

Te whakamahere tiaki i mua i te wā taumaha

Advance care planning

Workshop facilitation manual for DHB trainers

delivering the L1A one-day workshops

**Version 4.0 April 2021**

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# Introduction to the manual

Welcome to the Workshop Facilitation Manual for DHB trainers to deliver the advance care planning one-day workshop. It is based on the L1A Facilitator Manual developed in 2017 by the national training team. This workshop forms part of the advance care planning training programme suite of training resources.

This manual does not attempt to cover the details about what advance care planning is – this information can be found in the Advance Care Planning Training Manual and in the advance care planning level one eLearning modules.

## Aim of the one-day workshop

There will be a wider understanding and implementation of advance care planning concepts & practice in the healthcare workforce.

## Objectives

To increase advance care planning activity across New Zealand.

## Learning outcomes for the L1A advance care planning workshops

Participants that attend the L1A advance care planning workshops will have:

* an in-depth understanding of advance care planning
* an in-depth understanding of the legal framework and how to use it
* the ability to take part in uncomplicated advance care planning conversations
* the ability to capture a consumer’s voice through conversations and documentation
* strengthened their knowledge of tikanga and mātauranga Māori (Maori knowledge).

## Additional information

Workshop trainers need to be familiar with the following documents and resources:

* The four advance care planning eLearning modules
* Video: Legal framework for medical decision-making
* Video: Overview of advance care planning in Aotearoa New Zealand
* Advance care planning: A Guide for the New Zealand Healthcare Workforce (Ministry of Health, 2011)
* Ethical Challenges in Advance Care Planning (National Ethics Advisory Committee, 2014)
* Advance Care Planning Training Manual 2021
* Advance Care Planning Communication Skills Manual
* The Hui Process: a framework to enhance the clinician-consumer relationship with Māori
* The three [learning and education modules on understanding bias in health care](https://www.hqsc.govt.nz/our-programmes/patient-safety-day/publications-and-resources/publication/3866/) modules.

Teaching should be in line with these resources.

# Te Tiriti o Waitangi and advance care planning

Te Tiriti o Waitangi is regarded as one of the founding documents of government, in Aotearoa New Zealand. “Te Tiriti forms the foundation for government on the basis of protections and acknowledgement of Māori rights and interests within the context of a shared citizenry” (Cabinet Office, 2019).

The advance care planning programme is committed to embedding and enacting Te Tiriti o Waitangi by working with Māori to ensure that the advance care planning initiatives are tailored for, and relate with, Māori communities.

As part of our Tiriti commitment the advance care planning program actively:

* partners with Māori worldview leaders, experts and whānau Māori to develop solutions based on mana motuhake (Māori self-determination)
* uses information that includes Māori worldview priorities, experiences, and solutions
* makes mātauranga Māori (Māori knowledge) central in our efforts to influence change
* encourages the sector to develop active Te Tiriti partnerships with tangata whenua (the indigenous people) so that improvement benefits Māori and help to achieve health equity.

Please refer to Chapter 3 of the advance care planning Training Manual for more background information about the principles of Te Tiriti.

# Health equity and advance care planning

Health equity is a national priority. Disparities in health status occur between different groups within our population, such as age, gender, socioeconomic position, geographical region, and ethnicity. In Aotearoa New Zealand, ethnic inequalities between Māori and non-Māori New Zealanders are the most persistent and pervasive inequities in health.   
  
As health professionals, it is important that our practice aims to reduce and dismantle health inequities, and role model best practice.

Tools and resources to promote equitable access and participation to advance care planning for Māori can be found in Chapter 3 and 5 of the Advance Care Planning Training Manual 2021.

# Ngā kupu Māori

Te reo Māori is one of Aotearoa New Zealand’s three national languages and is widely used within healthcare. The use of te reo Māori is recognised as an important cultural competency in healthcare and is a significant contributor to the clinician-consumer relationship as it shows consideration of cultural difference and inclusion of matāuranga Māori.

The following are kupu Māori used in this document:

|  |  |
| --- | --- |
| **Hui** | meeting |
| **Karakia** | prayer or invocations |
| **Karakia mō te kai** | prayer before food |
| **Karakia timatanga** | opening prayer |
| **Karakia whakamutunga** | closing prayer |
| **Kaupapa** | the business at hand |
| **Kia kaha** | translates as – be strong, stand strong |
| **Kōrero** | To speak or have a discussion |
| **Kupu Māori** | Māori word |
| **Mana** | this is a concept with many shades of meaning including prestige, authority, control, power and influence |
| **Mana motuhake** | the ability of Māori to determine things according to their values and what they think is important. Māori self-determination |
| **Mātauranga Māori** | Māori knowledge |
| **Mihimihi** | Mihimihi are usually held at the beginning of a hui in the form of introductions. The format of a mihimihi includes a welcome (mihi), recitation of your genealogy (pepeha) or where you come from, and who you are in relation to this (whānaungatanga) |
| **Pepeha** | a genealogical statement as Maori, descending from ancesters |
| **Pōwhiri** | rituals of encounter, or welcome ceremony |
| **Tā** | this a translation of the knighthood title – Sir |
| **Tangata whenua** | the indigenous people of Aotearoa New Zealand |
| **Tautoko** | To provide support, sustain, encourage. To provide advocacy. |
| **Te ao Māori** | the Māori worldview; acknowledges the interconnectedness and interrelationship of all living and non-living things. It strongly influences every aspect of the culture and contributes to the Māori holistic view of the world |
| **Te reo Māori** | the Māori language |
| **Tikanga Māori** | Māori protocol or way of being. It’s important to remember that tikanga may differ in hospitals, marae, iwi, workplaces etc. as each rōpū establishes their own tikanga |
| **Wānanga** | in this context it means workshop |
| **Whakapapa** | Genealogy. Reciting whakapapa was, and is, an important skill and reflected the importance of genealogies in Māori society in terms of leadership, land and fishing rights, kinship and status. |
| **Whakatauakī** | proverbs where the person who said it first is known |
| **Whakataukī** | proverbs that the person who first said it first, is not known |
| **Whakawhānaungatanga** | a te ao Māori process of establishing relationships. It’s about making connection, developing relationships through commonality and/or difference. It involves connecting with the consumer and their whānau on a personal level often through connections with whenua, whānau involvement or the use of te reo Māori |
| **Whānau Māori** | a term commonly used to denote people who identify as Māori |
| **Whenua** | Land. |

# The role of the workshop trainer

The role of the trainer is to deliver the process, maintain safety, facilitate learning, and model the communication skills used in the advance care planning training programme. Facilitation skills are covered in more detail in the facilitation skills chapter.

**Deliver the process**

The trainer is responsible for delivering the workshop, as described in this manual.

This means being familiar with all aspects, ensuring understanding of what the key purpose of each session is, and what is needed to deliver it.

**Maintain the safety**

The second key task is to lead the group in a way that maintains the emotional, cultural and spiritual safety for both individuals and the group.

**Facilitate the learning**

The final task is to facilitate the group in learning the skills necessary to have advance care planning conversations and to use advance care plans in their workplaces.

