

# **Ethical Challenges in Advance Care Planning**

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# 1 Introduction

- 1.1 The National Ethics Advisory Committee, Kāhui Matatika o te Motu (NEAC), is an independent advisor to the Minister of Health on ethical issues of national significance concerning health and disability matters.
- 1.2 This document aims to explore *ethical challenges* that health professionals face in advance care planning, and to provide practical assistance to help ensure good outcomes for consumers and health professionals from the advance care planning process.
- 1.3 The advice in this document is primarily aimed at health professionals, but it may also be helpful to members of the public. This advice has been developed following feedback from a range of health professionals, based on their experiences of the ethical challenges encountered in advance care planning. We are grateful to everyone who has contributed to this work.
- 1.4 Other practical challenges in advance care planning identified by health professionals are summarised in the appendix. NEAC will share this information with groups and organisations that might be able to further investigate these concerns.

## 2 What is advance care planning?

- 2.1 Advance care planning is a voluntary process of discussion and shared planning for future health care between a person and health professionals. Advance care planning applies to a range of conditions and situations, including where:
- a patient plans for their medical care when they know they will have temporary incapacity (for example, if they undergo treatment or a procedure)
  - a patient's condition will, or is likely to, deteriorate and decisions about their care or treatment will need to be made for when they are not competent or their capacity fluctuates
  - plans are made for dealing with the later stages of a terminal condition.
- 2.2 The advance care planning process aims to help a person to think about what matters to them and how this might affect their health and their future care and treatment. Advance care planning may also provide a person with an opportunity to consider personal and other issues, such as preferences about place of death, identifying family or friends they might want to share personal information with, or addressing religious or spiritual needs.
- 2.3 Advance care planning is not about euthanasia or assisted dying, or resource allocation. While these controversial topics are often bundled together with advance care planning, there is a clear distinction between the planning process, on the one hand, and the options that patients do or ought to have on the other.
- 2.4 The role of the health professional in advance care planning is to guide a person to explore and, if they wish, document their wishes, values and preferences in an advance care plan. It may also involve working with them if they wish to make and document an advance directive about future treatment and care that would best meet their needs. A successful advance care planning process relies on health professionals maintaining a relationship with a person that is based on trust, honesty and respect.
- 2.5 NEAC supports people being offered the opportunity to take part in advance care planning. A person's decision to commence advance care planning discussions should be a voluntary one. Any decision by a person to decline to take part in advance care planning discussions, or any views expressed by a person during these discussions, should not adversely affect the care and/or treatment they receive.
- 2.6 The value of the advance care planning process can lie simply in its providing the opportunity for people to discuss, and reflect on, what matters to them. At times, the process of advance care planning discussions may result in:
- **an advance care plan**, which articulates a person's wishes, values and preferences relevant to their current and future health care, and, with the person's consent, is shared with their health care team and future health care providers, and/or

- **an advance directive**, a written or oral directive in which a person makes a choice about a possible future health procedure, and this choice is intended to be effective only when that person is no longer competent,<sup>1,2</sup> and/or
  - **appointing an enduring power of attorney**, where a person (when they are competent) appoints another person to act for them should they become mentally incompetent.<sup>3</sup>
- 2.7 An advance care plan, advance directive and enduring power of attorney are ways in which a person's specific preferences regarding their future health care and/or treatment can be documented.
- 2.8 Where an advance care plan is developed, this should be documented and, with the person's consent, shared with their health care team and made available to future health care providers.
- 2.9 There are differing views on and interpretations of when advance care planning should occur. Some consider that advance care planning should be undertaken by everyone, including healthy people, and be a regular part of everyday life. Others believe advance care planning is of value primarily for someone already in contact with the health system because they are more likely to have a sense of their wishes and options. This document focuses on advance care planning as it now exists: primarily offered in the context of oncology services, aged care, end-of-life care, and services for people with long-term health conditions.
- 2.10 Ideally, advance care plans will be freely drawn up by competent, well-informed people who make it clear what they want to happen in circumstances they correctly anticipate. Where this is the case, the plans should be followed by health professionals. However, not all plans will be or even could be so ideal. Much of this document is about how to facilitate advance care planning so that if a plan is made, it will be as close as possible to the ideal.

## Issues not covered in this document

- 2.11 The advance care planning process will include discussion of the treatment and care options available to a person, but this document does not discuss whether euthanasia or high-cost treatment options should be considered among those options.
- 2.12 Advance care planning requires that the person is competent to take part in the planning process. This document does not therefore consider advance care planning for people who lack this capacity, including young children or adults with a condition that affects their ability to make decisions (for example, acute severe psychiatric illness, or significant cognitive disorder such as advanced dementia).

