

# The assessment of competency and coercion in the End of Life Choice Act 2019

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## ABSTRACT

The eligibility criteria of the End of Life Choice Act 2019 specify the person must be competent to make an informed decision about assisted dying. The patient must initiate the conversation about assisted dying, and then it is incumbent on health professionals to perform a skilled exploration of the person's suffering and rationale. The legal standards for competence must be met. Common mental health and cognitive disorders that may impact on decision-making must be recognised. The context and the authenticity and consistency in choice are important elements. Education and training of involved health practitioners is required to ensure the assessment process is robust. A comprehensive approach is necessary to determine the autonomy of the decision and for the protection of the rights of the individual.

The matter of medically assisted dying can be difficult to discuss in a dispassionate way. For doctors it may raise many conflicts: the duty to preserve life yet the duty to relieve suffering, the duty to respect patient autonomy yet the duty to do no harm. In psychiatric practice, there is the issue of suicide prevention. And clinicians have their own family, religious and cultural foundations and life experiences, which inform perspectives on this complex topic.

The fact of this matter is that assisted dying will become lawful in New Zealand from 7 November 2021. The End of Life Choice Act 2019 (the Act) will give people who experience unbearable suffering from a terminal illness the option of asking for legal medical assistance to end their lives, and clinicians across the health and disability sector will be asked about assisted dying.<sup>1</sup>

## Eligibility criteria

A person must meet all of the criteria to be eligible for assisted dying (Figure 1). Importantly, 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.

A discussion on the challenges of accurate prognosis or the definition of *advanced state* or *unbearable suffering* is beyond the scope of this paper. However, as noted in the First Annual Report on Medical Assistance in Dying in Canada (2019), suffering is closely tied to loss of autonomy and loss of ability to engage in meaningful life activities or perform activities of daily living.<sup>2</sup> It has been recognised for decades that the request for medical assistance in dying is usually motivated by multiple interactive factors, including both physical and psychological suffering and a desire to control the circumstances of one's death.<sup>3</sup>

## Medical practitioner cannot initiate discussion

According to Section 10 of the Act, a medical practitioner cannot initiate a conversation that is *in substance* about assisted dying. This concept was introduced in the supplementary order paper by Mr David Seymour, Member of Parliament for Epsom, as a safeguard similar to what is in place in Victoria, Australia. This

prohibition overrides the right to be fully informed where Right 6(1b) of the Code of Health and Disability Services Consumers' Rights (the Code) states that a person has a right to the information that a reasonable person in their circumstances would expect to receive, including "an explanation of the options available." Doctors will need to be mindful in the exploration of a person's suffering, as Section 10 of the Act limits frank discussion regarding future management. It raises issues for how a clinician responds to a patient expressing the wish to die or hasten their death and/or suicidal ideation. Discussion around suicide may be important and indeed preventative. It may be challenging to navigate when a patient asks about all the treatment options without specifically asking about assisted dying. Once the person directly enquires about assisted dying, Right 6 of the Code applies in full.

Research suggests that it is generally the well-educated who seek medically assisted dying.<sup>4</sup> Therefore, Section 10 may discriminate against groups who are not aware of this option or are in some way constrained, shamed or fearful. The importance of the doctor-patient relationship and delicate skill in the exploration of the issues cannot be understated. Time needs to be taken to enable a person-centred conversation in trust but without influence. This will protect against suboptimal decisions, clinician distress or, in the worst-case scenario, being subject to proceedings by the Health and Disability Commissioner.

If a medical practitioner with a conscientious objection is asked by a person about assisted dying, they have certain responsi-

bilities under the Act. Once the Section 11 request is made, the attending medical practitioner has to undergo certain steps in the process. These are detailed in the Act and on the Ministry of Health website.

## Assessment of competency

Inherent to the eligibility criteria is the assessment of competency. In the Code and common law, there is the presumption of competence. However, under the Act, there is no presumption; the person requesting assisted dying must be assessed and found competent to make an informed choice and be competent at the time the medication is administered. Under Section 6, "competent" requires the person to be able to understand, retain and use or weigh information as part of the process of making the decision, and then communicate the decision (Figure 2). These legal standards for competence should be well familiar to clinicians. They form the backbone to the assessment of informed consent as outlined in the seminal paper of Appelbaum & Grisso.<sup>5</sup>

Under Section 11, the attending medical practitioner is further required to *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.* If it is suspected on reasonable grounds that a person is not expressing their wish free from pressure from any other person, under Section 24 the attending medical or nurse practitioner is required to take no further

**Figure 1:** Section 5 Meaning of person who is eligible for assisted dying.

- a. be aged 18 years or over
- b. be a citizen or permanent resident of New Zealand
- c. suffer from a terminal illness that is likely to end their life within 6 months
- d. be in an advanced state of irreversible decline in physical capability
- e. experience unbearable suffering that cannot be relieved in a manner that the person considers tolerable
- f. be competent to make an informed decision about assisted dying.

action and to inform the patient of the same.

