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advance care planning

Te whakamahere tiaki i mua i te wā taumaha
Advance care planning

One day workshop

Strengthening our understanding of advance care planning, having and documenting conversations

Health Quality & Safety Commission New Zealand

V5 March 2022

1

Kua tawhiti kē tō haerenga mai, kia kore e haere tonu. He tino nui rawa o ōu mahi, kia kore e mahi nui tonu.

You have come too far, not to go further. You have done too much, not to do more.

Tā Himi Hēnare (1911-1991)
(Sir James Hēnare)

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3

Introductions - mihimihi

Your pepeha (if you wish)

Your name

Your professional role and/or something about yourself

Expectations for the day

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Outline of the morning

- What do we know so far?
- Sharing experiences of advance care planning
- Clarifying legal framework
- Case discussions
- Strategies for approaching advance care planning conversations using DVD material

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Outline of the afternoon

- Structuring advance care planning conversations
- Practicing and documenting advance care planning conversations
- Advance care planning in practice
- What is happening locally

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Working Agreement

What do you need to ensure your own personal safety?

What do you think you need to do to support others?

What do we all have to do to ensure we can benefit in the training?

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What do we know about advance care planning?

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What is advance care planning

Advance care planning is a process of discussion & shared planning for future health care. It **involves an individual, whānau & health care professionals.**

Advance care planning gives people the opportunity to develop & express **their** preferences for future care based on:

- their values, beliefs, concerns, hopes & goals
- a better understanding of their current & likely future health
- the treatment & care options available.

(ACP Cooperative 2013)

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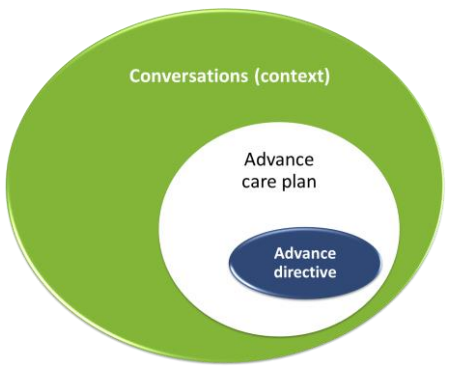
9



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Considering your own advance care plan

- How did you find it?
- Were you able to share your preferences? Discuss with family?
- How might this experience affect how you approach ACP with your patients (if at all)?

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Your workplace advance care planning experiences

- What have been your advance care planning experiences in the workplace?
- What have you found to be effective?
- What have you found challenging?

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12

Cultural safety

- What does cultural safety mean to you?
- What gets in the way?
- What might be some of the solutions?

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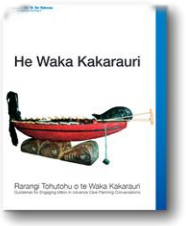
13

Cultural safety – engaging with Māori



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14

Keri Kaa's story

- ADD VIDEO

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15

Legal framework

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Legal standing of advance care planning

- The Code of Health and Disability Consumers' Rights (the Code) promotes consumer choice and autonomy in planning and receiving health care.
- Advance care planning is consistent with this approach and facilitates clinical decision making and the provision of health care services that respect the rights and preferences of individuals.
- The Code has legal status as a regulation made under the Health and Disability Commissioner Act.

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Developing an advance directive

An advance directive is **consent or refusal** to **specific** treatment(s) which **may or may not** be offered in the future when the person no longer has capacity.

Legally binding if valid

Three criteria must be met for it to be valid:

- Informed
- Competent
- Voluntary

Cannot be created on behalf of another person

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18

Using an advance directive

- The clinician must determine if the directive is valid:
  - When created, the person was
    - Informed
    - Competent
    - Free of undue influence
- Person must have intended the advance directive to apply in the current circumstances
- An advance directive does NOT need to be in writing

In the absence of reasonable grounds to doubt validity, it should be honoured

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19

Patient presents unwell …

- Clinician considers: "what treatment would be appropriate to offer this person?"
  E.g. antibiotics
- Is the person competent to consent or refuse?
  – *Yes => person consents or refuses treatment*