Therefore, the trainer needs to be very familiar with:

* advance care planning concepts including the legal framework
* strategies for integrating advance care planning conversations into everyday clinical practice
* strategies for managing various advance care planning challenges in the workplace including ethical dilemmas
* different ways of initiating and progressing advance care planning conversations for various types of individuals and in various settings
* what clinicians need to know in order to engage Māori with advance care planning

During the workshop, the trainer also needs to:

* consistently demonstrate communication skills excellence
* ask relevant questions to support the group to discover effective ways of initiating and progressing advance care planning conversations and manage barriers and challenges
* maintain cultural safety for workshop attendees

# Overview of the workshop

There are ideally 10 - 12 participants and one trainer per workshop.

|  |  |
| --- | --- |
| 0BTime | 1BSession |
| **08:15 – 08:30** | **Tea/coffee** |
| **08:30 – 09:00** | Welcome and karakia  Mihimihi (introductions)  Outline of the day  Working Agreement |
| **09:00 – 09:30** | Advance care planning discussion building on e-Learning modules |
| **09:30 – 10:00** | Legal framework in the context of advance care planning and advance directives |
| **10:00 – 10:15** | Using an advance care plan |
| **10:15 – 10:30** | **Tea/coffee break** |
| **10:30 – 11:15** | Discussion of case scenarios in groups |
| **11:15 – 12:30** | Communication skills for advance care planning  Having an advance care planning conversation – video demonstration and discussion |
| **12:30 – 13:00** | **Lunch** |
| **13:00 – 14:30** | Structuring and documenting an advance care planning conversation  Advance care planning conversation and documentation practice |
| **14:30 – 14:45** | Putting it all together:  Incorporating advance care planning into everyday practice |
| **14:45 – 15:15** | Wrap up  Individual goals  Evaluations |
| **15:15 – 15:30** | Opportunity to discuss local advance care planning practices |
| **15:30** | **Karakia whakamutunga (closing karakia)**  **Close of workshop** |

###### Tasks to be completed prior to the workshop

* Check with the venue where toilets are located, fire and emergency procedures and any other relevant venue specific information you need to know to keep you and the group safe.
* Check all participants have completed pre-course questionnaires online or collect completed hard copies as they arrive. If they have not completed it, ask them to complete it prior to the session.
* Ensure attendance register is completed.
* Provide participants with name badges.

###### Flip charts to be prepared

At least 3 sheets of flip chart paper are required (or use whiteboard):

* Working Agreement with headings (and space to scribe beneath them):
  + Confidentiality
  + Respect
  + Participation
  + Responsibility
  + Timekeeping/Mobile Phones
* 1 sheet headed ‘Agenda items’ or ‘Parking lot’
* 1 sheet headed ‘Communication strategies.’

‘Agenda items’ sheet: This can be used throughout the workshop to write up any specific questions or issues that come from the group that need to be covered during the workshop. This may include questions for the local advance care planning representative about local processes, resources and so on. This person may be the trainer, one of the participants, or may have been invited to join the group briefly at the end of the workshop. If not joining at the end, please forward the questions to the local advance care planning representative and ask that they get back to the group via email.

###### Prework for people coming to the workshop

It is recommended that people attending the L1A workshops do the following preparation before arriving:

1. Do the ACP L1 learning modules
2. Watch ‘An overview of advance care planning in Aotearoa New Zealand’ video on the landing page of the website
3. Watch the three implicit bias videos
4. Watch ‘Legal Framework for medical decision-making’ video

###### Printing

Ideally this should be organised by the local advance care planning training administration support. Printing should be prepared the day before the training.

|  |  |
| --- | --- |
| **Resource** | **Number to print** |
| 1. Participant details | 1 (per facilitator) |
| 2. Agenda | 1 (per facilitator) |
| 3. Sign-in sheet | 1 |
| 4. Pre-course questionnaire | 6 (spare) |
| 5. Anne slide handout | One for every two participants |
| 6. Legal case scenarios | 4 copies of each of the five case scenarios |
| 7. Conversation practice case studies | 6 copies |
| 8. Documentation worksheets | 18 copies |
| 9. Post-course expectations | One per participant |
| 10. Post-course questionnaire | One per participant |
| 11. Participant evaluation | One per participant |
| 12. Slideshow printout | One per participant/email post workshop |
| 13. The Hui Process (research article) | email post workshop |

**At the end of the day**

* Ensure everyone does the post course confidence questionnaire and evaluation before they leave.
* Gather together all the following paperwork, scan and email to national team ([acp@hqsc.govt.nz](mailto:acp@hqsc.govt.nz)):
  + Pre and post course confidence questionnaires
  + Evaluations
  + Sign-in sheet
  + Spreadsheet with participant details

# Facilitating the sessions

This section is an overview of each session. Use this together with the notes under the slides for what to say and how to run each session.

## Welcome and karakia, housekeeping and introductions

**Aim**

The purpose of this session is to welcome people to the workshop, and to introduce the workshop and yourself to the group, and the group to each other. (Slides 1-3).

**Time:** 15 minutes

*Tip – you may be feeling nervous before the workshop kicks off. It can be useful to remember the group members are also feeling anxious about how they will be perceived and whether they will perform well. So, starting with enthusiasm and high energy is important to set the tone, even though you may be feeling conspicuous.*

Welcome(SLIDE 1)

This is the initial welcome to the workshop, and the greatest opportunity to set the tone.

**Include a karakia timatanga (opening karakia)**  
A karakia and translation is offered below. We encourage the use of this opening karakia to enable the group to settle-in, take pause and focus their attention to the moment.

Karakia creates a starting point and brings our focus to the kaupapa (the business at hand). This tikanga Māori (Māori protocol), is used to enhance the mauri (life-force) of the day’s interactions and begins to weave matāuranga Māori (Māori knowledge), into the day’s proceedings.

Karakia is not primarily the domain of religion; it can be about acknowledging the elements and creating a safe environment to move forward with the day’s activities.  
  
It is preferrable that you kōrero (speak) Māori for this karakia To support your pronunciation of the opening karakia (below) – please listen to the audio recording on YouTube – the link is provided in the pre-reading.

|  |  |
| --- | --- |
| *Tukua taku wairua kia rere ki ngā taumata*  *Hei ārahi i āku mahi*  *Kia mau kia ita*  *Kia kore ai e ngaro*  *Kia pupuri kia whakamaua kia tina (tina!)*  *Haumī e*  *Hui e*  *Tāike e!* | Let my spirit ascend to the top-most summits  as a guide for all that I do,  keep it safe so that it will not be lost,  preserve and maintain it.  Join!  Gather!  Intertwine! |

**Additional information about karakia**

Karakia, in their true essence, are ritual chants invoking spiritual guidance and protection. It is an opportunity to welcome tīpuna (ancestors) and kaitiaki (spiritual guardians) to inspire and support the work to be done during the day.

Karakia – translates as *prayers* or *incantations*. They are generally used to ensure a favourable outcome to important events such as hui (*meetings*), wānanga (workshops), medical procedures etc. They also signify the commencement or end of an important kaupapa (the business at hand) and cause people to focus their attention and to be present.

Karakia are used to:

1. Start the wānanga (karakia timatanga) – see page 10
2. Close the wānanga (karakia whakamutunga) – see page 26
3. Bless food (karakia mō te kai) – see page 30

**Kupu Māori (Māori words)**

Refer to the glossary on page 7

Whakatauakī - Māori proverb (SLIDE 2)

Refer to the notes under the slide.

Whakatauakī are used to give guidance, engender collective thought and personal reflection. This particular whakatauakī was chosen for the advance care planning programme to help us think about advance care planning in terms of a journey – both for people on their healthcare journey and healthcare staff on their professional journey.

You do not need to share the following information about Tā James Hēnare with participants. However, it’s important that facilitators are familiar with the background of the author as it is the mana of the author that brings mana, or prestige, to the whakatauakī.

**Tā Himi Hēnare** (1911-1990F[[1]](#footnote-1))Ngāpuhi, Ngāti Hine, [Ngāti Whātua](https://teara.govt.nz/en/biographies/5h15/.teara.govt.nz/en/ngati-whatua), Te Rarawa, Ngāti Kahu, Te Aupōuri

Tā Himi Hēnare (Sir James Hēnare), was born at Mōtatau in the Bay of Islands. He was the descendant of many great northern Rangatira (Chiefs), including Hōne Heke and Kawiti.

His father, Taurekareka Hēnare, was of Ngāpuhi and Ngāti Whātua descent, and was an elected Member of Parliament representing Northern Māori from 1914 to 1938. His mother, Hera Paerata, was of Te Rārawa, Ngāti Kuri and Te Aupōuri, and Henare had seven siblings.

