New Zealand House of Representatives
Te Whare Māngai o Aotearoa

Petitions Committee
Komiti Whiriwhiri Take Petihana

54th Parliament
October 2024

Petition of Louise Duffy: Barbie's bill: Make advance care plans count

Presented to the House of Representatives
by Greg O'Connor, Chairperson

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Petition of Louise Duffy

Recommendation

The Petitions Committee has considered the petition of Louise Duffy—Barbie's bill: Make advance care plans count—and recommends that the House take note of its report.

Request to ensure medical advance directives are followed

The petition was presented to the House on 25 July 2023. It requests:

> That House of Representatives implement a national register for standardised medical advance directives and mandate that those directives are followed, and note that 6,785 people have signed a similar petition online.

The Petitions Committee of the 53rd Parliament began considering the petition. We resumed consideration in the 54th Parliament. We received submissions from Louise Duffy, the Ministry of Health | Manatū Hauora, Health New Zealand | Te Whatu Ora, and the Health Quality and Safety Commission | Te Tāhū Hauora.

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 four criteria, which are that:

- 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 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 plans for end-of-life care.

Enduring power of attorney

Under the Protection of Personal and Property Rights Act 1988, an individual may grant another person an enduring power of attorney.[2] This would enable the appointed person to make healthcare decisions on the individual's behalf when they are mentally incapable of

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

2 New Zealand Government, *Protection of Personal Property Rights Act 1988*.

doing so themselves. However, a medical certificate must be provided before an enduring power of attorney can be exercised on behalf of a mentally incapable individual.

Comments from the petitioner

Ms Duffy told us that on 6 October 2021 her mother, Barbie, suffered a major stroke at her home in Methven. Before this event, Barbie had established an advance directive. According to the petitioner, 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… [where the] condition is unlikely to be reversible or improve".

Following an operation to remove the blood clot that caused the stroke, we were told that Barbie was given fluids and medication. The petitioner thinks these actions contradicted the conditions of Barbie's advance directive. Ms Duffy told us that unclear communication by hospital staff surrounding her mother's condition and the petitioner's status as her attorney heightened an already distressing situation. A month after the stroke Barbie regained some cognition. From this point onwards, she refused food, fluids, and medication. Barbie passed away 58 days later.

In the petitioner's view, her experience with the medical system demonstrated its unwillingness and inability to implement advance directives that withhold care. Ms Duffy observed that although the Ministry of Health has a robust framework for advance directives and care plans, it was not practised as it was intended to be in Barbie's case. She said that change is needed. Ms Duffy would like to see an advance directive and care plan system that provides certainty and establishes an easy and effective system for patients, families, and medical and care teams.

The petitioner said she would like three changes made to the system. The first would be to establish a nationwide electronic database for advance directives and care plans. This would ensure that first responders and hospital medical teams had immediate access to advance directives. The second change would see the creation of a standardised form for directives and care plans. The forms would need to be validated every 3–5 years to verify the patient's current wishes. Finally, the petitioner would like to see legislative change to ensure that the informed consent contained within advance directives and care plans is followed.

Comments from the Ministry of Health

The Ministry of Health acknowledged Ms Duffy's petition and the loss of her mother. It told us that it supports the use of advance care planning and advance directives. In 2011, the ministry published *Advance Care Planning: A guide for the New Zealand health care workforce*.[3] It also developed the *Healthy Ageing Strategy 2016–2026*.[4] The strategy includes an action plan that highlights the importance of advance care planning and incorporates several actions that support the use of advance care plans.

The ministry submitted that the current legislation and regulatory framework provides for the use of advance directives and care plans and the enduring power of attorney. It noted that

[3] Ministry of Health, *Advance Care Planning: A guide for the New Zealand health care workforce*.

[4] Ministry of Health, *The Healthy Ageing Strategy 2016–2026*.

under the *Code of Health and Disability Services Consumers' Rights*, individuals have the legal right to use an advance directive. Healthcare providers must take into account an advance directive when deciding which services to provide to a person who is deemed to be mentally incompetent. We heard that the Health and Disability Commissioner is reviewing the code.

The ministry said that the health workforce may lack capability and awareness when it comes to implementing advance directives and care plans. However, it said that requiring advance directives to be followed in all circumstances "could be unwise", and a level of clinical flexibility is needed. We heard that an advance directive may not be followed if the patient's clinician considers that it is not valid or if the advance directive does not reflect a change in circumstances or the individual's current preferences. The ministry stressed that shared decision-making between the patient, family members, and health professionals empowers individuals to retain a degree of autonomy, minimises the potential for conflict, and reduces stress for family members.

Comments from Health New Zealand

Health New Zealand told us it strongly supports advance care directives because they are a valuable tool in modern healthcare that allows for autonomy and choice with end-of-life planning. It is aware that advance directives are not easily understood or used consistently nationwide. We heard that there are also challenges with the provision of information at the point of care, especially outside the South Island.