– *No => Look for valid advance directive*

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20

Decision-making cascade

Valid advance directive

EPoA – cannot withhold standard life-sustaining treatment

Medical decision-making

Ascertainable preferences – apply patient preference

Best interests - other suitable people

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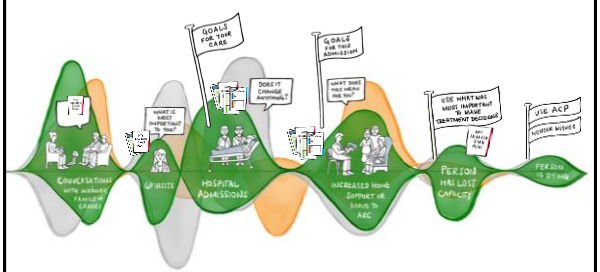
21

Advance care planning is a process



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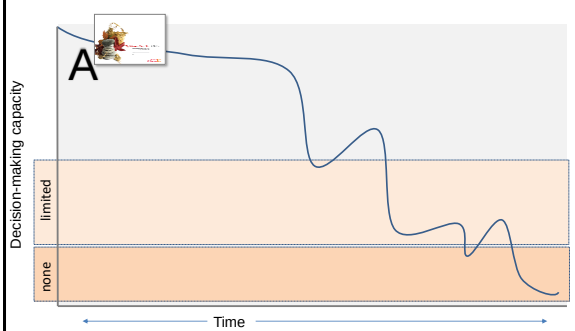
22

Using advance care plans



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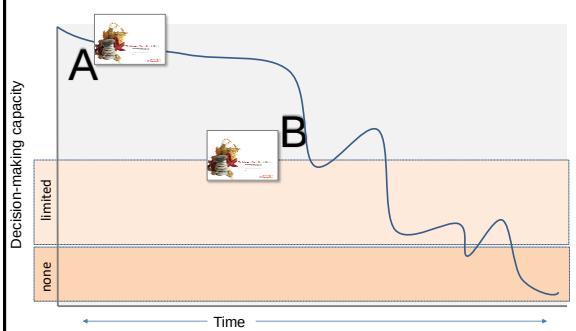
23

Using advance care plans



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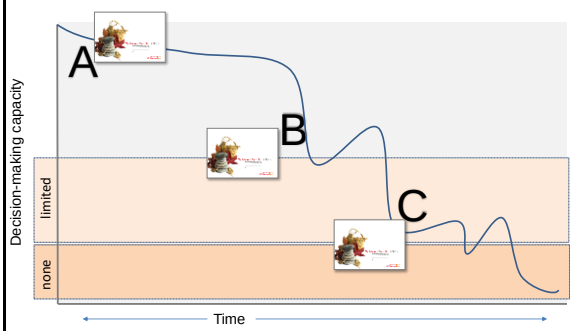
24

Using advance care plans



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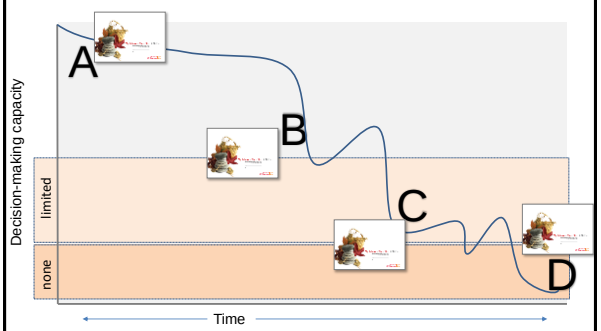
25

Using advance care plans



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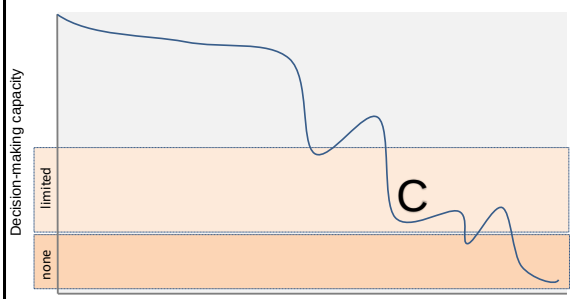
26

Using advance care plans



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Morning Tea

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28

Group activity – case studies

Purpose – to have you think about advance care planning application within the legal, ethical & cultural framework.

