering and the goals of medicine. Oxford University Press, 1991

s10 Assisted dying must not be initiated by health practitioner

A health practitioner who provides any health service to a person must not, in the course of providing that service to the person,

— (a) initiate any discussion with the person that, in substance, is about assisted dying under this Act; or

(b) 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.

Practice point #1

Questioning around suicidal ideation

What do you think about euthanasia?

s11 Request made

The attending medical practitioner must—

(a) give the person the following information:

- (i) the prognosis for the person's terminal illness; and
- (ii) the irreversible nature of assisted dying; and
- (iii) the anticipated impacts of assisted dying

b) personally communicate by any means (for example, by telephone or electronic communication) with the person about the person's wish at intervals determined by the progress of the person's terminal illness; c) ensure that the person understands their other options for end-of-life care; and (d) ensure that the person knows that they can decide at any time before the administration of the medication not to receive the medication; and (e) encourage the person to discuss their wish with others such as family, friends, and counsellors; and (f) ensure that the person knows that they are not obliged to discuss their wish with anyone; and (g) ensure that the person has had the opportunity to discuss their wish with those whom they choose; and

- (h) do their best to ensure that the person **expresses their wish free from pressure** from any other person by—
- (i) conferring with **other health practitioners** who are in regular contact with the person; and
 - (ii) conferring with members of the person's **family approved by the person**

Practice Point #2

What do we advise if a person declines engagement with family?

s24 No further action to be taken if pressure suspected

If, at any time, the attending medical practitioner or attending nurse 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 medical practitioner or nurse practitioner must—

- (a) take no further action under this Act to assist the person in exercising the option of receiving assisted dying; and
- (b) tell the person that they are taking no further action under this Act to assist the person in exercising the option of receiving assisted dying; and
- (c) complete an approved form recording

Three statutory roles within the Act

- The Support and Consultation for End of Life in NZ (SCENZ); group of health practitioners, responsible for standards of care and medical/legal procedures.
- The Registrar (assisted dying) – checks processes for compliance and receives complaints
- End of Life Review Committee reviews reports about assisted death under the Act and reports to registrar about compliance

Practice Point #3

If a medical practitioner with a conscientious objection is asked by a person about assisted dying, they have certain responsibilities under the Act.

They **must**

- inform the person of their objection
- tell the person that they have the right to ask the SCENZ Group for the name and contact details of a medical practitioner who is willing to participate in assisted dying
- ensure continuity of care is maintained for a person requesting assisted dying.

The Process

- The person asks to start the process for assisted dying.
- The attending medical practitioner assesses if they are eligible.
- An independent medical practitioner assesses if they are eligible.
- If required, a psychiatrist is asked to provide a competency assessment.
- The person is confirmed as eligible and chooses when the medication will be administered.
- The attending medical practitioner, or an attending nurse practitioner, writes the appropriate prescription and informs the Registrar.
- The Registrar confirms the correct process has been followed.
- A pharmacist dispenses the medication.
- The medication is administered by the attending medical or nurse practitioner, or self-administered by the person.
- The assisted death is confirmed and reported to the Registrar.

Competence

- No presumption of competence under the Act.
- The person requesting assisted dying must be assessed and found competent to make an informed choice about assisted dying.
- This includes being competent at the time the medication is administered
- A person must be assessed by two medical practitioners and found eligible by both before the process can continue
- If competence is not established by one or both practitioners then a third opinion is given by a psychiatrist

s6 Meaning of competent to make an informed decision about assisted dying

In this Act, a person is **competent to make an informed decision about assisted dying** if the person is able to—

- (a) **understand** information about the nature of assisted dying that is relevant to the decision; and
- (b) **retain** that information to the extent necessary to make the decision; and
- (c) **use or weigh** that information as part of the process of making the decision; and
- (d) **communicate** the decision in some way.

s15 Third opinion to be given by psychiatrist if competence not established to satisfaction of 1 or both medical practitioners

(3) The psychiatrist must—

(a) read the person's medical files; and

(b) examine the person; and

(c) reach the opinion that—

(i) the person is competent to make an informed decision about assisted dying; or

(ii) the person is not competent to make an informed decision about assisted dying

Existing frameworks and current responsibilities

- The Ministry's obligations under Te Tiriti o Waitangi (Te Tiriti)
- The Code of Health and Disability Services Consumers' Rights (the Code) applies when providing assisted dying services, with the HDC oversight.