Assessing a person's capacity to decide to bring forward their death and then ensuring that the request is an autonomous wish, freely expressed without coercion, requires a skilled and considered approach to assessment. Given the gravity and finality of the decision, there needs to be certainty. The involved health practitioners will need to develop skills and allow time for this task-specific assessment of capacity to decide. The assessors will also need to be aware of their own issues where it has been shown that those with a previous bias against assisted dying are more likely to deem a person incapable than those who were neutral or accepting of the option.<sup>6</sup>

There will be questions around patients' understanding of the underlying condition, the available treatments and the prognosis, the access to palliative care and other end of life care options. Of note, under Section 33, an advance directive cannot provide for assisted dying. However, a previously thought through advance care plan may facilitate discussion on important aspects, such as significant others and spiritual needs. The understanding of the legal process, the medication and procedure, the effect and possible complications and the impact on family and friends will be discussed. The length of time that assisted dying has been considered, the consistency of the expressed wish, the option to change their mind or withdraw at any time and a review of the decision at intervals will be necessary. This educative process by the attending medical practitioner, performed in

tandem with the comprehensive assessment, will take place over time and may involve several consultations. This is followed by a second assessment and opinion by an independent medical practitioner. If competence is not established to the satisfaction of either medical practitioner, a third opinion must be obtained from a psychiatrist. This lengthy process is essential and must be robust, yet it may be difficult for some with a terminal illness to endure.

Most standardised tests of competency focus upon the procedural aspects of the capacity to decide. The NICE Capacity and Consent Tool provides guidance on criteria to use when assessing decisional mental capacity.<sup>7</sup> The MacArthur Competence Assessment Tool for Treatment is widely used with validity across a variety of populations.<sup>8</sup> The Aid to Capacity Evaluation, developed to help clinicians systematically evaluate capacity when a patient is facing a medical decision, has the potential to be adapted for this clinical domain.<sup>9</sup> Although useful, assessment tools have their limitations. Self-identity and decision-making capacity are dynamic and change with the individual's network of relationships, and their cultural and social context. This may be particularly relevant for Māori, tikanga Māori and taha whānau principles. A relational autonomy approach, which promotes understanding and incorporating a person's interpersonal context, is used to assess authenticity, consistency and social dimensions with the decision to be made in line with the person's values, commitments and beliefs and in continuing interactions with others.<sup>10</sup>

**Figure 2:** Section 6 Meaning of competency.

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.

## Comorbid conditions that may impact on competency

In a terminally ill patient, there are potential comorbid cognitive and mental health disorders that require recognition. They are, in essence, any condition that may impact on attention, memory, executive function, reasoning and judgment. The presence of a mental illness or cognitive disorder does not automatically preclude decision-making capacity, yet there needs to be careful assessment to determine that competency is preserved.

Depression may be comorbid with terminal illness and compound feelings of hopelessness and burdensomeness. In patients with cancer with a poor prognosis of <3 months life expectancy, the presence of depression has been shown to be associated with requests for euthanasia.<sup>11</sup> However, the request may depend on one's state, with the expressed wish for euthanasia in depressed older people mostly being resolved upon treatment for depression.<sup>12</sup> The presence of other mental illnesses that may impact on capacity, such as a psychotic or substance use disorders, need to be recognised and teased out. Delirium is a common, if not inevitable, complication of dying. The diagnosis of delirium in the medically frail may be difficult and confounded by patient discomfort, anguish, restlessness, fatigue and drowsiness. Even within cognitive fluctuations—so-called “lucid intervals”—underlying higher cortical functioning is likely to be subtly impaired.<sup>13</sup>