<sup>1</sup> Clause 4 of the *Code of Health and Disability Services Consumers' Rights* (the Code).

<sup>2</sup> Right 7(5) of the Code gives every consumer the right to use an advance directive in accordance with common law.

<sup>3</sup> For further information about advance care plans, advance directives and enduring power of attorney, please refer to the Ministry of Health guidance for health professionals: [www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce](http://www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce)

### 3 Advance care planning in practice

- 3.1 Advance care planning can be beneficial. It has the potential to enable a person to obtain some control over their lives by providing a mechanism for their wishes, values and preferences to be understood and respected by health professionals. Advance care planning can help reduce uncertainty where health professionals make decisions on behalf of a person who lacks capacity. It may also help to reduce potential family conflict by prompting early, sensitive discussion between a person and their family members about illness, how best to manage their care, and death and dying.
- 3.2 However, advance care planning is not a panacea. It carries potential risks and tensions even when it is done well, and these can be exacerbated by an inadequate process. For instance, advance care planning must find a balance between documenting specific instructions that in unforeseen circumstances may not be what the person would have wanted, as well as non-specific expressions of wishes that must then be interpreted, not by the person, but by their family members and health professionals. Advance care planning can also be done badly. It is unclear whether an inadequate advance care planning process is better than no planning process at all, but a good process is clearly a desirable goal. Research on the impact of advance care planning on patient outcomes will inform this debate.

## 4 Challenges and solutions

4.1 Below we discuss four common ethical challenges in advance care planning and provide practical solutions to help prevent and resolve these challenges.

### Whether to interpret advance care plans to ‘the letter’ or in principle

4.2 The wording of an advance care plan should reflect the beliefs and values of the person. However, the wording of an advance care plan may not always accurately reflect that person’s views in a specific situation. This problem may arise even when planning is done conscientiously, but it can be exacerbated where:

- (a) the advance care planning process has been rushed or viewed as a ‘tick box’ exercise by the health professional
- (b) unexpected events in an otherwise predictable disease trajectory arise
- (c) health professionals do not have the necessary skills to help the person to clearly articulate their views
- (d) the person’s views have changed and there have been no opportunities to update the advance care plan.

4.3 In these situations, health professionals may have to decide whether to follow the exact wording of an advance care plan where this might conflict with what they think the person would have wanted.

### Practical solutions

- Allow sufficient time for the advance care planning process, and bear in mind that this may need to take place over several discussions rather than in one session.
- Facilitate a conversation to help people explore and express their own wishes, values and preferences. You should expect to have biases, but be aware of them and take care not to impose them.
- Advance care planning is a *process*. It involves ongoing discussions with a person and opportunities to regularly review and update their advance care plan, particularly where their circumstances change.
- It might be appropriate for an advance care plan to be non-specific so that the ‘spirit’ of the plan can be applied by health professionals to the immediate situation. Health professionals should consider using open wording in plans, such as ‘I would like the doctor to consider ...’.
- In other circumstances it might be appropriate for an advance care plan to outline a specific direction in relation to a specific situation.

### **Case example A**

Ms E is a 30-year-old woman. Her elderly father recently died from cancer following a period of prolonged medical intervention in hospital. She found this very distressing and felt strongly that she did not want this to happen to her if she was in a similar situation.

Ms E talked to her GP about developing an advance care plan that would make clear that she did not want to be subjected to invasive life-prolonging interventions if she was ever hospitalised with a life-threatening condition. Her GP, Dr L, was concerned how her statement might be read if she was admitted to hospital in the immediate future with a life-threatening condition. If she was expected to make a full recovery, the treating clinicians would need to interpret her plan. In other words, the treating clinicians would need to decide whether Ms E had intended them to follow the explicit 'letter' of the plan to withhold life-saving treatment, or the 'spirit' of her plan, which is not to be subjected to invasive procedures at the end of life that are unlikely to relieve pain and suffering, improve quality of life or significantly prolong life.

After speaking with Ms E about her experience with her father's death and her own views, they agreed to document in an advance care plan that Ms E would wish to avoid invasive procedures that are unlikely to lead to much improvement where she is at the end of life. Dr L talked to Ms E about reviewing her plan if her health status changes.