Where Act overrides the Code

Under the Act, a health practitioner cannot raise assisted dying with a person.

- this overrides Right 6 (1)(b), which states that a person would expect to receive 'an explanation of the options available'.

However, once the person raises assisted dying, Right 6 applies in full.

Under the Act:

- a person's competence must be assessed as part of the process; this overrides Right 7(2), which states a person must be presumed competent.
- advanced directives are not allowed; this overrides Right 7(5), which states that advanced directives may be used in accordance with common law.

Practice Point #4

Advance directives cannot be used to request assisted dying

s32 Other rights and duties not affected

- (1) Nothing in this Act affects a person's rights to—
 - (a) refuse to receive nutrition
 - (b) refuse to receive hydration
 - (c) refuse to receive life-sustaining medical treatment

- (2) Nothing in this Act affects a medical practitioner's duty to alleviate suffering in accordance with standard medical practice.

Practice Point #5

s34 Welfare guardians have no power to make decisions or take actions under this Act

Other interesting bits

- **s35 Effect on contracts of death under this Act**

A person who dies as a result of assisted dying is, for the purposes of any life insurance contract, or any other contract,—

(a) taken to have died as if assisted dying had not been provided; and

(b) taken to have died from the terminal illness referred to in section 5(1)(c) from which they suffered.

- **s36 Restrictions on making public details of assisted dying deaths**

- **s37 Immunity from criminal liability** -A health practitioner who does all or any of the following is immune from criminal liability under section 179 of the Crimes Act 1961

Assessment of Competency

s6 In this Act, a person is **competent to make an informed decision about assisted dying** if the person is able to—

- (a) **understand** information about the nature of assisted dying that is relevant to the decision; and
- (b) **retain** that information to the extent necessary to make the decision; and
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- (d) **communicate** the decision in some way.

Medical Assistance in Dying Canada 2019

First Annual Report

- In 2019 MAID accounted for 2% of all deaths
- Average age was 75.2, majority receiving palliative care
- Suffering was closely tied to loss of autonomy and loss of ability to engage in meaningful life activities or to perform ADLs
- One quarter of requests did not result in assisted dying
 - of these cases 7.8% were deemed ineligible
 - of those deemed ineligible;
 - 32.2% were not capable of making decisions with respect to health
 - 17% could not provide informed consent
 - 1.6% request was not voluntary

Physicians' experiences with assisted dying in Netherlands

Evenblij et al BMC Family Practice (2019) 20:177

- Third evaluation of the Dutch Euthanasia Act, 12 page questionnaire sent out to 3000 medical practitioners; GPs, physicians and psychiatrists.
- Asked about most recent case where patient did not have cancer and made the request, about most recent case they had refused a request and most recent case they had granted the request.

- Amongst those who reported about a refused request, concerns were noted about assessing whether criteria were met, dealing with the relatives of the patients and the reactions of other care providers.
- 60.3% felt pressured by the patient cf 13.2% in those who granted
- 31.7% felt pressured by relatives cf 6.2% in those who granted
- More pressure to grant the request in the patient >80 years

- Distress due to pressure from the patient to grant the request, the assessment process and whether patient meets the criteria, performing the procedure and the administrative burden
- Older GP felt the pressure more- found the experience burdensome, heavy responsibility and emotional

Protecting against coercion

Whānau, carers and welfare guardians do not have any power to make decisions about assisted dying on behalf of someone else.

s11 (h) The attending medical practitioner must:

do their best to ensure that the person **expresses their wish free from pressure** from any other person by—

- (i) conferring with **other health practitioners** who are in regular contact with the person; and
- (ii) conferring with members of the person's **family approved by the person**

United Nations Convention on the Rights of Persons with Disabilities



Article 12: Equal recognition before the law

Article 16: Freedom from exploitation, violence and abuse

Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.

It is now routine, in all capacity assessments, to assess the 'freedom' of the decision, namely to consider: is the person being influenced in making the decision?

