New Zealand House of Representatives
Te Whare Māngai o Aotearoa

Health Committee
Komiti Whiriwhiri Take Hauora

54th Parliament
August 2025

Briefing on the advance directive system

Presented to the House of Representatives
by Sam Uffindell, Chairperson

Contents

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Recommendation

The Health Committee has considered a briefing on the advance directive system, and recommends that the House takes note of its report.

About this briefing

In October 2024 we received a letter from Louise Duffy, who advocates for the establishment of a nationwide electronic database for advance directives and care plans. Ms Duffy shared with us that her mother's advance directives had not been honoured by medical teams following a medical emergency. She subsequently identified several issues with the current advance directive system. We resolved to open a briefing to investigate the matter, and invited Louise Duffy to meet with us.

Advance directives and care plans

The Code of Health and Disability Services Consumers' Rights gives any person who is legally competent the right to make an advance directive.[1] An advance directive is a statement signed by a person setting out the treatment they would or would not want in the event of becoming unwell in the future. To have legal authority, an advance directive must meet the following four criteria:

- The individual had capacity to make the directive at the time.
- The individual was fully informed of the benefits and risks of consenting to or refusing specific treatment at the time.
- The individual intended the directive to apply to the present circumstances.
- The decision was made free from undue influence.

An advance care plan is a more comprehensive written record that includes an individual's wishes, preferences, values, and goals that are relevant to all current and future medical care. The care plan can be developed in collaboration with family, whānau, and healthcare professionals. Advance care plans include advance directives and plans for end-of-life care.

Background

On 6 October 2021, Barbie Duffy suffered a major stroke at her home in Methven. Before this event, Barbie had established an advance directive. According to her daughter Louise, the directive gave Barbie's consent to withdraw from care, so she could pass away, if she were to suffer from a serious loss of mental or physical capacity. Following an operation to remove the blood clot that caused the stroke, Barbie was given fluids and medication, which Ms Duffy said contradicted the conditions of her mother's advance directive. We heard that,

[1] Health and Disability Commissioner, *Code of Health and Disability Services Consumers' Rights*.

two weeks after the stroke, her mother was assessed and was found to lack mental capacity. However, a month after the stroke, she was able to regain some cognition. From this point onwards, she refused food and fluids. Barbie passed away 58 days later without the aid of medication.

Ms Duffy believes her mother's advance care plan should have been followed. She points out that, if it had been, Barbie would have died medicated and semi-conscious 7–10 days after the stroke, while naturally unable to swallow.

Comments from Louise Duffy

Ms Duffy told us that there are two medical options that can be involved in end of life: assisted dying and an advance directive that withholds care. She said the End of Life Choice Act 2019 allows eligible individuals to choose assisted dying and is supported by a comprehensive system that includes safeguards, reporting, and independent monitoring. She said the advance directive system is underpinned by three pieces of legislation, two guidelines, and case law, but it is not effectively administered.[2]

Although the advance directive system should support a person's choice at the end of life, we were informed that not all advance directives are followed. Ms Duffy suggested four main reasons for why an advance directive is not adhered to:

- The advance directive is unclear or invalid.
- Clinicians are unaware of an advance directive.
- The advance directive is not applicable to the current situation.
- The clinician chooses not to follow an advance directive.

We heard that the fourth reason is responsible for the distressing situation that Ms Duffy and her family found themselves in. Ms Duffy explained that for an advance directive to be followed, a doctor needs to assess the patient and provide a prognosis stating that they lack mental capacity. This prognosis confirms that the criteria have been met to activate the advance directive. We were told that both doctors who treated Barbie Duffy chose not to assess her mental capacity, nor provide a clear prognosis. This was despite brain scans and medical notes that demonstrated she lacked capacity and that her advance directive condition of "permanent, irreversible, and severe loss of mental or physical capacity" had been met.

Ms Duffy proposes changes to the advance directive system that could address the first two problems—lack of clarity, accessibility, and validity.

First, she recommends replacing the advance directive template provided by the Health Quality and Safety Commission with one that focuses on outcomes that people can easily understand. This template would specify possible outcomes of a severe medical event that would require the activation of an advance directive. It would also include simple

[2] The Acts—New Zealand Bill of Rights Act 1990, Health and Disability Commissioner Act 1994, Protection of Personal and Property Rights Act 1988

Regulations—Health and Disability Commissioner Regulations (Code of Health and Disability Services Consumers' Rights) 1996, Advance Care Planning Guide 2011

Case law—Chief Executive of the Department of Corrections v Shaw [2024] NZHC 2976.

descriptions of treatment and life-sustaining options that would enable a person to create a clear and effective advance directive.

The second change Ms Duffy proposes is the inclusion of advance directives on a medical database that is accessible nationwide. This would ensure that medical teams can access advance directives anywhere and anytime. Ms Duffy mentioned HealthOne, a South Island-wide electronic health record system that enables registered healthcare providers to access and share patient information. No such database exists in the North Island.

The third change Ms Duffy suggests is a system that reviews existing advance directives. Patients would be regularly asked to confirm or update their advance directives to ensure that they are current and valid.

Template of the Health Quality and Safety Commission

We note that the advance directive template provided by the Health Quality and Safety Commission requires a person to list all the medical situations that they could face and the treatments they do or do not want to receive. We think this template could be hard to fill out if a person is not familiar with medical terms. We find the advance directive template suggested by Ms Duffy easy for people to understand, focusing on possible outcomes with simple descriptions for treatment and life-sustaining options. We encourage the Health Quality and Safety Commission to consider reviewing its advance directive template to make it easier to complete. We think the third change proposed by Ms Duffy, regarding a review system for existing advance directives, could provide certainty for medical personnel that a person's advance directive is current and valid.

Petitions Committee report

Louise Duffy petitioned Parliament on this matter. We have considered the report that the Petitions Committee presented in October 2024.[3] The Petitions Committee urged the Health Quality and Safety Commission to strengthen healthcare professionals' understanding of the legal requirements regarding advance directives and care plans. It also acknowledged the need for healthcare professionals to retain some clinical flexibility, and to use their discretion to decide whether an advance directive applies to the situation at hand.

Our conclusion

We acknowledge the loss of Louise Duffy's mother, Barbie, and the distress caused by the interactions between Ms Duffy and healthcare professionals following Barbie's stroke. We thank Ms Duffy for her advocacy and her work to improve the advance directive system.

We consider that issues with the current advance directive system call for urgent reform. We welcome Ms Duffy's proposal that advance directives be included on a medical database to be accessible nationwide. Therefore, we would welcome any Government consideration regarding the establishment of a nationwide register of advance directives. We think that a nationwide register is an important step towards a more effective advance directive system.

[3] Petitions Committee | *Final Report (Petition of Louise Duffy)*.

Appendix

Committee procedure

We met between 11 December 2024 and 13 August 2025 to consider this briefing. We heard evidence from Louise Duffy on 11 December 2024 and 29 January 2025.

Committee members

Sam Uffindell (Chairperson)
Dr Hamish Campbell
Dr Carlos Cheung
Ingrid Leary
Cameron Luxton
Hūhana Lyndon
Jenny Marcroft
Debbie Ngarewa-Packer
Hon Dr Ayesha Verrall

Related resources

The documents we received as advice and evidence for this briefing are available on the Parliament website, along with recordings of our meetings on 11 December 2024 and 29 January 2025.