

Aide Mémoire

Health New Zealand
Te Whatu Ora

Responding to the Health Select Committee's Report on Advance Directives

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To:	Hon Simeon Brown, Minister of Health		
From:	Jane Goodwin, Acting National Advance Care Planning Programme Lead		
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Contact for further discussion (if required)

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Attachments

Appendix 1: Advance care planning definitions

Purpose

1. This aide memoire provides you with advice in response to the Health Select Committee's recommendations to include advance directives on a nationwide medical database and to consider establishing a national register of advance directives. It also addresses other Committee recommendations relating to the advance directive template and systems for reviewing existing directives

Summary

2. In October 2024, the Health Select Committee received the letter from Louise Duffy who advocates for the establishment of a nationwide electronic database for advance directives and advance care plans, after her mother's advance directive was not honoured by medical teams in 2021. A report was opened and the Committee met with Ms Duffy on two occasions.
3. The Committee's final report made two key recommendations:
 - a) Advance directives be added to a nationwide medical database.
 - b) A national register for advance directives be established.
4. It also indicated support for Ms Duffy's alternative advance directive template, and processes to regularly review directives to ensure they are up-to-date.
5. Health NZ supports improved access to advance care planning, which includes advance directives, but has concerns about these recommendations. Specifically:
 - a) We caution against standalone databases or registers that are not integrated into clinical workflows, as they risk siloing critical advance care planning information.
 - b) We consider the alternative template for advance directives to have inaccuracies, is not aligned with best practice, and does not provide the guidance needed to develop a clear and legally valid advance directive.
 - c) Current work to embed patients' shared goals of care into clinical workflows provides opportunities to ensure patients' preferences are current and actionable.

Background

The Petition of Louise Duffy

6. In August 2023, the Petition Committee received the *Petition of Louise Duffy: Barbie's bill: Make advance care plans count*.¹ This petition requested:
 - a) A national database of advance directives and advance care plans.
 - b) Standardised templates for advance directives and advance care plans.

¹ Louise Duffy, PET1294 – Submission to the Petitions Committee” (2023) New Zealand Parliament, [Louise Duffy - New Zealand Parliament](#)

- c) Legislative requirements that advance directives be followed.
- 7. In April and June 2024 Health New Zealand | Te Whatu Ora (Health NZ) and Te Tāhū Hauora | Health Quality & Safety Commission (Te Tahu Hauora) provided written and verbal submissions this petition.²
- 8. The Petition Committee's response:
 - a) Noted inconsistent implementation of regulatory framework used for advance directives and care plans.
 - b) Encouraged Te Tahu Hauora to improve training and education for health care professionals about the legal requirements of advance directives and advance care plans.
 - c) Recognised clinicians still need clinical flexibility when providing treatment and that the context to advance directives is important.
 - d) Saw value to developing a nationwide integrated electronic system that includes advance care planning and advance directive information.
 - e) Encouraged whānau discussion about advance care planning and advance directive information to reduce stress and guide treatment.³

Advance care planning in New Zealand

- 9. The Tō tātou Reo advance care planning programme was established in 2011 to provide national leadership in advance care planning across Aotearoa New Zealand.
- 10. The programme delivers subject matter expertise, strategic oversight, and implementation support; develops education, tools, and resources to support advance care planning processes; and enables individuals and clinicians to ensure a person informs care throughout their life.
- 11. From 2018 to 2024, tō tātou Reo advance care planning operated as a third-party funded programme hosted by Te Tāhū Hauora. In July 2024, it transitioned from Te Tāhū Hauora to Health NZ.
- 12. Advance care planning processes enable people to express preferences for future care based on personal values, an understanding of current and anticipated health status, and awareness of available treatment and care options and may include:
 - a) Conversations with whānau and/or clinicians.
 - b) An advance care plan.
 - c) An advance directive.