Health New Zealand said that another challenge for health professionals is whether an advance directive applies to unplanned situations. For example, an advance directive is written by someone with cancer, but once in remission the directive remains. Another illness may befall them, or they may be involved in a car accident, presenting a challenge for medical professionals in how to proceed with treatment. Health New Zealand agreed that Ms Duffy's suggestion of using standardised forms for advance care planning would support the clarity and accessibility of this information for healthcare professionals.

We were told that even if a standalone nationwide database were established for electronic advance directives and care plans, that database might not always be consulted. Rather, Health New Zealand considers it would be more appropriate to have a "single source of truth". This single source would see the inclusion of an advance directive as part of a person's electronic medical record. We heard that this has already been implemented to some extent in the South Island, where a shared electronic medical record can be accessed by healthcare professionals. On the front page of this record is a box indicating that an advance care directive exists. However, there are limitations. If a person from the South Island falls ill in the North Island, this information would not be available.

Health New Zealand thinks it would be unwise to legally mandate that advance directives be followed in every situation. This is because the criteria that underpin their legal authority may not have been met. It noted that the directive would become invalid if the individual "did not anticipate that the advance directive would apply to the circumstances in which they find themselves". It also acknowledges that a person's preferences can change over time, so an advance directive can become outdated. Health New Zealand emphasised that advance directives need to be reviewed and updated regularly and when circumstances change.

Comments from the Health Quality and Safety Commission

The Health Quality and Safety Commission told us it agrees with the intent of Ms Duffy's petition. It would also like to see an advance directive and advance care system that is easy to navigate and that provides certainty for patients, whānau, and medical and care teams. However, it suggested that there may be alternative approaches that would achieve similar outcomes.

The commission observed that creating a standalone nationwide database for electronic advance directives and care plans could risk separating important advance directive information from a patient's main medical record. However, it would endorse an integrated approach that provided advance directives and care planning information alongside a proposed single national electronic health record. It said that such an approach was in development as part of Health New Zealand's Hira programme.[5] An integrated system would simplify access to advance care plans and directives, especially when decisions can be time critical.

We heard that the commission supports the availability of standardised templates for advance directives, and provides one on its website. However, it thinks including a list of treatment options and outcomes that are selected or declined in advance could be problematic for two reasons. First, the options listed may not apply to the person's current situation. Second, a list would not acknowledge a person's unique medical history. The commission told us that it encourages a "shared goals of care" approach instead. This approach involves clinicians, patients, and whānau exploring appropriate care and treatment options that reflect the patient's values and enable treatment decisions to be tailored to the person's individual circumstances.

The commission thinks there is still a lot of work to do on advance care planning. It recognises that there are opportunities to strengthen workforce training so clinicians are more aware and informed of their legal requirements relating to advance care plans and advance directives. The commission would continue to promote the "shared goals of care" approach as a way of communicating and actualising the wishes of an individual. It also aims to consistently distribute resources about advance care planning. These resources will provide education, guidance, and subject-matter expertise if similar situations arise in the future.

Our response to the petition

We thank the petitioner for sharing her difficult experience with her mother's advance directive with us. We commend her advocacy and her work to improve the system for other people who choose to engage in advance care planning. We are sorry to hear that Ms Duffy's mother passed away in such distressing circumstances.

We are concerned that the implementation of the regulatory framework that provides for the use of advance directives and care plans has not been consistent. We urge the Health Quality and Safety Commission to strengthen the understanding of healthcare professionals

[5] Health New Zealand, Hira—connecting health information.

about the legal requirements regarding advance directives and care plans through continuous and comprehensive training and education.

At the same time, we think that healthcare professionals need to have some clinical flexibility when providing treatment, especially in emergency situations. It is important that medical professionals have the discretion to decide whether an advance directive applies to the situation at hand. Additional information that provides some context about who the person is and what their values are would help clinicians to know what is important to that person.

We understand the value of developing a nationwide integrated electronic system that includes a person's health record and advanced care planning information and directives. We encourage people to talk with their whānau and healthcare provider about advance care planning and advance directives. This process can reduce anxiety and stress for whānau when a situation arises where a person no longer has the capacity to communicate their wishes. It also provides guidance for medical professionals regarding treatment options that reflect the person's values.

Appendix

Committee procedure

The petition was referred to the Petitions Committee of the 53rd Parliament on 25 July 2023. It met on 24 August 2023 to consider it. On 6 December 2023, the petition was reinstated with the Petitions Committee of the 54th Parliament. We met between 14 December 2023 and 17 October 2024 to consider it. We received written submissions and heard oral evidence from the petitioner, the Ministry of Health, Health New Zealand, and the Health Quality and Safety Commission.

Committee members

Greg O'Connor (Chairperson)
Carl Bates
Kahurangi Carter (to 8 May 2024)
Greg Fleming
Francisco Hernandez (from 8 May 2024)

Related resources

The documents we received as evidence in relation to this petition are available on the Parliament website.

A recording of our hearing on 23 May 2024 can be accessed online on the Parliament website.