AD Provider resource: Helping your patients pick a date for their assisted death

What is this study about?

Time is a silent yet salient factor in assisted dying decision-making. Unique to New Zealand, the End of Life Choice Act 2019 requires patients to set a date in advance. Knowing the date of death provides whānau with the unique opportunity to plan and ensure that all the things that need to be said are said, family stories are shared, relationships repaired, affairs organised, and memories are made in the lead up to and on the day of the death. While having a date has its advantages, patients and families report that this is also surreal, confronting and difficult. It also forces them to try and find the 'right time'.

After talking with 15 people eligible for AD, their family members and their AD providers, researchers identified four phases in the process of choosing a date: deciding how and when to draw a line in the sand; the final countdown; a date with death; and retrospectively, interpreting that the assisted death happened at the right time.

Types of date decision-making:

Intuitive and embodied:
Some people have a sense of when the right time is, often grounded in the physical body.

Relational:
Others want to make sure their supporters are comfortable with the date.

Situational:
For others, the timing depended on their suffering. Some sought extra scans and monitored the rate of decline to try to predict when they would die.

Picking a date is an embodied, relational, situational decision that balances the time left, families' wishes, providers' needs, and AD regulations (the 'two working day' rule).

A date with death produces practical and existential-spiritual questions for patients and their families, such as how to spend their last days and hours. For some people, planning around a chosen date deepened gratitude and supported emotional preparation; for others, it intensified the weight of anticipation, highlighting the complexity of grieving a chosen death.

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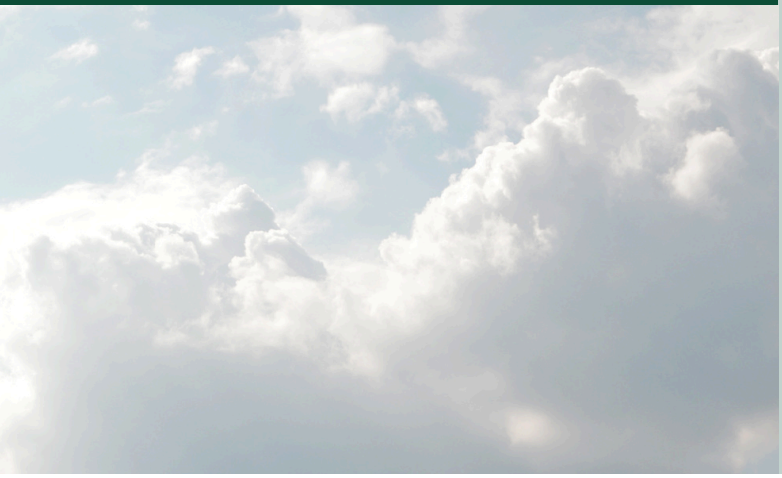
To help patients pick a date, AD providers should consider:

- Exploring patients' and families' preferences and values regarding end-of-life to inform date-setting;
- Discussing the types of decision-making patients might use to decide;
- Educating others that the idea of the right time is contrived as well as possibly helpful for making sense of AD;
- Encouraging the patient to consider multiple "pencilled in" date options as alternatives to the notified date
- Being available and flexible as much as possible;
- Checking in sensitively (but not too regularly) about the date to help manage workload and make the necessary arrangements.

AD providers should inform patients and their families of:

- Your availability for AD provision;
- That the date can be changed, multiple times if necessary, within the legislation framework;
- The most important thing is that they're ready, not to worry about paperwork or others' timetables;
- That the AD can be provided by another AMP/NP if you're not available;
- Indicators of decline to look out for that might mean a date change;
- The kinds of things some people consider when deciding on their date, such as having time for important conversations with loved ones, or to be able to participate in a special occasion or event;
- The types of things they might consider when planning their assisted death, including how the day of death proceeds.

Acknowledgements: We sincerely thank the patients, families and providers who generously shared their experiences with the AD service. Their openness and insights have been invaluable to this research and have contributed meaningfully to our understanding of access barriers to AD service.



Ethics approval statement: The ethical aspects of this study have been approved by the Northern A Health and Disability Ethics Committee through the full review pathway [ref 2023 EXP 18493; 2021 EXP 11454].

Funding statement: The research team received funds from the Health Research Council (22/710) and the Cancer Society (F.20F).

This research is based on: Young, J. E., Lyons, A. C., Dew, K., & Egan, R. (2026). Is there a right time to die? How patients, families and assisted dying providers decide on and anticipate a date with death. *Death Studies*, 50(1), 103–115. Read here.

Dehkhoda, A., Young, J., et al. (forthcoming). Grieving Assisted Dying: A Synthesised Grief Framework. *Death Studies*. Link to follow.

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