Law vs Lore

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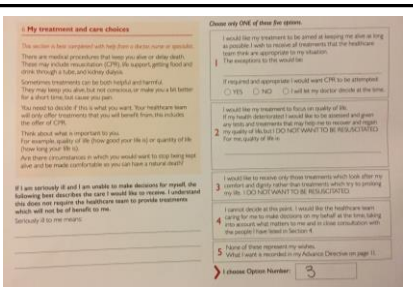
29



In the following circumstances:	I would like my care to focus on:	I would accept the following treatments:	I would wish to refuse or stop the following treatments:
Cardiac arrest	*Active resuscitation if full recovery likely*	*CPR*	*Resuscitation if brain damage is likely*
Stoke or brain injury			*Not for active resuscitation*

30

Communication skills brainstorm

- What communication behaviours are helpful when initiating an advance care planning conversation?
- What skills can we use to support the person to share what's important to them?
- What might be particularly relevant to Māori?

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31

Having an advance care planning conversation

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32

LUNCH

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33

Structuring an ACP conversation

- Introduction
- Talking about advance care planning
  - Gather information
    - Assess understanding of current and likely future health
    - Explore what's important
  - Information and planning
- Close

Acknowledge

Empathise

Follow cues

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34

Structuring an ACP conversation

- Introduction
  Mihi and whakawhānaungatanga
- Kaupapa – getting down to the work of the conversation
  - Gather information
    - Assess understanding of current and likely future health
    - Explore what's important
  - Information and planning
- Poroporoaki and close

Acknowledge

Empathise

Follow cues

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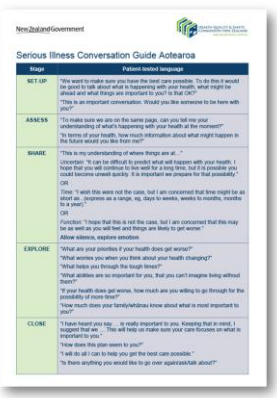
35



Serious Illness Conversation Guide Aotearoa

Stage	Patient-tested language
SET-UP	"We want to make sure you have the best care possible. To do this it would be good to talk about what is happening with your health, what might be ahead and what things are important to you? Is that OK?" "This is an important conversation. Would you like someone to be here with you?"
ASSESS	"To make sure we are on the same page, can you tell me your understanding of what's happening with your health at the moment?" "In terms of your health, how much information about what might happen in the future would you like from me?"
SHARE	"This is my understanding of where things are at…" Uncertain: "It can be difficult to predict what will happen with your health. I hope that you will continue to live well for a long time, but it is possible you could become unwell quickly. It is important we prepare for that possibility." OR Time: "I wish this were not the case, but I am concerned that time might be as short as…(express as a range, eg, days to weeks, weeks to months, months to a year)." OR Function: "I hope that this is not the case, but I am concerned that this may be as well as you will feel and things are likely to get worse." Allow silence, explore emotion
EXPLORE	"What are your priorities if your health does get worse?" "What worries you when you think about your health changing?" "What helps you through the tough times?" "What abilities are so important for you, that you can't imagine living without them?" "If your health does get worse, how much are you willing to go through for the possibility of more time?" "How much does your family/whānau know about what is most important to you?"
CLOSE	"I have heard you say … is really important to you. Keeping that in mind, I suggest that we … This will help us make sure your care focuses on what is important to you." "How does this plan seem to you?" "I will do all I can to help you get the best care possible." "Is there anything you would like to go over again/ask/talk about?"