² Health New Zealand | Te Whatu Ora (2024) Petition of Louise Duffy: Barbie's bill: Make advance care plans count. [Health New Zealand | Te Whatu Ora \(Petition of Louise Duffy\) - New Zealand Parliament](#)

Te Tāhū Hauora Health Quality & Safety Commission (2024) Petition of Louise Duffy: Barbie's bill: Make advance care plans count. [Health New Zealand | Te Whatu Ora \(Petition of Louise Duffy\) - New Zealand Parliament](#)

³ Petitions Committee (2024) Final report: Petition of Louise Duffy – Barbie's bill: Make advance care plans count. [Petition of Louise Duffy: Barbie's bill: Make advance care plans count](#)

13. An advance directive is defined as a person's consent or refusal to specific treatments that may be offered in the future when they lack decision-making capacity. An advance directive is legally binding if valid — i.e. the person was competent and informed when the directive was created, undertook the process voluntarily, and intended it to apply to the current situation. Further definitions of key advance care planning terms are outlined in Appendix 1.
14. *My Advance Care Plan & Guide*⁴ is the nationally endorsed advance care planning template, co-designed with New Zealanders and their clinicians to support person-centred decision-making and the development of contextual and legally valid advance directives. *My Advance Care Plan & Guide* is now hosted by Health NZ.

Discussion

Health NZ supports improved access to advance care planning documents that are integrated into health record systems

15. In response to the petition, the Health Select Committee recommended:
 - a) Advance directives be added to a nationwide medical database.
 - b) A national register for advance directives be established.
16. Health NZ supports enhancing the national availability of advance care planning documents and integrating advance care planning documents, including advance directives, into existing and developing electronic health record systems. Integration will need to ensure:
 - a) critical advance care planning information is presented alongside the patient's wider health context.
 - b) critical advance care planning information is presented alongside the patient's wider health context.
17. While a national system to share advance care planning documentation is not currently in place, there are mechanisms in many parts of the country to share this important information and work underway to expand coverage:
 - a) **South Island:** Uses Health Connect South and HealthOne to share advance care plans and directives via integrated electronic medical records, with alert and navigation functions to enable quick access to the *My Advance Care Plan & Guide* template. The system is available across hospitals, most primary care settings, ambulance services, and a growing number of aged care facilities.
 - b) **North Island:** Many districts have local systems (medical records or regional electronic platforms) that support advance care plans, advance directive and shared goals of care sharing. All systems have alert functionality to prompt clinician access. The Accelerate Programme is implementing the Centric Suite of digital tools which includes Shared Goals of Care and will connect with HealthOne when it is rolled out across the North Island. This will enable a similar system to what is available in the

⁴ [My Advance Care Plan & Guide](#)

South Island.

Health NZ also has concerns with the proposed alternative advance directive template

18. The Health Select Committee noted that Te Tāhū Hauora's advance directive template could be hard to fill out if a person is not familiar with medical terms. It also noted that the template suggested by Ms Duffy is easy for people to understand and focuses on possible outcomes with simple descriptions for treatment and life-sustaining options.
19. Health NZ does not support the proposed template and instead supports the current *My Advance Care Plan & Guide* template as it is designed with plain-language options, clinical support prompts, and legal safeguards.
20. The current template is not a standalone tool; it is embedded within the broader *My Advance Care Plan & Guide*. This guide recommends developing directives with clinical support, and includes five plain-language goals of care options, information on rights under the Code of Health and Disability Services Consumers' Rights, an explanation of the optional signing process, and prompts to share the completed document with clinicians, legal decision-makers, and whānau.
21. The advance directive template is designed to meet legal requirements and aligns with best practice by encouraging people to develop their directives with a trusted clinician, reflecting the person's values and goals, providing context and supporting interpretation in complex clinical situations. Training is available to support clinicians understand the legal and clinical criteria for valid advance directives
22. Most users of *My Advance Care Plan & Guide* choose to express their wishes through the five plain-language goals of care options, rather than using the provided advance directive template, congruent with international research and best practice recommendations.
23. Health NZ does not consider the alternative template suggested by the petitioner to be an appropriate replacement for the existing template and guidance.
24. The alternative template provides a list of treatments and outcomes for a person to accept or decline. This list is inherently limited - a list outlining all potential medical treatments and outcomes would be limitless. As such, because advance directives are limited to the specific treatment and situation specified, if the scenario isn't covered in the template, the directive cannot guide care. This approach also does not acknowledge the nuances of a person's unique medical history or current health circumstances.
25. Tick-box formats may also encourage a person to complete their direction without input from their clinician(s). This means that if selections are not relevant to the person's individual health situation, or are clinically contradictory, they risk invalidating the advance directive on the grounds that the person was not adequately informed.
26. International experience also shows such tools can create unrealistic expectations about treatment availability, especially when not medically indicated.

