

Ethical challenges in advance care planning

Draft for consultation

November 2013

1. Introduction

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.

This consultation draft 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.

The advice in this consultation draft is primarily aimed at health professionals. It may also be helpful to members of the public. This advice has been developed following feedback from a range of health professionals about their experiences of the ethical challenges in advance care planning. We are grateful to everyone who has contributed to this project to date.

Other *practical challenges* in advance care planning identified by health professionals are summarised in the appendix. NEAC intends to share this information with groups and organisations that might be able to further investigate these concerns.

2. What is advance care planning?

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 when they are not competent or their capacity fluctuates
- plans are made for dealing with the later stages of a terminal condition.

The advance care planning process aims to assist a person to think about what matters to them and how this might impact on 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.

The role of the health professional in advance care planning is to guide a person to explore and, if they wish, to document their beliefs and values 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.

NEAC supports people being offered the opportunity to take part in advance care planning and a person's decision to commence advance care planning discussions is a voluntary one. Any decision by a person to decline to take part in advance care planning discussions, or any views, values or preferences expressed by a person during these discussions, should not adversely affect the care and/or treatment they receive.

The process of discussion may result in an advance care plan and/or an advance directive for their future health care and/or a decision to appoint an enduring power of attorney.¹ Right 7(5) of the Code of Health and Disability Services Consumers' Rights (the Code) states that 'Every consumer may use an advance directive in accordance with the common law'. However, people might simply find that the value of the advance care planning process lies in the opportunity to discuss, and reflect on, what matters to them. Where an advance care plan and/or advance directive is developed this should be documented and, with the person's consent, shared with the health care team and made available to future health care providers.

There are different views 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 is, primarily being offered in the context of oncology services, aged care and services for people with long term health conditions.

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, this will be as close as possible to the ideal.

Issues not covered in this document

This document does not consider 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. 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.

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 capacity, including young children or adults with a condition that affects their ability to make decisions, for example acute psychiatric illness, or significant cognitive disorder such as advanced dementia.

3. Advance care planning in practice

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 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.

¹ For further information about advance care plans, advance directives and enduring power of attorney, please refer to the Ministry of Health guidelines for health professionals

www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce

However, advance care planning is not a panacea. Advance care planning carries potential risks and tensions even when it is done well and these can be particularly 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 and 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, moreover, can be done badly. While we do not know whether an inadequate advance care planning process is better than no planning process at all, a good process is clearly a desirable goal. Further research about the impact of advance care planning on patient outcomes will be important to inform this debate.

4. Challenges and solutions

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

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

The wording of an advance care plan should best reflect the beliefs and values of a person. However, the wording of an advance care plan may not always accurately reflect that person’s views. This problem may arise even when planning is done conscientiously since the future is not certain. But it can be exacerbated where the advance care planning process has been rushed or viewed as a ‘tick box’ exercise by the health professional, where health professionals do not have the necessary skills to help the person to clearly articulate their views or the person’s values have changed and there have been no opportunities to update the advance care plan. 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

- Health professionals should allow sufficient time for the advance care planning process.
- The health professional should facilitate a conversation to help people explore and express their own beliefs and values.
- Advance care planning is a *process*. It involves on-going 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 the ‘spirit’ of the plan can be applied by health professionals to the immediate situation. Consider using open wording in plans such as “I would like the doctor to consider...”. In other circumstances, it may be appropriate for an advance care plan to outline a specific direction in relation to a specific situation.

Case example:

Ms X 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 X 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 is ever hospitalised with a life threatening condition. Her GP, Dr Y, was concerned that such a statement might mean that if she were to be admitted to hospital in the immediate future with a life threatening condition but was expected to make a full recovery, the treating clinicians would need to interpret whether Ms X 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 lead to much improvement.

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

When to develop a plan: timing should enable autonomy

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 health professionals. A person may be legally competent to make their own decisions but their judgment or ability to understand complex information might have been significantly compromised by events at the time an advance care plan was developed. Examples might include, where an 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, for example, after being diagnosed with a serious illness.

Practical solutions

- Health professionals should have the skills and ability to judge when is an appropriate time to approach someone about advance care planning. Capacity to develop a plan needs to be construed in a broad manner, not only in the limited context of whether they have legal capacity to consent.
- Consider assessing the capacity of a person to take part in advance care planning discussions, for example where 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 and preferably before an acute medical situation. This provides them with the opportunity to think about what medical care or treatment they might want without additional stress or pressure.
- Advanced 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:

Mrs X 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 Y.