## **When to develop a plan: timing should enable autonomy**

- 4.4 The timing and context of advance care planning and the development of any subsequent advance care plan or advance directive can have a significant impact on its usefulness, both to a person and to health professionals.
- 4.5 A person may be legally competent to make their own decisions, but their judgement or ability to understand complex information may have been significantly compromised by events at the time an advance care plan was developed. Examples include where a frail older person is required at short notice to develop a plan before an aged care facility will accept them as a resident, or where a patient develops a plan at a time of acute stress, such as after being diagnosed with a serious illness.

## **Practical solutions**

- Health professionals should have the skills and ability to judge the appropriate time to approach someone about advance care planning. The capacity to develop a plan means not only determining whether a person has a legal capacity to consent, but also whether the time is right (for example, acknowledging when a person is upset or under a lot of stress).
- Repeat the offer to have an advance care planning discussion, as a person's willingness to engage in the process may change.

- Consider assessing the capacity of a person to take part in advance care planning discussions (for example, do they have a condition that might affect their capacity to make decisions?).
- Respect a competent person's view or decisions, even if their decisions appear irrational to others. Right 7(2) of the Code states that 'Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent'. Right 7(3) states that 'Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence'.
- Initiate advance care planning discussions with a person as early as possible, preferably before an acute medical situation, or once an acute medical situation has stabilised. This provides them with the opportunity to think about what medical care or treatment they might want without additional stress or pressure.
- Advance care plans should be regularly reviewed by the person and their health professional so that the plan can be adapted to reflect changing circumstances.
- If the person agrees, involve other members of the health care team and people who are close to them in advance care planning discussions.

### **Case example B**

Mrs D is a 60-year-old woman who lives with her husband. She has been feeling unwell and her GP refers her to an oncologist, Dr R. At her consultation with Dr R several weeks later, Mrs D is told that she has bowel cancer. Mrs D is extremely upset by the prognosis and is in shock. Her husband has not accompanied her to the appointment. Mrs D tells Dr R that she would like to make an advance care plan during the appointment to make it clear that she wants every medical treatment and intervention available so that she can live for as long as possible.

Dr R recognises that Mrs D's expressed wishes about wanting to live as long as possible is a perfectly normal and valid response but wants to make sure that any advance care plan Mrs D might wish to make as part of the advance care planning process is only documented once she has had time to consider the information that she needs and wants following her diagnosis.

Dr R listens to Mrs D and documents the views she expresses during the appointment. Dr R reassures her that she will be provided with all treatments and interventions that the health care team believe would be beneficial and explains that there will be many opportunities to discuss her views, concerns and fears. He suggests they continue the discussion at her next appointment and suggests she might wish to involve her husband, or another person close to her, in the process.

At her next appointment Dr R discusses with Mrs D what matters to her and how this might affect her care and treatment options. Mrs D decides that she would like to write an advance care plan, and Dr R is happy to help her do this. Dr R stresses the importance of regularly reviewing the plan and they agree to revisit her plan each month, or earlier if she wishes.

## Misunderstanding and ill-informed decisions

- 4.6 There is always the risk that people will misunderstand the purpose of an advance care plan or how it will be used in the future. Good communication by health professionals during the advance care planning process can help reduce this risk through effectively communicating the benefits and limits of advance care planning and engaging in an open discussion about future care and treatment.
- 4.7 Advance care planning also requires a person to be able to communicate well with their health professional. For some individuals this can be challenging (for example, if they have poor health literacy and cannot understand what is being asked of them during advance care planning discussions). Similarly, a learning or speech impairment can affect a person's ability to communicate well with their health professional. Language may also be a barrier.
- 4.8 Some believe that an advance decision they make about refusing treatment is a 'binding contract' that they cannot review or change, or that an advance care plan is designed to limit their treatment or care. Others might be fearful that if they agree not to receive one type of treatment they will be denied other life-saving treatment by doctors. This may result in someone requesting 'anything and everything' in their plan, some of which may not be clinically appropriate at the time.

## Practical solutions

- Make sure that as part of the advance care planning process people have the information they need and want in order to understand: the purpose of any advance care plan they develop, the process of developing and reviewing a plan, and how their plan would be used by health professionals to make future decisions about their care and treatment.
- Make sure that people have an opportunity to ask questions, and that these are answered honestly and fully.
- Do not pressure or coerce people into making or documenting advance care decisions if they do not want to. People living in residential care or those who are very ill or frail may be particularly vulnerable to being pressured into making an advance care plan. Some people might feel that simply discussing their views with a health professional is sufficient.
- Encourage people to involve their family members or others close to them in the advance care planning process, where appropriate. This may help family members to better understand the purpose of an advance care plan and how it will be used. It may also help them to better understand what the person wants.
- Health professionals who undertake advance care planning should have adequate training, including in good communication skills.
- Where people have a learning disability or communication difficulties but are able to make informed decisions, health professionals will need to carefully consider their approach to advance care planning. You should maximise the person's ability to participate as well as offering to include the person's support person in the discussions. You may need to break down the planning process into small steps,

possibly using visual cues and plain-language descriptions. Extra time may be required to explain issues properly, and information may need to be repeated a number of times before the person fully understands. You may also wish to check and confirm with the person that everyone involved in the process understands the discussions.