Older patients with comorbid cognitive impairment may initiate a request. Mild or even moderate cognitive impairment does not necessarily preclude the capacity to decide. In this situation, there would be a careful assessment of cognition with a focus on working memory and frontal executive function. Exploring aspects of autobiographical memory are important in the assessment of authenticity and consistency in the expressed wish.<sup>14</sup> In disorders of the frontal lobe, bedside tests of verbal fluency, trail-making and clock-face tests can be performed, but it is abstract thinking and the ability to reason or use and weigh relevant information that are vital in the

evaluation of judgment. It is important to ensure that retained language function is not confabulation or masking deficits in underlying conceptual thinking, as seen in frontal lobe dysfunction.<sup>15</sup>

The presence of aphasia may hamper the assessment, and a speech-language therapist may be required to facilitate communication. Moreover, there needs to be careful screening, as there is increasing evidence that the higher-level executive skills of judgment, flexibility, planning and foresight can be affected in association with aphasia.<sup>16</sup>

Cancer-related cognitive decline (CRCDD) associated with the diagnosis and/or treatment is a more subtle disorder of cognition, compared to other neurodegenerative disorders. In these patients there can be deficits in memory, attention, executive function and speed of processing information. The rates of CRCDD may vary from 10–50%, depending on the variables, including the cancer type and therapy. The mechanisms are not fully understood, and symptoms can persist long after the therapy.<sup>17</sup>

## Protection against coercion

This is perhaps the most difficult aspect in the process of assessment. Article 16 of the United Nations Convention on the Rights of Persons with Disabilities mandates the right of freedom from exploitation, violence and abuse. It is now considered to be routine in all capacity assessments to assess the “freedom” of the decision. Under Section 11(h) of the Act, the attending medical practitioner is required to *do their best* to ensure that the person expresses their wish free from pressure from any other person. This is arrived at by conferring with health practitioners, such as medical colleagues, nurses, social workers and others who are in regular contact with the person, and by conferring with members of the person's family *approved by the person*. If ever there was a decision that had to be autonomous, it should be the request to end one's life, yet discussion and family consultation would seem crucial in most cases.

One question to consider will be whether the person requesting assisted dying contemplated the potential adverse impact

of their death on their loved ones. Families may report feeling pressured to accept a relative's wish for assisted dying, especially if "threatened" with the alternative prospect of their suicide. The assessing health practitioner will become versed in relevant probing questions to discover who suggested the idea, who may benefit, whether the individual may feel like a burden or whether there are financial or other pressures. The individual must be assessed on their own, yet this may be challenging for the terminally ill due to the understandable physical presence of the attending whānau and carers (Figure 3).

Discussion with family allows for an opportunity to explore family perceptions, to screen for coercion and to resolve issues underlying the request. In family meetings, signs of possible coercion may be observed, such as individuals talking over the patient or the patient deferring to others.<sup>18</sup>

A considered and cautious approach is necessary to ensure that the request for assisted dying is free from coercion. Under Section 24 of the Act, if at any time the attending medical or nurse practitioner suspects on reasonable grounds that a person who has expressed the wish to receive assisted dying is not expressing their wish free from pressure from any other person, the health practitioner must take no further action under the Act and inform

the person that they are doing so. Health practitioners may also need to consider their broader professional obligations in the situation where there are evident risks to a patient.

## Conclusion

The option of assisted dying will become available for New Zealanders. The End of Life Choice Act 2019 is person-centred, with the role of whānau and family being important yet guided by the patient. The eligibility criteria include the requisite competence to make this final decision and that the choice is voluntary. A comprehensive approach is essential in the assessment of capacity and vulnerability to coercion. Education, training and support for involved health practitioners is being rolled out by the Ministry of Health. The competency cell of Section 6 needs to be complemented with an assessment of the person's capacity for reflection; the impact of distorting influences, such as overpowering emotions, depression or other mental illness; and in certain conditions, a review of cognitive function. An assessment of psychosocial context is required to assess authenticity and consistency. A comprehensive approach to assessment of both the procedural and contextual elements is vital as a safeguard to protect the vulnerable in our society.

**Figure 3:** Questions on context and freedom of choice.

When did you first think of assisted dying as an option?  
 Did someone suggest assisted dying as an idea?  
 Are you requesting assisted dying for yourself or others around you?  
 If others, who will benefit from your assisted dying and how?  
 Are you feeling any pressure from others to request assisted dying?  
 Do you feel you may be a burden to others?  
 Do you have any significant financial concerns?  
 Do you have any concerns for your family after you die?  
 Is there anything we need to know that you don't want your family or others to know?



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Nil.

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