27. In addition, the alternative template:

- a) Contains clinically inaccurate descriptions of treatment and presents a narrow, input-focused scope (e.g., a focus on the administration of artificially administered nutrition and/or hydration).
- b) Does not allow for additional treatment preferences to be recorded (i.e., treatment preferences outside of the pre-specified list).
- c) Lacks guidance on how to complete the directive such as clinical support, signing, and sharing — all essential for effective use.

28. These limitations undermine the intent to provide a clear and valid advance directive.

We also support regular reviews but recognise these are person owned documents

29. Finally, the Committee noted that a review process for advance directives could provide greater certainty for medical personnel that a person's directive is current and valid.

30. Health NZ supports regular review of advance care directives but notes that:

- a) Advance care plans and advance directives are personal documents, not clinical records. While regular review is encouraged, responsibility for review and updates lies with the individual, similar to a will.
- b) More formalised review systems would require investment in infrastructure and workforce, noting that district-level advance care planning resources vary, affecting capacity for education, support, and public awareness.

Shared goals of care will improve the recognition, use, and review of advance directives and advance care plans

31. Since Ms Duffy's mother's admission in 2021, shared goals of care is being successfully implemented across inpatient and aged residential care settings in New Zealand. Shared goals of care provides a mechanism to activate prior advance care planning in real-time clinical contexts and addresses many of the concerns raised by Ms Duffy in both her Petition and Select Committee submissions.

32. In situations where a person lacks capacity (as in the case of Ms Duffy's mother), shared goals of care documentation prompts clinicians to refer to any valid advance directive or advance care plan, and to engage with legally appointed decision-makers and those who know the person well to inform clinical decision-making.

33. We consider embedding shared goals of care into clinical workflows provides further opportunities to ensure preferences are current and actionable. Several districts now include shared goals of care summaries in hospital discharge documents, helping identify discrepancies and prompting review.

Appendix 1: Advance care planning definitions

Advance care planning

- Advance care planning supports individuals and whānau to reflect on what matters to them now and in the future, including end-of-life preferences, and to communicate these to treating clinicians.
- The advance care planning process enables people to express preferences for future care based on personal values, beliefs, concerns, hopes, and goals; understanding of current and anticipated health status; and awareness of available treatment and care options.
- Advance care planning helps clinicians understand the person and their whānau, enabling the health system to better meet and support their needs.
- Advance care planning tools include advance care plans, advance directives and shared goals of care.

Advance care plan

- An advance care plan captures what is important to the person and outlines preferred care and treatment if they are unable to communicate. The plan may include an advance directive.
- An advance care plan has legal standing, promoting patient autonomy and supporting clinical decision-making in line with the Code of Health and Disability Services Consumers' Rights.
- *My Advance Care Plan & Guide* is the nationally endorsed advance care planning template, co-designed with New Zealand consumers and clinicians to support legally valid, person-centred decision-making.

Advance directive

- An advance directive is defined as a person's consent or refusal to specific treatments that may be offered in the future when they lack decision-making capacity.
- An advance directive is legally binding if valid — i.e. the person was competent and informed when the directive was created, undertook the process voluntarily, and intended it to apply to the current situation (Right 7(5) of the Code).
- In *My Advance Care Plan & Guide*, any advance directives are recorded in Section 6, alongside the person's goals of care.

Shared goals of care

- Shared goals of care is a collaborative process between clinicians, patients, and whānau to explore values and treatment options and agree on a care goal for the current admission and if the patient deteriorates.
- Shared goals of care represent targeted advance care planning for a specific episode of care, comprising both discussion and documented decision/plan.

- Two versions of the shared goals of care plan are currently available: one for hospital admissions and one for aged residential/long-term care facilities.

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