- Where language may be a barrier, you will need to consider whether an interpreter is needed. More importantly, you must be able to work with an interpreter effectively so that information and resources can be provided to patients and their families in their preferred language.
- If a person with a disability is accompanied by support staff (for example, a caregiver or family member), you still have a critical role in facilitating advance care planning, particularly in explaining their health care options and ensuring the person is able to make these decisions.

### **Case example C**

Mr F is 87 years old man with severe chronic obstructive pulmonary disease (COPD). He has worked with his GP, Dr B, to develop an advance care plan that states that he does not want medical interventions, such as antibiotics, to be administered to him when his COPD deteriorates further.

Three weeks later Mr F visits his GP practice with a persistent cough. Dr B is unavailable so he sees a different GP, Dr G, who prescribes him with a course of antibiotics for his bronchitis. Dr G is alerted to the existence of Mr F's advance care plan through his medical record and after reading the plan thinks it would be prudent to clarify for Mr F that his plan does not in any way stop him from taking the antibiotics to treat his bronchitis. He does not want Mr F to feel unsure about whether he should take the antibiotics in case he feels that he would be violating some kind of 'agreement' with Dr B.

Mr F tells Dr G that he is comfortable that he is in no way restricted by his advance care plan. Dr G suggests that Mr F talk to Dr B if he has any further questions or wants to review his plan and records their discussion in Mr F's medical record.

### Case example D

Miss P is 48 years old and has a learning disability. She is able to make simple decisions, and with the use of picture cards she understands that she is unwell and needs medical intervention to help her. She has been receiving treatment for continuous stomach pain that has recently been diagnosed as life limiting. Miss P attended all appointments accompanied by her elderly parents, who have no legal orders in place to make decisions on her behalf.

Her GP, Dr S, suggests they consider advance care planning for Miss P, and that others who may be significant to Miss P also participate in this process.

After a number of discussions with Miss P, her family and friends, an advance care plan is written in plain English documenting Miss P's wishes and preferences. Dr S assures Miss P and her family that the plan can be revisited at any time for changes.

## Different models of decision-making

- 4.9 New Zealand's culturally diverse population suggests that a single model for advance care planning may not always be appropriate. It is important to recognise and respect different cultural practices and attitudes towards advance care planning. For example, some cultures value collective decision-making that involves family and whānau, while other cultures value individual rights and autonomy. Others believe that it is not appropriate to discuss illness or death and may be reluctant to talk about their future health care needs as part of advance care planning.

### Practical solutions

- Everyone should have the opportunity to take part in advance care planning, but health professionals must respect the wishes of those who do not wish to engage in such discussions.
- Approach advance care planning discussions sensitively. If you are unsure how best to do this, or how to respond to any non-clinical issues raised by the person, you should refer to relevant information and advice on advance care planning.
- Health professionals should ask the person about how they think the health care team can best meet their cultural beliefs, practices and values. This may help to avoid making assumptions about any particular group or groups of people.
- If a person agrees, involve family, whānau and others close to them in advance care planning discussions and in decision-making about future care and treatment. But remember that no one can make an advance directive on behalf of another person.
- Health professionals who undertake advance care planning should also take part in cultural competency training, where practicable.

### **Case example E**

Mr N is a 68-year-old man with early-stage Parkinson's disease. Mr N's local iwi nurse, Nurse W, would like to provide Mr N with an opportunity to talk about advance care planning before his condition deteriorates, particularly given the risk of developing dementia as his Parkinson's progresses.

Mr N responded positively to Nurse W's offer to talk about advance care planning with him and he wants to involve his whānau in the discussions. Mr N would like to talk to his whānau about the options for his future care and to come to an agreement with them about the best arrangement. Nurse W suggests that Mr N invite to his next appointment those whānau members that he would like involved in his advance care planning discussion.