At an early age Hēnare was recognised as someone who would provide service to his people. Kaumātua (elders) provided education in tikanga and matāuranga Māori (Māori cultural beliefs and knowledge) and he attended Te Aute Māori Boys College in the Hawke’s Bay.

Henare served with the 28th Māori Battalion as a Lieutenant Colonel and after the war undertook years of public service. He was awarded both the CBE (1966) and the KBE (1978). He was a well-respected orator who made many influential speeches and was held to esteem for his mana, leadership, and the promotion of Māori values, customs, and reo (language). This whakatauakī was written in 1989.

**Kupu Māori (Māori words)**

Refer to the glossary on page 7.

Housekeeping (SLIDE 3)

Follow prompts under the slide

### Introductions - Mihimihi (SLIDE 4)

This is the opportunity for those present to introduce themselves by sharing a little bit about where they come from and who they are in relation to this. Mihimihi (introductions), enable the group to begin to make connections with each other and note commonalities. The kupu Māori (the Māori word) for this process is whakawhānaungatanga.  
  
The aim of mihimihi, in this context, is to engender engagement and participation by attendees and develop a learning and sharing space that has a sense of friendliness and safety.

Mihimihi consists of:

1. Mihi – this is a greeting. For example – Tēnā koutou. Nau mai haere mai. Hello everyone.

2. Pepeha – this is about developing connection through whakapapa (genealogy), or where you are from. We have provided pepeha templates to help you (see below).   
  
We encourage you to say your pepeha in te reo Māori. To support your pronunciation – please listen to the audio recording on YouTube – the link is provided in the pre-reading.

3. Whānaungatanga – this is about developing connection through shared experiences. In the context of the workshop, this could include saying where you work and your engagement with advance care planning.

Whakawhānaungatanga is also attended to through the establishing of a working agreement, and through the discussions that occur throughout the workshop.

**Why introduce yourself with pepeha?**

The use of pepeha by trainers at advance care planning workshops is an expression of tikanga Māori and embodies the intention to weave matāuranga Māori throughout the advance care planning programme in alignment with the principles of Te Tiriti o Waitangi.

The integration of pepeha and te reo Māori in this environment aims to strengthen your confidence with speaking te reo Māori and enrich your practice with tikanga Māori. It also role models best practice for your colleagues and workshop participants.

**What is pepeha?**  
Pepeha is a traditional Māori custom which holds great significance on whakapapa and connection to whenua. For Māori, pepeha is a genealogical statement descending from ancestors. In recent times a format of pepeha has been developed to include non-Maori New Zealanders in the tradition of establishing connections and developing relationships.

**How do you create a pepeha?**  
We have provided two templates to help you create your pepeha and there is a recorded example of pepeha in the YouTube link sent with your pre-reading.

Choose one of the following templates (or something similar), for your pepeha.

**Option One** – use this template, particularly if you identify as Māori

|  |  |
| --- | --- |
| **Tēnā koutou katoa** | *Greetings to you all* |
| **Ko tēnei taku whakapapa** | *This is my whakapapa* |
| **Ko \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ te maunga** | *My ancestral mountain is ……* |
| **Ko \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ te awa** | *My ancestral river is ……* |
| **Ko \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ te iwi** | *My iwi is ……* |
| **Nō \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ āhau** | *I am from …...* |
| **Ko \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ te ingoa whānau** | *My surname is …..* |
| **Ko \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ tāku ingoa** | *My name is …..* |
| **Nō reira tēnā koutou, tēnā koutou, tēnā koutou katoa** | |

**Option Two** – you could use this template if you do not identify as Māori

|  |  |  |
| --- | --- | --- |
| **He uri ahau nō tawhiti** | *My ancestral origins are in distant lands.* | |
| **Ko \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ te whenua** | *My ancestral land is …..* | |
| **\*\*Ka mihi ahau ki tēnei whenua me ōna uri** | I greet this land and acknowledge its descendants | |
| **Ka mihi au ki te maunga \_\_\_\_\_\_\_\_\_\_\_\_** | I acknowledge the mountain ….. | |
| **Ka mihi au ki te awa \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_** | I acknowledge the river ….. | |
| **Nō \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ āhau** | *I am from …...* | |
| **Nō \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ te whare kainga** | *My home is …..* | |
| **Ko \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ te ingoa whānau** | *My surname is …..* | |
| **Ko \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ tāku ingoa** | *My name is …..* | |
| **Nō reira tēnā koutou, tēnā koutou, tēnā koutou katoa** | |

**\*\***this is an optional extension

*Tip: Remember that if your introduction is lengthy, participants’ introductions are also likely to be lengthy, which will challenge timekeeping.*

*Tip: Refer to the You Tube video for help with pronunciation.*

Introduce any other person(s) present and:

* Explain why they are there (for example to observe the delivery of the course).
* Where appropriate, seek agreement from the group to be observed.

### Outline of the day (SLIDES 5 & 6)

**Aim**

To set out the structure of the workshop, so participants know something of what the day will look like.

**Time:** 5 minutes

Refer to the notes under the slides

Working agreement (SLIDE 7)

**Aim**

The aim is to generate a working agreement or list of ground rules for the workshop in order to promote a safe and effective learning environment for everybody.

**Time:** 10 minutes

You will need the pre-prepared flip chart with headings, and pens.

The working agreement should be generated by the group and added to by the trainer, if necessary, to ensure completeness. It is a living document and can be added to during the day if needed.

*Tip – if group appears confused or unsure prompt them by asking “what behaviours do you want to see from the other members of the group that will support your learning today?”*

**Confidentiality**

Clarify exactly what is meant by confidentiality.  Ask the group to negotiate what they wish to remain confidential and what may leave the room.  For example, that learning may be ‘taken out of the room’ but personal disclosure, consumer information and organisational/workplace disclosure must remain confidential to the group.

**Respect**   
Clarify what is meant by respect.  Ask the group what they look for from their colleagues to show that they are being respected; what does respect look like?  This might include such things as:

* Space for each other’s opinions, enabling everyone to contribute
* Sensitivity to, and support for, others’ views and difficulties
* Non-judgmental and constructive comments – which should be positively framed

**Participation**  
Briefly explore the group’s expectation of participation. Include:

* Everyone to participate in interactive sessions

*Tip – reiterate that the group are going to learn a lot from each other, that the value lies in the ideas and experiences shared. Check in with the group that they are all okay with participating and assure them that if you do call on them they are able to pass.*

* Giving space for everyone to contribute (e.g. “sharing the air-time”)

**Responsibility**

There are two aspects to this

* Taking responsibility for one’s own learning
* Taking responsibility for one’s own personal health and emotions

Ensure examples shared are in the professional context.

**Mobile phones and time keeping**

Phones off or on silent / flight mode. Check that everyone is ok not to be disturbed by their phone within the sessions.

Trainer will commit to finishing on time. Ask that delegates are ok to commit to returning from breaks on time.

Exploring advance care planning(SLIDES 8 – 15)

**Aim**

Through facilitated discussion:

* To enable participants to affirm their experience and knowledge of advance care planning to date, and to recognise knowledge gaps.
* To provide space for participants to share experiences of doing their own advance care planning and how that might impact their conversations with the people they will support.
* To allow for sharing of workplace experiences of advance care planning.
* To enable the group to explore cultural aspects of advance care planning.

###### Time: 30 minutes

Consider writing up any uncertainties, challenges or knowledge gaps that are not appropriate to address here, on flip chart or whiteboard (‘Agenda Items’), to ensure these things are addressed through the course of the day. This may include questions about local advance care planning processes.

What do we know about advance care planning? (SLIDE 8)

Use this slide to elicit what the group know about advance care planning and why it is important, and to establish the main knowledge gaps, if any, which will need to be covered in this session.