At her consultation with Dr Y several weeks later, Mrs X is told that she has bowel cancer. Mrs X is extremely upset by the prognosis and is in shock. Her husband has not accompanied her to the appointment. Mrs X tells Dr Y that she would like to make an advance directive during the appointment to make it clear that she wants every medical treatment and intervention available to be administered so that she can live for as long as possible.

Dr Y recognises that Mrs X's expression about wanting to live as long as possible is a perfectly normal and valid response but wants to make sure that any advance directive Mrs X might wish to make is developed once she has had time to consider the information that she needs and wants following her diagnosis. Dr Y listens to Mrs X and documents the views she expresses during the appointment. He 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 that they continue this discussion at her next appointment and also suggests that she might wish to involve her husband, or any other person close to her, in the process.

At her next appointment, Dr Y discusses with Mrs X what matters to her and how this might impact on her care and treatment options. Mrs X decides that she would like to write an advance directive and Dr Y is happy to help her do this. Dr Y 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

Poor communication by health professionals during the advance care planning process may mean that people do not understand the purpose of an advance care plan or how it will be used in the future. For example, a person may believe that an advance decision they make about refusing treatment is a 'binding contract' that they cannot review or change, or a person (or their family members) may be led to believe that an advance care plan is designed to limit their treatment or care, for example where health professionals do not properly explain why a potentially harmful treatment, such as attempted cardiopulmonary resuscitation (CPR), might not be offered to a frail elderly person.

Others might make ill-informed decisions in an advance care plan about future medical treatment because they are fearful that if they agree not to receive one type of treatment they will be denied other lifesaving 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 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 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.

Case example:

Mr X is an 87 year old man with severe chronic obstructive pulmonary disease (COPD). Mr X has worked with his GP Dr Y to develop an advance care plan in which it 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 X visits his GP practice with a persistent cough. Dr Y is unavailable so he sees a different GP, Dr Z, who prescribes him with a course of antibiotics for his bronchitis. Dr Z is alerted to the existence of Mr X's advance care plan through his medical record and after reading the plan thinks it would be prudent to clarify for Mr X that his plan does not in any way stop him from taking the antibiotics to treat his bronchitis. He does not want Mr X 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 Y.

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

Different models of decision-making

Advance care planning supports and promotes the concept of patient autonomy and a patient-centred decision-making model. However New Zealand's culturally diverse population suggests that a single model for advance care planning may not always be appropriate. For example, some cultures value collective decision-making that involves family and whānau. Others believe that it is taboo 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 that do not wish to engage in such discussions.
- Approach advance care planning discussions sensitively. If a health professional is unsure how best to do this or how to respond to any non-clinical issues raised by the consumer, they should refer to relevant guidelines on good practice in advance care planning.
- Health professionals should consider asking a 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 take part in cultural competency training where practicable.

Case example:

Mr X is a 68 year old man with three adult children. He has early stage Parkinson's disease. Mr X's GP, Dr Y, would like to provide Mr X 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 X responded positively to Dr Y's offer to talk about advance care planning with him and he wants to involve his family in the discussions. Mr X would like to talk to his family about the options for his future care and to come to an agreement with the family about the best arrangement. Dr Y suggests that Mr X invite to his next appointment the family members that he would like involved in his advance care planning discussion.

Mr X's wife and son attend his next appointment with Dr Y. Mr X's family members are able to hear from Mr X 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 family. They talk at some length about whether this arrangement would best meet the needs of Mr X and his family. Mr X 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.

Other sources of information and advice

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

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

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

Our voice: tō tātou reo

Advance Care Planning website

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 intends to 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 on behalf of a person who lacks capacity in the face of an advance directive.

On the other hand, this may suggest a misunderstanding or uncertainty by health professionals about how the law applies. For example, there is anecdotal evidence that some health professionals do not understand the difference between an advance care plan, advance directives and enduring power of attorney; or that they wrongly believe an advance directive must be written and signed by a person in order to be valid.

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, the person. 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 and in particular in primary care settings. GPs might be reluctant to initiate discussions about advance care planning with patients as 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 with patients, 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.