'Red flags' for undue influence

- The psychosocial environment; the nature of the relationship with the 'influencer'
- The social circumstances; the presence of family conflict, psychological and/or physical dependency on a carer, isolation and sequestration
- The personal factors; physical illness, disability and/or sensory impairment; substance misuse; mental illness; cognitive disorders, psychological factors including mourning and grief, personality disorders

Relational Autonomy and risks of coercion

- Older people
 - highest rate of suicide internationally
 - may be particularly vulnerable under this legislation
 - interpersonal contexts, especially the frequently dependent nature of their relationships and comparatively greater health burden, combined with other psychosocial factors such as perceived burdensomeness influencing decision making.
- Decisions to end one's life are never undertaken in a vacuum

Relational Autonomy

- Our identity is shaped by social environments and our interactions with other people
- Self-identity and decision making capacity are dynamic and change with the individual's network of relationships, and their cultural and social context
- For Maori, individual decisions in the cultural context: *tikanga Maori* and *taha whanau*
- Relational autonomy approach promotes understanding and incorporating a person's interpersonal context when assisting them to make choices in line with their sense of self and values

Authenticity and Consistency

- Most tests of decision making capacity focus upon **procedural** aspects

Are the persons' decisions, beliefs, values and commitments identified as their own, congruent with their sense of self and identity

- Assessment of **context**- authenticity, consistency and social dimensions, which may include interactions with others

The issue of autonomy and requests for assisted dying are complex

Family consultation would seem to be important if not essential

- Has the person requesting assisted dying considered the potential adverse impact of their death on their loved ones?
- Distorted perceptions of relationships and how their death might affect family and friends are relevant
- Families may report feeling pressured to accept a relative's wish for assisted dying especially if 'threatened' with the alternative prospect of their suicide
- Discussion with family allows an opportunity to explore these perceptions, and potentially resolve issues underlying the decision to request assisted dying
- Discussion with family/carers may be important in the assessment of freedom of choice

Issues to consider in the assessment

- The competency cell of s6
- The capacity for reflection and self-awareness
- Distorting influences-overpowering emotions, depression or other mental illness, substance use, demoralisation, feeling like a burden
- Cognitive function; delirium or dementia
- Personality factors- lack of self-esteem or being deprived of educational and social opportunities may impair capacity to reflect and adapt
- External factors- dependency and role of carers through to being subject to physical, emotional or verbal abuse

Cognitive Impairment

- Cognitive impairment may be comorbid with a terminal illness
- Delirium vs *'terminal restlessness'* and *'terminal anguish'*
- Ensure not retained language or confabulation yet impaired conceptual thinking
- Cognitive impairment may impede accurate appraisals of relationships e.g. changes in personality or family alliances, persecutory ideas, and apathy/passivity
- Mild cognitive impairment does not preclude capacity to decide

'Chemo brain'

- Cancer-related cognitive decline after a diagnosis and/or treatment
- Problems with memory, attention, executive function and speed of processing information
- More subtle than other neurodegenerative disorders of CNS
- Rates vary from 10%-50%
- Mechanisms not fully understood and can persist after therapy

Aphasia

- Aphasia is defined as an impairment in the understanding or transmission of ideas by language
- Presence of aphasia may hamper the assessment
- Higher level executive skills; judgment, flexibility, planning and foresight can be effected in association with aphasia; careful screening in such patients.
- Speech-language therapist to facilitate communication in the assessment of capacity to decide.

Depression

- Depression; not uncommonly comorbid with terminal illness and may influence decision-making capacity
- Depression in patients with cancer with a poor prognosis of < 3 months life expectancy; associated with requests for euthanasia
- State-dependent; preferences for euthanasia in depressed older people mostly resolved upon treatment for depression
- Presence of depression does not automatically preclude decision making capacity

Comprehensive assessment

1. The person's understanding of their condition and prognosis
2. Their perceptions of quality of life
3. Their reasons for requesting assisted dying
4. Their ability to give informed consent; process of reasoning
5. Assess for co-existing or complicating conditions
6. Explore social/relationship factors and impact on loved ones
7. Consistency and authenticity in expressed wishes

Practice Point # 6

The assessment of capacity to decide, and, ensuring the expressed wish is free from pressure, requires skill and careful consideration

Conclusion



- Assisted dying is here by law from 7 November 2021
- You cannot raise the option with patients
- If a patient raises it you have an obligation to inform them of the SCENZ group and to continue to provide good clinical care
- There is no presumption of competence
- The role of whanau/family is important yet guided by the patient
- A Welfare Guardian or Advance Care plan has no weight in this law
- The assessment of capacity and vulnerability to coercion- a comprehensive careful approach is necessary

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