*Tip - Say you want to hear at least one thing from everyone – this promotes group cohesion and supports quieter participants to contribute. Telling them in advance means both trainer and participants have the same expectations.*

Summarise the main points of the discussion before moving on.

Additionally: this section is the time to start planting seeds about the core themes that need to be carried through the day, including:

* 1. advance care planning is not just for when we cannot talk for ourselves - the information about values, beliefs, hopes and what is important to the person is invaluable in the design and delivery of all care in a person-centric health system.
  2. advance care planning is person-led. It is our role to support people to think about, talk about and hopefully document their preferences, to start conversations, to pick them up again or to ensure that someone else has the information to do so.
  3. Cognitive impairment - including a person with all degrees of cognitive impairment as much as is possible is important.
  4. Culture – never assume, ask. Treat each individual, no matter what their ethnicity, as having individual needs and preferences. For some this might be collective decision-making with the person’s whānau.
  5. Introducing advance care planning is about gathering information and understanding the person, what they understand about their health situation, what is on their minds and then using the information and understanding to make advance care planning relevant to them.

*Tip - These themes are incorporated in many of the sessions during the workshop. If these were not raised by the group or if you do not get an opportunity to mention them here, don’t worry, there will be lots of other opportunities to ensure these core themes are discussed and understood by the group.*

What is Advance Care Planning? (SLIDE 9)

Use this to clarify the definition, highlighting what was missing from the discussion so far.

The ‘circles’ slide (SLIDE 10)

Use this to highlight the connection between the conversations, written plan and advance directives. Details of that are incorporated in the notes for this slide.

*Tip – it is important to reiterate that conversations and thinking are the most important part of the process, that could lead to an advance care planning which might include an advance directive if the person has very specific views about treatments they would or would not want.*

*This works the other way too, an advance directive without the wider preferences, values and beliefs that are often captured in advance care planning are not easy to validate. If there are also conversations that support what is in an advance care plan and advance directive, then the advance directive is much more likely to be appropriately used.*

Considering your own advance care planning (SLIDE 11)

Explore the group’s experiences of considering their own advance care planning. Encourage them to share how doing this has affected how they approach advance care planning with people and their whānau (if at all).

*Tip – the group are likely to share stories of how this is hard for younger, well people and that they may have thought about it, maybe spoken about it but haven’t got around to writing anything down. There are a couple of a key points to summarise here for the group – that it is hard to make specific choices when you have little idea of what the future might hold AND thinking about and talking about what really matters if time were short is invaluable, as it informs the choices we will need to make in the future.*

### Your workplace advance care planning experiences (SLIDE 12)

Use this slide to give the group the opportunity to share some of their experiences of advance care planning in their workplace. It is important to give some room for this because if there are people in the group who have had frustrations or challenging experiences, they need to have the opportunity to share them and be heard. If this is not done, there is a risk they will not be able to fully engage in the remainder of the session or feel it is not relevant to them. (The “gather before you give” approach).

Acknowledge what has been said but do not try to solve problems that surface.

Summarise key themes from the discussion before moving on.

Cultural Safety (SLIDE 13)

Use this slide to explore how people from different cultures may experience advance care planning conversations differently. Consider some of the ways in which we might facilitate culturally appropriate advance care planning practices. Draw the conversation towards the conclusion that everyone needs a customised approach based on what they would like you to take into consideration.

Refer to the notes under the slide.

**Additional background information**

A culturally competent practitioner can contribute to wellbeing by integrating cultural and clinical elements within their practice. Cultural competence requires an awareness of cultural diversity and the ability to function effectively and respectfully when working with and treating people of different cultural background.

Cultural differences can impact on the quality of communication and impact consumer/clinician relationships. There is evidence that misperception and lack of connection between people from non-dominant ethnic groups, such as Māori and Pacific Peoples, and health professionals is not uncommon and negatively impacts engagement. Poor engagement between people and clinicians is associated with poor outcomes for both the person and the clinician.

Chapters 3 and 5 of the advance care planning Training Manual provide guidance to support access and participation in advance care planning.

Culturally safe practice with whānau Māori includes the following:

* Ask people how their name is pronounced if you’re not sure.
* Acknowledge the role of whānau as a key health determinant of Māori and actively include them in conversations (with the consumer’s permission).
* When planning an advance care planning appointment ask the consumer if they would like whānau to be present, or if they would like a or kaimahi hauora Māori (Māori health worker) to be contacted for support
* Ask who the whānau, or support people with the consumer are and how they fit in to their life.
* Aim to greet people in their own language and learn a few simple te reo phrases.
* Be aware of the environmental factors that may affect the consumer and their whānau engagement with services.
* Build on your knowledge of indigenous belief systems including views on mana, death and dying, reliance upon whānau and karakia (prayer).

Refer to the paper by C Lacey et al - The Hui Process: a framework to enhance the clinician-consumer relationship. New Zealand Medical Journal 2011; 124:1347. This paper describes a method of integrating cultural competency practice, specific to Māori, in the clinician-consumer relationship.

Not many of us can claim to be experts in the culture or realities of others. You can, however, become expert in reflecting on your own culture and attitudes that inevitably shape your practice. Respect and humility lay the foundations for a mutual exchange where the locus of control sits with the person and their whānau. Accepting that your own reality is no more valid than anyone else’s, will help you navigate advance care planning conversations.

For the advance care planning conversation to meet its objectives it is important that the clinician first:

* understands their own cultural values, beliefs and practices and the influences these have on practice
* understands their own assumptions, biases and stereotypes that are held about groups of people and how these can shape practice
* can identify power held and how it is used in practice
* critically analyses the diverse realities that influence people’s health and wellbeing
* recognises and respects diversity among groups of people

### 

### Cultural Safety - Engaging with Māori (SLIDE 14)

Refer to the notes under the slide

See chapter 5 of the Advance Care Planning Training Manual for additional background information.

**Keri Kaa’s story** (SLIDE 15)

This is a 4-minute video that is embedded into the workshop slideshow (v3 and later) and on click should play. Remember to check that this works before you start the workshop.

Refer to the notes under the slide to introduce the video.

### Legal stuff (SLIDES 16 – 21)

**Aim** to ensure all participants are fully cognisant of legal definitions/terms and any queries they may have are addressed.

**Time**: 30 minutes

SLIDE 16: Brief. Refer to notes under the slide

SLIDE 17: Clarify and build on the group’s contributions using the slide. You do NOT need to go through all the detail of the Code of Rights. Some detail is provided here for facilitator understanding and in case questions are asked.

The process of advance care planning is a reflection of society’s desire to respect personal autonomy while also holding to the traditional medical values of beneficence (the moral obligation to act for the benefit of others) and non-maleficence (the obligation not to inflict harm on others).

Five of the rights within the Code of Health and Disability Consumers’ Rights (the Code) Code are particularly relevant and applicable to advance care planning. These are the rights to:

* dignity and independence (Right 3)
* services of an appropriate standard (Right 4)
* effective communication (Right 5)
* be fully informed (Right 6)
* make an informed choice and give informed consent (Right 7).

From HDC [website](https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/) the Code has legal status as a regulation made under the Health and Disability Commissioner Act.

**Key point - each right imposes a corresponding legal duty on health care providers – we are obliged to give voice to and respect consumer choices. What is captured in an advance care plan must be taken into consideration.**

SLIDE 18: Refer to notes under the slide

SLIDE 19: Refer to notes under the slide

SLIDE 20: Go through the decision-making process using a simple example to demonstrate.

*Tip: Use a simple example such as the person presents with a chest infection.*

SLIDE 21: Clarify the decision-making cascade using this slide. After doing this, note the top step is black and white, and subsequent steps become more and more grey – indicating increasing uncertainty about what the right decision might be.