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36

Conversation practice

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37

Conversation practice

In pairs:
- Choose role – consumer/clinician
- Read the first case
- Agree a name for consumer
- Have conversation (10 minutes)

- Change role - read the other case - REPEAT process

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38

Documentation

- What is the purpose of documenting?
  - Legal requirement
  - Conversation can be appropriately continued
  - Everyone knows what was agreed as next steps
  - Information that was shared can be used
- How might we capture the information?
  - Progress notes / daily record
  - Advance care planning notes page
  - Advance care plan
  - Shared goals of care form
  - Discharge / referral letter

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39

Documentation practice

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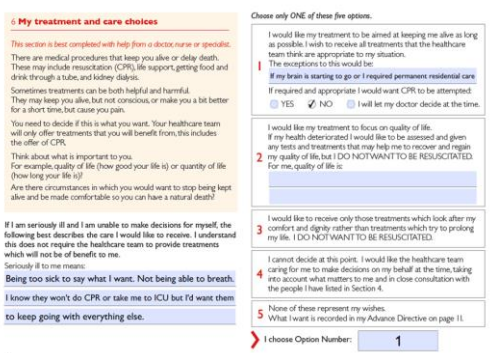
40



6 **My treatment and care choices**

This section is best completed with help from a doctor, nurse or specialist.

There are medical procedures that keep you alive or delay death. These may include resuscitation (CPR), life support, getting food and drink through a tube, and kidney dialysis.

Sometimes treatments can be both helpful and harmful. They may keep you alive, but not conscious, or make you a bit better for a short time, but cause you pain.

You need to decide if this is what you want. Your healthcare team will only offer treatments that you will benefit from, this includes the offer of CPR.

Think about what is important to you. For example, quality of life (how good your life is) or quantity of life (how long your life is)?

Are there circumstances in which you would want to stop being kept alive and be made comfortable so you can have a natural death?

If I am seriously ill and I am unable to make decisions for myself, the following best describes the care I would like to receive. I understand this does not require the healthcare team to provide treatments which will not be of benefit to me.

Seriously ill to me means:

Being too sick to say what I want. Not being able to breath.

I know they won't do CPR or take me to ICU but I'd want them

to keep going with everything else.

Choose only ONE of these five options.

1 I would like my treatment to be aimed at keeping me alive as long as possible. I wish to receive all treatments that the healthcare team think are appropriate to my situation. The exceptions to this would be:
If my brain is starting to go or I required permanent residential care
If required and appropriate I would want CPR to be attempted:
YES ✓ NO I will let my doctor decide at the time.

2 I would like my treatment to focus on quality of life. If my health deteriorated I would like to be assessed and given any tests and treatments that may help me to recover and regain my quality of life, but I DO NOT WANT TO BE RESUSCITATED. For me, quality of life is:

3 I would like to receive only those treatments which look after my comfort and dignity rather than treatments which try to prolong my life. I DO NOT WANT TO BE RESUSCITATED.

4 I cannot decide at this point. I would like the healthcare team caring for me to make decisions on my behalf at the time, taking into account what matters to me and in close consultation with the people I have listed in Section 4.

5 None of these represent my wishes. What I want is recorded in my Advance Directive on page 11.

I choose Option Number: 1

10

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41

In the following circumstances	I would like my care to focus on	I would accept the following treatments	I would wish to refuse or stop the following treatments
If I have lost capacity and can no longer recognize my family	To allow a natural death	Comfort measures	Any life-prolonging interventions
If I required permanent care in a residential aged care facility	To allow a natural death	Comfort measures	Any life-prolonging interventions
In all other circumstances	Prolonging my life	All life prolonging interventions available to me. This includes antibiotics and BIPAP	-

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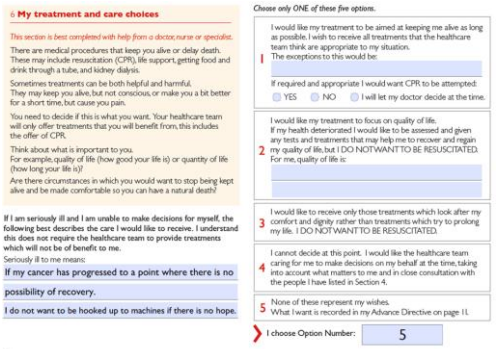
42

Documentation practice

In pairs:

- Read the narrative that has been given to you
- Discuss and write down how you might document "what serious illness means to them" and which option to choose (1 – 5)
- Discuss and write down how you might document advance directives based on the narrative
- Repeat for the second narrative

43



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Sometimes treatments can be both helpful and harmful. They may keep you alive, but not conscious, or make you a bit better for a short time, but cause you pain.