At his next appointment with Nurse W, Mr N brings along his wife and son, as well as two other members of his wider whānau. Mr N's whānau are able to hear from Mr N that he would prefer to be cared for in a private residential facility when he is unable to look after himself, to minimise the burden that he perceives his illness puts on his whānau. They talk at some length about whether this arrangement would best meet the needs of Mr N and his whānau. Mr N decides that, beyond his preferences being documented in his medical notes, he does not feel that it is necessary to write an advance care plan and is comfortable that those close to him and his GP understand how he wishes to be looked after as his Parkinson's disease progresses.

### **Case example F**

Mrs C is an 85-year-old woman with type two diabetes. Mrs C is a recent immigrant, but her adult children have lived in New Zealand for over 20 years. Mrs C is always accompanied by one of her children at her regular check-ups with her GP, Dr H. Her children help Mrs C with any language difficulties over medical terms and appear to have an active role in helping their mother make health care decisions.

Dr H recognises that Mrs C holds traditional cultural views towards her health. Dr H is unsure how Mrs C and her family will respond to the suggestion of advance care planning. However, Dr H believes it is important that Mrs C is given the opportunity to discuss and consider the process of advance care planning rather than to assume that this is not something Mrs C would wish to pursue.

When Dr H suggests advance care planning at Mrs C's next appointment, Mrs C and her children decline to take part. Dr H respectfully accepts this decision, but explains that they can revisit advance care planning at any time in the future.

## 5 Other sources of information and advice

*Advance Care Planning: A guide for the New Zealand health care workforce*

Ministry of Health (August 2011)

[www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce](http://www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce)

*Advance Directives in Mental Health Care and Treatment*

Office of the Health and Disability Commissioner

[www.hdc.org.nz/media/30071/brochure-%20advance%20directives.pdf](http://www.hdc.org.nz/media/30071/brochure-%20advance%20directives.pdf)

*Advance Directives, Living Wills and Questions about Competence*

Office of the Health and Disability Commissioner

[www.hdc.org.nz/education/presentations/advance-directives,-living-wills-and-questions-of-competence](http://www.hdc.org.nz/education/presentations/advance-directives,-living-wills-and-questions-of-competence)

Our Voice: Tō Tātou Reo

Advance Care Planning website

[www.advancecareplanning.org.nz/](http://www.advancecareplanning.org.nz/)

# Appendix: Practical challenges in advance care planning

Some of the main practical challenges raised by participants of NEAC's preliminary consultation are summarised below. NEAC will share this feedback with groups and organisations that might be able to further investigate and address these concerns.

## Legal framework

Participants reported that there was a lack of clarity about the law as it relates to advance care plans, advance directives and enduring power of attorney. This may indicate problems or gaps in the law, such as a lack of clarity about the extent to which an enduring power of attorney is required to take into account any advance directive given by the person they represent, or whether a written advance care plan would constitute an advance directive for legal purposes. Others have noted the lack of case law testing the actions of a health professional when they make a decision in the face of an advance directive on behalf of a person who lacks capacity.

Health professionals have varying levels of knowledge and understanding of these legal issues, including what it means in practice. For example, there is anecdotal evidence that some health professionals do not understand the difference between an advance care plan, an advance directive and enduring power of attorney; others believe an advance directive must be written and signed by a person in order to be valid. Others have raised the need for greater clarity at the interface, and for definitions that distinguish between advance care planning, advance directives and enduring power of attorney.

## Accessibility and information technology

Participants reported problems with the accessibility of advance care plans by different health professionals and between different health care settings, such as between primary care, aged care facilities, ambulance services and emergency departments. Where a treating doctor has no knowledge of, or is unable to access, an advance care plan, there is a risk that a patient's preferences and wishes for medical treatment will not be met. It can also result in family members having to repeatedly inform health professionals about the person's previously expressed wishes.

Several participants advocated for a centralised electronic system to securely store advance care plans that can be accessed and updated following discussions with, and with the consent of, individuals. Participants provided some examples of good practice where alerts have been set up across different electronic systems to prompt health professionals to access an advance care plan where one is available.

## Funding

Participants expressed concern about the lack of centralised funding for advance care planning activity in New Zealand, particularly in primary care settings. GPs might be reluctant to initiate discussions about advance care planning with patients because this often time-consuming process is not recognised within the current funding model.

## Health professional training

Participants emphasised the need for health professionals involved in advance care planning to take part in appropriate training, particularly communication skills training. Health professionals without the necessary communication skills may be uncomfortable or reluctant to initiate or facilitate conversations about advance care planning, or it may result in a poor advance care planning process for the person. NEAC acknowledges that communication skills training is a significant component of the National Advance Care Planning Cooperative's level 2 training programme.