*Tip: If you need an example of a situation where the EPoA cannot withhold standard life-sustaining treatment, consider: someone who has a strong beliefs about not using of blood products. They have an accident, are unconscious and need blood to save their life. The EPoA would not legally be able to refuse blood as it is considered life-saving.*

Screen for any questions about the legalities before moving on.

The advance care planning process and tools (SLIDE 22)

Refer to the notes under the slide

Using advance care planning – Anne’s journey (SLIDES 23 - 27)

Use these slides to put it all together so far, and to demonstrate several points:

* Advance care planning as a process
* Conversations change over time
* How advance care planning is used to guide care – both when the consumer is competent and when no longer competent
* How advance care planning is used to make future clinical plans
* How the Serious Illness Conversation Guide and Shared Goals of Care are part of the advance care planning process
* How the advance care planning process is used when the person is cognitively impaired and cannot make their own healthcare decisions.
* Legal and professional obligations throughout the process.

###### Morning Tea – 15 minutes

During morning tea, you need to set up the videos for the session pre-lunch (if not already done).

Ensure food and drink are taken in a difference space (even if in the same room) than the discussions. This is because talking about death and dying is considered tapu (sacred) and eating and drinking in the same space is considered by Māori to be disrespectful.

Case studies (SLIDE 29)

**Aim**

* To explore the ‘grey’ of the legal framework
* To explore cultural challenges in the context of advance care planning
* To explore using and interpreting advance care plans.

**Time** 45 minutes

**You need**

* To choose three case scenarios to use (consider basing this decision on the delegates’ work settings/roles). See Appendix One for copies of the five case scenarios.
* Copies of each of the case scenarios so that each delegate in small group has their own copy to read.
* The Facilitator’s copy of the case scenarios.

Set up and run the exercise as per notes under the slide.

### Communication skills for advance care planning (SLIDES 31 – 32)

**Aim**

The aim of this session is to explore how to initiate and progress an advance care planning conversations and recognise the communication skills that facilitate this. Basic communication skills and strategies are identified, which can then be drawn on in the next exercise.

**Time** 1 hour15 min

Communication skills brainstorm (SLIDE 31)

**Aim**

To prepare for the next session by brainstorming communication behaviours that facilitate advance care planning conversations.

**Time** 15 min

**You need**

* One sheet blank flip-chart paper or whiteboard, and flipchart/whiteboard pen

Set up and run the exercise as per notes under the slide.

Having an advance care planning conversation (SLIDE 32)

**Aim**

* For the participants to explore different ways of approaching an advance care planning conversation.
* To identify the structure of the conversation
* To identify the impact that certain behaviours have on the consumer and on the progression of the conversation.
* To recognise that it is not necessary to use the words ‘advance care planning’ in order to have an advance care planning conversation.
* To recognise that advance care planning conversations can be integrated into other ‘tasks’ and clinical work.

**Time** 60 minutes

**The exercise**

You will run two videos, one well person (Bob) and one unwell person (Gladys). Start with Bob.

Each video is run in sections.

Each section is run in a similar way:

* You will play a video in sections (this is pre-prepared on the video).
* Between each section facilitate a discussion with the group using the facilitation notes in the transcript (Appendix Two).
* Encourage the group to come up with various ways to start and then proceed through the conversation, considering the impact of each behaviour on both the consumer and the direction of the conversation.
* Highlight that there are many different ways to approach the same conversation, and that what is demonstrated on the video is one of them.
* At the end of the video, summarise the learning, or the behaviours/skills that the group are taking away as useful in initiating and progressing an advance care planning conversation.
* Highlight the key components of the conversation structure.
* At the end of the second video, compare and contrast the two conversations.

Wrap up before lunch by summarising the morning sessions and signposting what will be happening after lunch.

**Optional karakia before lunch** – to be used if food is provided in the same space as the discussion.

|  |  |
| --- | --- |
| Tēnei te whakamoemiti  Mō ngā ringawera I whakaritea I ēnei kai   * mai i te rangi * mai i te whenua * mai i te taio Mauri ora ! | We give thanks to the hands who prepared this food - from the sky - from the land - from the environment Good health ! |

**Lunch – 30 minutes**

During lunch set up the slide show again to start at slide 34.

## **Structuring an advance care planning conversation** (SLIDES 34 – 36)

**Aims and objectives**

* To summarise and pull together the communication behaviours that have been covered so far, into a strategy for an advance care planning conversation.
* To have an appreciation of the “Hui Process” (a copy of the paper describing this process is included in your training materials)
* To have an awareness of the Serious Illness Conversation Guide and when to use it

**Time** 5 minutes

**The exercise**

Refer to the notes under the slide for details of how to guide this discussion.

* Relate to the videos and explore why structure was important in those conversations.

If needing to reinforce the importance of structure, consider asking:

“Thinking back to the conversation with Gladys, what would have happened if we didn’t have a structure?”

*We could have been talking about Rex and her crafts for several hours, going around in circles!*

* Use slide 34 to discuss structure in general terms
* Move on to slide 35 to discuss the Hui process. This engagement process integrates culturally specific principles of greeting and relationship building to develop effective therapeutic relationships and provide a physical and spiritual safe space for Māori to engage with healthcare services.
* Move to slide 36 to provide a brief overview of the Serious Illness Conversation Guide, highlighting the commonalities with the structure just discussed.
* Ensure the following is covered (prompt if necessary):
  + Set up conversation, including asking permission, mihi and whakawhānaungatanga
  + Importance of making the conversation relevant to the person and kaupapa
  + Providing information should come AFTER gathering information – the importance and impact of “gather before you give”; to ensure conversation is relevant to the individual
  + Summarising and poroporoaki

## Conversation practice (SLIDES 37 – 38)

**Aims and objectives**

Opportunity for participants to put into practice what has been discussed regarding introducing and progressing an advance care planning conversation.

**Time** 35 minutes

**The exercise**

Set up and run the exercise according to the notes under the slides.

If anybody wants to practice using the hui model, you might like to put up that slide for their reference during the exercise (slide 35).

Documentation (SLIDE 39)

**Aims and objectives**

To prepare for the documentation practice and put documentation into context. The relevance of documentation is highlighted, and there is an opportunity for brief discussion about where advance care planning conversations can be documented.

**Time** 30 minutes

Refer to the notes under the slide for details of how to guide this discussion.

### Documentation practice (SLIDES 40 – 47)

**The exercise**

Set up and run the exercise as per notes under the slides.

Refer to Appendix 3 for cases and narratives.

## Putting it all together (SLIDE 48)

**Time** up to 15 minutes

An opportunity to summarise what has been covered.

Opportunity to think about how advance care planning can be incorporated into everyday practice; and how advance care planning can start to become ‘business as usual’. Also an opportunity to consider how we might increase access and participation with Māori.

It is important that participants have a sense of how they might incorporate advance care planning into their professional practice, and into their organisational routines. The discussion will depend on the needs of the group and how much of this has already been discussed. Don’t labour; however, provide adequate opportunity for participants to consider and briefly discuss between them. Refer to notes under the slide for prompts if needed.

**Local advance care planning discussion**

If the workshop facilitator is the one providing local advance care planning information (i.e., there is no guest joining the group) then this can be done here. Remember to address any relevant questions on the ‘Agenda items’ sheet. If any questions cannot be answered at that time, let the group know that you will email them responses.

If there is a guest joining the group, invite them in once the group has completed the evaluations.

## Wrap up, goals and post-course expectations

Refer to the notes under the slide

## Karakia Whakamutunga (Closing Karakia) (SLIDE 49)

An opportunity for everyone to join in bringing the workshop to a close.

**He Karakia Whakakapi**

|  |  |
| --- | --- |
| Kia whakairia te tapu Kia wātea ai te ara Kia turuki whakataha ai Kia turuki whakataha ai Haumï e! Hui e! Tāiki e! | *Restrictions are moved aside So the pathway is clear To return to everyday activities* |

Warmly thank the group for their hard work and contributions over the course of the day.