You need to decide if this is what you want. Your healthcare team will only offer treatments that you will benefit from, this includes the offer of CPR.

Think about what is important to you. For example, quality of life (how good your life is) or quantity of life (how long your life is)?

Are there circumstances in which you would want to stop being kept alive and be made comfortable so you can have a natural death?

If I am seriously ill and I am unable to make decisions for myself, the following best describes the care I would like to receive. I understand this does not require the healthcare team to provide treatments which will not be of benefit to me.

Seriously ill to me means:

If my cancer has progressed to a point where there is no possibility of recovery.

I do not want to be hooked up to machines if there is no hope.

Choose only ONE of these five options.

1 I would like my treatment to be aimed at keeping me alive as long as possible. I wish to receive all treatments that the healthcare team think are appropriate to my situation.
The exceptions to this would be:

If required and appropriate I would want CPR to be attempted:
YES NO I will let my doctor decide at the time.

2 I would like my treatment to focus on quality of life.
If my health deteriorated I would like to be assessed and given any tests and treatments that may help me to recover and regain my quality of life, but I DO NOT WANT TO BE RESUSCITATED.
For me, quality of life is:

3 I would like to receive only those treatments which look after my comfort and dignity rather than treatments which try to prolong my life. I DO NOT WANT TO BE RESUSCITATED.

4 I cannot decide at this point. I would like the healthcare team caring for me to make decisions on my behalf at the time, taking into account what matters to me and in close consultation with the people I have listed in Section 4.

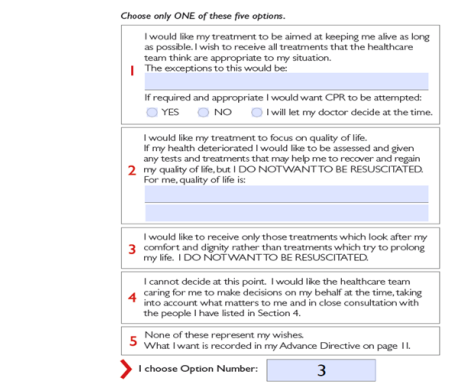
5 None of these represent my wishes.
What I want is recorded in my Advance Directive on page 11.

I choose Option Number: 5

44

In the following circumstances	I would like my care to focus on	I would accept the following treatments	I would wish to refuse or stop the following treatments
An accident or sudden acute event when I am still managing independently at home	Recovery to my current level of function i.e. living at home independently	Whatever interventions the medical team feel are appropriate given my other underlying health conditions	Nil
Progression of my cancer	To allow a natural death	Comfort measures	Any interventions or treatments aimed at prolonging my life including CPR

45



Choose only ONE of these five options.

1 I would like my treatment to be aimed at keeping me alive as long as possible. I wish to receive all treatments that the healthcare team think are appropriate to my situation.
The exceptions to this would be:

If required and appropriate I would want CPR to be attempted:
YES NO I will let my doctor decide at the time.

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4 I cannot decide at this point. I would like the healthcare team caring for me to make decisions on my behalf at the time, taking into account what matters to me and in close consultation with the people I have listed in Section 4.

5 None of these represent my wishes.
What I want is recorded in my Advance Directive on page 11.

I choose Option Number: 3

46

In the following circumstances	I would like my care to focus on	I would accept the following treatments	I would wish to refuse or stop the following treatments
All circumstances	Allowing me to die naturally and with dignity.	Comfort measures	Any life-prolonging interventions. Please no fuss, no tubes, no poking or prodding
All circumstances	I would prefer not to be admitted to hospital.	-	-
Dysphagia/ swallowing difficulties	-	-	Feeding tube

47

Putting it all together

- Becoming advance care planning ambassadors
- Incorporating advance care planning into our everyday practice
- Promoting advance care planning as 'business as usual' in our workplaces
- Ensuring we are effectively engaging Maori with advance care planning

48

Karakia whakamutunga (closing karakia)

Kia whakairia te tapu
Kia wātea ai te ara
Kia turuki whakataha ai
Kia turuki whakataha ai
Haumī e! Hui e! Tāiki e!

Restrictions are moved aside
So the pathway is clear
To return to everyday activities

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49