## Course evaluations & post-course questionnaire

**Time** 10 minutes

Hand out:

* Post-course questionnaire
* Workshop evaluation form

Ask all participants to complete before leaving. Point out that the evaluation form has 2 pages.

If there is a guest joining the group to speak about advance care planning in the local area, invite them to join once evaluations are completed.

If there is no guest speaker, participants are free to go once they have completed their evaluations.

## Local discussion (guest speaker)

**Time** Up to 15 minutes

If there is a local advance care planning representative joining the group, invite them to join at this point. Remember to address any relevant questions on the ‘Agenda items’ sheet. If any questions cannot be answered at that time, ask the local representative to email the group their responses.

**Facilitation Skills**

**The role of the workshop trainer**

The role of the trainer is to deliver the process, maintain safety, facilitate learning and model the communication skills used in the advance care planning training programme. Facilitation skills are covered in more detail in the facilitation skills chapter.

**Deliver the process**

The trainer is responsible for delivering the workshop, as described in this manual.

This means being familiar with all aspects, ensuring understanding of what the key purpose of each session is, and what is needed to deliver it.

**Maintain the safety**

The second key task is to lead the group in a way that maintains the safety for both individuals and the group.  This includes ensuring cultural safety.

**Facilitate the learning**

The final task is to facilitate the group in learning the skills necessary to have advance care planning conversations and to use advance care planning plans in their workplaces.

Therefore, the trainer needs to be very familiar with:

* advance care planning concepts including the legal framework
* strategies for integrating advance care planning conversations into everyday clinical practice
* strategies for managing various advance care planning challenges in the workplace including ethical dilemmas
* different ways of initiating and progressing advance care planning conversations for various types of individuals and in various settings
* strategies for engaging Māori in advance care planning

The trainer needs to be able to:

* identify key communication behaviours in practice within the context of a consultation, and recognise and understand the responses to the behaviours
* articulate what they see to the group
* prioritise the learning needs of the group
* be able to ask key questions to direct the group to focus on the key areas of learning
* know when to be directive to teach a group the required information, and when to facilitate a discussion which enables the participants to come to their own realisations
* maintain cultural safety within the group.

During the workshop, the trainer also needs to:

* consistently demonstrate communication skills excellence
* ask relevant questions to support the group to discover effective ways of initiating and progressing advance care planning conversations and manage barriers and challenges

**To model the skills**

At all times during the workshop, the trainer should be conscious of modelling the key behaviours that are central to the advance care planning training programme. For example, the trainer should make a conscious effort to actively acknowledge contributions, explore, clarify, use open questions, summarise, empathise, negotiate etc.  This allows the participants to experience how using the skills feels as a recipient.

**NB:** This process does not need to be made explicit to the participants.

**Key phrases, handy hints & tips**

**Key phrases - general**

* I can see …. I hear … I appreciate (NOT…. I understand)
* On the one hand … and on the other hand
* Is there ever a time when you have thoughts about / you have worried that …?
* I’m concerned it may not be quite so simple …

**Consider the following when communicating with the group:**

* Gather before you give/ask before you tell
* If you want someone to listen, listen to them first
* Say what you see
* Showing that you have heard not just knowing that you have heard
* If in doubt summarise
* Distinguishing between “thoughts” and “feelings” … thoughts drive feelings and feelings drive thought…. But BOTH are always present
* Chunking and checking when giving information

**Working with groups**

Many of the elements of the workshop, e.g. introductions, hearing what the participants want from the workshop, and setting ground rules will maximise the potential to develop healthy group dynamics.

The workshop trainer’s on-going role, once these things have been established, is to foster cohesion within the group and respond to any difficulties quickly to avoid dynamic issues developing.

*Tip – synonyms for cohesion: togetherness, solidarity, sticking together, bond*

**Cohesion**

The main function of the workshop trainer is to try and ensure that cohesion develops quickly.

**Signs of cohesion include**

* The participants beginning to share in the learning experience by contributing their ideas and comments
* The participants being constructive and helpful to one another rather than destructive or critical.
* Group members responding to one another in a reciprocal and supportive way and showing concern to understand what has been disclosed rather than ignoring or criticising contributions.

As cohesion develops, the level of disclosure should deepen from the disclosure of mere facts, to facts plus feelings, and then to expression of feelings that are appropriate to the context of discussion.

**Fostering cohesion**

The workshop trainer can reinforce the development of cohesion by:

* positively reinforcing all contributions from the group
* being non-judgmental of ideas
* using silence and humour to encourage
* scanning the group regularly for signs of unease
* actively inviting comments from more silent members early on in the discussions, so they know they are expected to be involved
* immediately reinforcing comments of a more personal nature e.g. feelings about a particular situation – since this legitimises disclosure and expression of feelings, as it does with consumers
* responding quickly to any difficulties.

NB: The work of Yalom (1971) has highlighted that when important disclosure is either ignored or criticised in a negative way, when the facilitator is critical, or when an individual in the group feels attacked and hurt, the following occurs:

* Reduction in confidence in knowledge or skills
* Failure to learn (wasted opportunity)
* Someone who is damaged or hurt from the experience
* A person suffers unacceptable level of embarrassment or distress
* A person is psychologically damaged or triggered

**Tips for balancing uneven contributions from the group**

Consider a general comment to the group along the lines of, ‘There’s some great discussion going on, and I’m wondering if we might hear from some of you who haven’t had the opportunity to share your thoughts yet …?’

If there are several enthusiastic contributors on one side of the room, consider asking for contributions from the other side of the room, turning your body to face the other side; for example, ‘We haven’t heard so much from this side of the room, what do you guys think?’

To encourage a quiet participant to join in:

* Make eye contact with them in the process of scanning the group, when you are seeking contributions from the group
* If they are nodding or appearing to agree with something someone has said, consider saying something along the lines of, ‘I see you were nodding there [name] – what’s been your experience?’
* If a particular point specifically relates to the person’s area of practice or something they have previously contributed, consider asking their thoughts on the discussion point, in relation to what they have previously said if possible
* Ensure contributions are acknowledged and that you demonstrate interest in what they say
* Avoid singling them out in a way that puts unreasonable pressure on them to contribute.

To support a more enthusiastic participant to allow time for others to contribute:

* Ensure their contributions are fully acknowledged, using empathy as needed, and then move your attention to the rest of the group
* If this technique is not effective consider being more overt: ‘Thank you [name], I wonder if we might hear from some of the others.’

**Responding to challenging behaviour**

Difficulties can arise when working with groups, particularly when participants feel obliged to attend rather than choosing freely to attend.  These difficulties can lead to challenging behaviours which manifest in different ways.

**Overt**: participants actively verbalising discontentment, unhappiness and anger.

Participants may:

* + use distracting tactics such as using mobile phones, talking to other participants
  + be sarcastic or disrespectful e.g. leaving the room
  + be domineering – not allowing others to talk, trying to take over.

**Covert**: participants are reluctant to join in discussion and activities, they can appear withdrawn or be using negative non-verbal behaviour

Challenging behaviour, whatever the nature, needs to be managed appropriately.

**Reasons for challenging behaviour**

Participants who exhibit challenging behaviours usually have an underlying problem or hidden agenda.

**Possible reasons**

* They are reluctant attendees at the workshop because:
  + they are frustrated by the required time commitment and its impact on their clinical commitments
  + they are experienced clinicians and don’t feel they need to attend.
* They feel challenged and / or anxious because there is an expectation that they will subject their skills or knowledge to the scrutiny of others.
* They have personal / professional issues that make them particularly vulnerable in relation to the workshop content.

**Managing a challenging participant - process for asking someone to leave the workshop**

N.B.  How you approach a participant will, to some extent, be defined by the individual situation and the person involved; however your approach should always be faithful to the model of communication used in the advance care planning training programme.

Our main aim is always to try and engage participants in the workshop by giving opportunity to express misgivings in their introductions and acknowledge them. As a result, the necessity for requiring someone to leave should be a rare occurrence.

However, if in spite of your efforts to acknowledge the validity of concerns raised and to engage the challenging participant(s) there is continued behaviour that is so severe that it threatens to disrupt the learning of others or leaves you feeling continually criticised / attacked, you may need to consider whether that participant (or those participants) should leave the workshop.

**Key steps**

* Ask to see the participant alone (preferably in a break).
* Acknowledge that you feel that person seems disaffected / disinterested / aggrieved and be ready to name the behaviours that you have witnessed.  Name the impact that this is having on other members of the group.
* Invite the participant to express concerns / issues that may be making it difficult to engage in the workshop.
* Acknowledge the response and value the difficulties whatever they are.
* If there are personal issues that make the workshop clearly inappropriate at this time:
  + Suggest the participant might leave now and re-book another time.
  + Offer to support them in this decision with their manager.
  + If the participant is reluctant to leave, deliver that advice more firmly.

If necessary:

* Explain your concern that the behaviour exhibited is likely to undermine the learning of other participants and is contrary to the working agreement (e.g. respect for others, including the facilitator).
* Remind the person that it is your responsibility to support and maintain both the learning environment and the working agreement.
* Ask the participant if they have any thoughts about how to resolve the difficulty.
* If the participant offers to behave in a way that resolves the problem, accept it.
* If there is no offer or what is offered is insufficient (e.g. I’ll sit there and say nothing then), offer a set of behaviours that would be acceptable.
* If the participant is unable to agree to them, explain that if he / she is unable to agree to the behaviours outlined, you have no alternative but to ask him / her to leave.

NB: You have a responsibility to that person and to other participants on the course who may not be able to engage fully if they feel someone else is vulnerable and is expressing that vulnerability by being critical or dismissive.

If the participant convinces you that they will be all right but there are clearly problems afterwards, speak to the person again and say, in spite of their willingness and / or wish to continue, they must leave.

**In addition:**

If possible, contact your identified person from the national advance care planning team for support / advice with managing a difficult situation. Alternatively, talk to another L1A trainer.

**Managing a participant who arrives late**

Ideally all participants will arrive before the start time. It becomes particularly difficult if participants arrive after the Working Agreement has been established as this may negatively impact on group dynamics if not managed effectively. This needs to be balanced with a demonstration of compassion for difficulties the late participant may be experiencing. The following are guidelines. Advice should be sought from a national trainer or other support person if there is uncertainty about managing a situation.

*Tip: Some facilitators have found it useful to ask participants before they attend to confirm their commitment to arrive on time and stay for the full workshop in addition to doing the pre-work.*

**If a participant asks if they can arrive late (i.e. it is planned ahead of the workshop) or there is an expected delay on the day of the workshop**

Generally, the answer would be ‘no’ to a request to start late. An exception might be if there are extenuating circumstances out of the participant’s control. In this case, they need to be there by 20 minutes after the start at the latest. In all cases they need to be able to stay until the end of the workshop.

**If a participant arrives late during a session (any time)**

This needs to be managed on a case-by-case basis.

* If they arrive before morning tea you welcome them into the group, acknowledging very briefly what has already been covered. Point out the Working Agreement and ask that they read it, say that this is what the group have decided as a way of working together. Introductions with the rest of the group can occur at morning tea.  Continue the session, thanking the rest of the group for allowing some space to acknowledge the late arrival.
* During the morning tea break ask to speak to the late arriving participant. If it is felt that they have missed too much to achieve the learning objectives of the workshop, you should suggest that they not continue. This needs to be approached as a negotiation. If it was an unavoidable crisis then you can tell them that you will endeavour to ensure they are prioritised for the next available L1A workshop.
* In any case, if they do not continue, you should let them know that someone will be in touch with them after the end of the day.
* Inform the support person of any participant that arrived late and about any decision made that the participant will not continue.
* If you need support with managing the situation or making a decision, try phoning one of the national trainers for support.

**If a participant arrives after morning tea**

You should ask the group to continue the current discussion and step out of the room with the late participant. You will need to inform them that they will not be able to participate, whilst modelling the programme’s communication approach (acknowledgement, empathy and so on).

##### Challenging Participant

Covert behaviourParticipant appears withdrawn, using negative non-verbal behaviour

Overt behaviourParticipant actively verbalising

discontentment, unhappiness,

anger, using distracting tactics

Speak to participant 1:1 at the first available opportunity

Establish nature and extent of concerns, issues

Acknowledge the behaviour and ask if the participant has any problem or concern.

(e.g I notice that you are very preoccupied with your phone, is there a problem?)

Acknowledge concerns and check out whether other group members feel the same

or

Acknowledge concerns and speak to participant on a 1:1 basis at the first available opportunity

Establish nature and extent of concerns, issues

Acknowledge that it must be difficult for the participant(s) to attend the workshop given how they are feeling

Refer to working agreement if applicable / appropriate

Negotiate solutions if possible

Highlight any areas that are non-negotiable (e.g. 100% attendance) and ask participant if they can accept this

If no

If yes

Continue with workshop

Participant should leave the workshop

**Managing a distressed participant**

Although it is not a common occurrence, a participant may become distressed for any number of reasons. For example, what is being discussed may strike a chord with them in relation to a specific raw situation for them personally or professionally.

You will have touched on what participants might do if they become distressed as part of the discussion whilst setting up the working agreement (self-responsibility). Remember what was discussed at this point should a situation arise.

Try to manage in the room where possible. However, the participant may choose to leave the room or be so distressed as to need to be taken out to recover.

Acknowledge the participant’s distress and ask them if there is anything they wish to share with the group, or if they need some time out.

If it is not possible to manage within the room, leave the room with the participant, asking the group to continue discussing the current topic.

If they wish to, discuss the issue/s with the distressed participant. However, AVOID a counselling approach. The discussion should be with a view to ensuring they are left in an emotionally safe place, and not with a view to resolving a deep underlying issue.

If needed send them for a walk and encourage them to return when they feel ok, or at next break depending on timing of the day.

You should return to the group. Explain that "XX will return later” or "XX has elected not to continue". Explain that on occasions this occurs in this type of training. Ensure the group do not feel guilty that they have contributed to someone leaving through providing critical feedback etc.

When the distressed participant returns, acknowledge them and continue. Check in with them again during break times.

**If the participant does not want to continue the workshop**

If the participant does not want to continue, talk them through this decision. Encourage them to stay as it is better for them to learn from the scenario, and the group is there to support them etc.

Ultimately it is ok for them to leave if they really feel they can't continue. In this situation, tell them you will phone them later - ensure you obtain their number. When in touch later, identify if additional support/counselling is required and where they can access this from.

Note: On-going support is not your responsibility; however, supporting the participant to identify they have an unmet need and to establish how/what can be done is the preferred option.

**Additional support**

If possible, contact your identified person from the national advance care planning Training team for support / advice with managing a difficult situation. Alternatively, talk to another advance care planning Trainer.

**Documentation**

Email the Programme Manager [acp@hqsc.govt.nz](mailto:acp@hqsc.govt.nz) with details of what took place and the nature of your responses as soon as possible after the Workshop, so that any associated communication received, or follow-up can be appropriately managed.

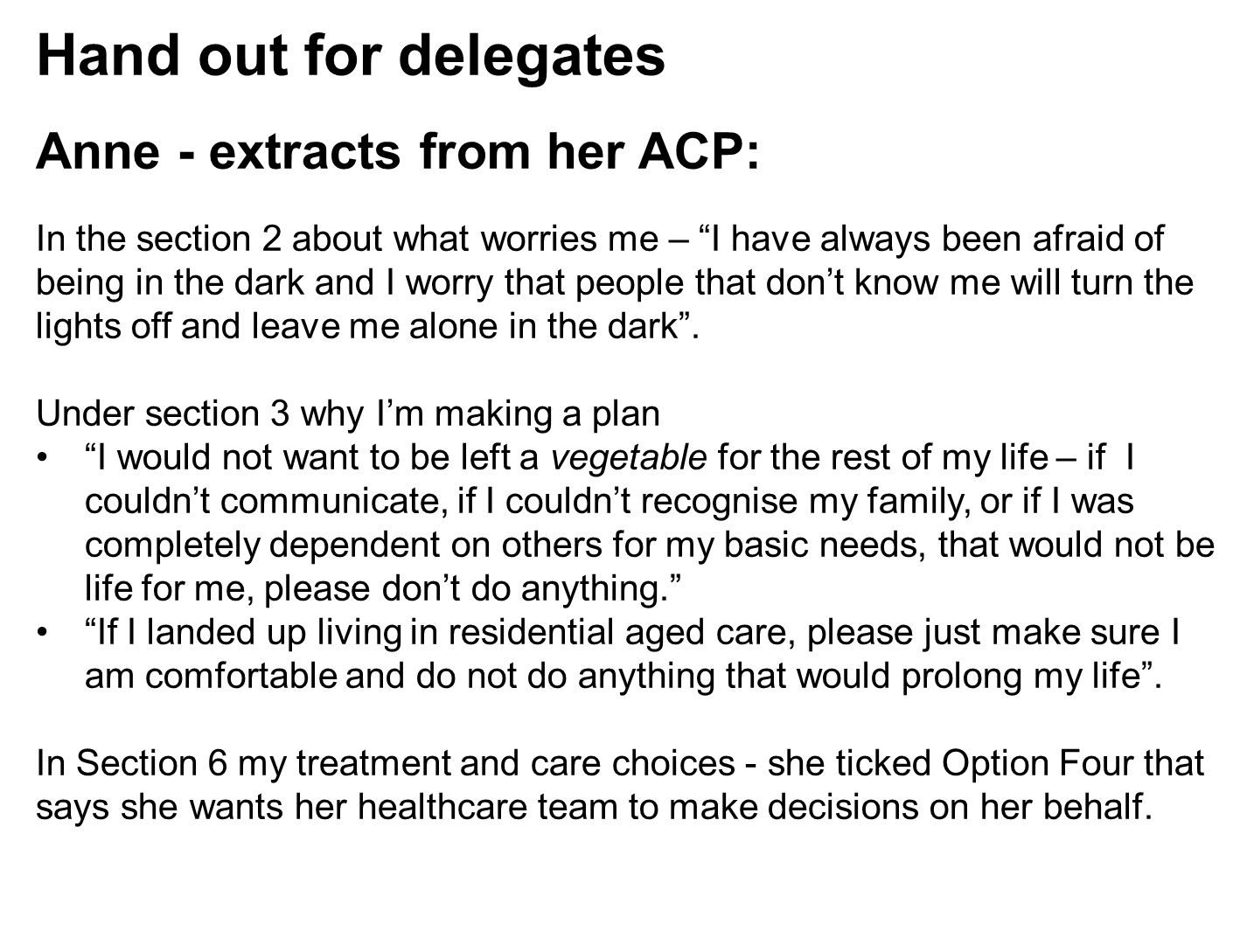
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# Appendix One – ANNE’s advance care plan extract hand out

The Anne advance care planning case notes including extracts from her advance care plan should be provided to the delegates before you start running through the advance care planning journey slides.

The PDF is included in the printing folder on your USB.

Here is a copy of the content:



# Appendix Two – Case Studies

Choose three case studies – there are five to choose from.

*The notes in italics might be helpful to consider when facilitating the feedback and brief group discussion.*

## Lillian – Case Study

*This case study highlights the issues related to interpretation of an Advance Directive, particularly in the absence of an advance care planning*

Background

Lillian is admitted to the emergency department. She is a 61 year-old lady who has a blocked Ventro Peritoneal shunt, needing surgery. She is stable but unconscious. Medical assessment on admission reveals no major cardiovascular or respiratory problems and there is a clear clinical picture of the required course of action. “Directive” on record noted:



Medical history on record:

* Congenital aqueduct stenosis ventro peritoneal shunt done 7 years ago. Spent 5 weeks in hospital.
* Extract from a clinic letter 2 months after surgery “…She was extraordinarily angry today. Apparently, she would have refused medical treatment at the time of her incident and is very upset that she was treated…”
* Last clinic notes 6 months ago: recurrent falls, alcoholism, cognitive decline, obesity, deafness, hypertension and hypercholesterolemia

Additional information discovered:

* The legal executive who witnessed the “directive” 5 years ago is unable to recall or reproduce another record of it
* Told that she lived alone and was independent
* Family are upset by the idea that we would do nothing and let her die. When asked if they thought she would agree to an operation – “she probably would, but I am not sure…”

**Issues for discussion**

1. Is it a valid advance directive?
   1. *Ask why? Or why not?*
   2. *Make reference to the legalities re ADs including the requirements for validity.*

*Tip: there is no right answer to this question, the debate about whether it is valid or not highlights that the clinicians asked to validate an advance directive have some discretion. So, to ensure that an AD is found to be valid (that there is no reasonable grounds not to find it valid – it is important to make it very clear, specific, sign it, date it, talk about it with your healthcare team and family, and wrap it into an advance care planning that spells out what is important and why you are refusing treatment.*

*The discomfort with this particular example is that the surgery that needs doing is simple and if they find the AD to be valid they cannot do the procedure and save her life. It creates an ethical dilemma where consumer autonomy could be seen as being in direct conflict with do no harm.*

1. If it is not, do you need to consider it?
   1. *Aim for ‘yes’ – remember decision-making cascade. Even invalid AD is part of the info gathered in order to make decisions. The clinician must step into the shoes of the person (gather and consider all information) and do what they believe the person would have wanted.*
2. What should the treating clinician do in this case (if he does nothing Lillian will die)?
   1. *If valid advance directive then treatment would be to make her comfortable – no surgery. If time, and you wish to explore further with group, could ask ‘what if it wasn’t valid?’*
   2. *If not valid then explore group’s responses - why should the treating clinician unblock the shunt?*
3. What would you do if Lillian was your mother?
   1. *No right or wrong. Ask ‘why?’*
   2. *Consider reference to trying to find out what is in Lillian’s best interests – what do we need to consider?*

**What really happened?**

Lillian was a case that an Anaesthetist was faced with. He moved her down the theatre list and spent a substantial amount of time trying to get more information to help the team make a call about the validity of the AD. After due consideration and consultation with colleagues he decided that he could not comfortably confirm the validity of the AD and so they performed a temporary procedure to allow Lillian to regain consciousness, so they could then ask her for her consent. She initially consented to the required surgery though expressed regret subsequently.

If the anaesthetist, and other members of the healthcare team, had access to documented, clear notes about what her concerns were when she decided she did not want surgery (in the form of an advance care planning or clinic notes) they would not have found themselves in the position they did – they would have had content and context for better decision-making. Instead we left the clinician in a very difficult position.

## Evan – Case Study

*This case study highlights the impact of ambiguous documentation and discusses the interpretation of advance care planning and advance directive documentation.*

**Presenting situation**

Evan is transferred to ED by ambulance after his daughter, Sally, finds him unresponsive at home in bed; he is breathing. The treating clinician tells Sally that he has had a cardiac event and that he is seriously ill; with treatment he may recover, although this is uncertain. They ask Sally (who is appointed EPA) what approach Evan would want them to take with his treatment. Sally remembers her dad has completed an advance care plan and hands it to the team. She says she was not part of the conversation when he documented the advance care plan, and they have not discussed it.

Extracts from Evan’s advance care plan (signed by Evan and his GP):

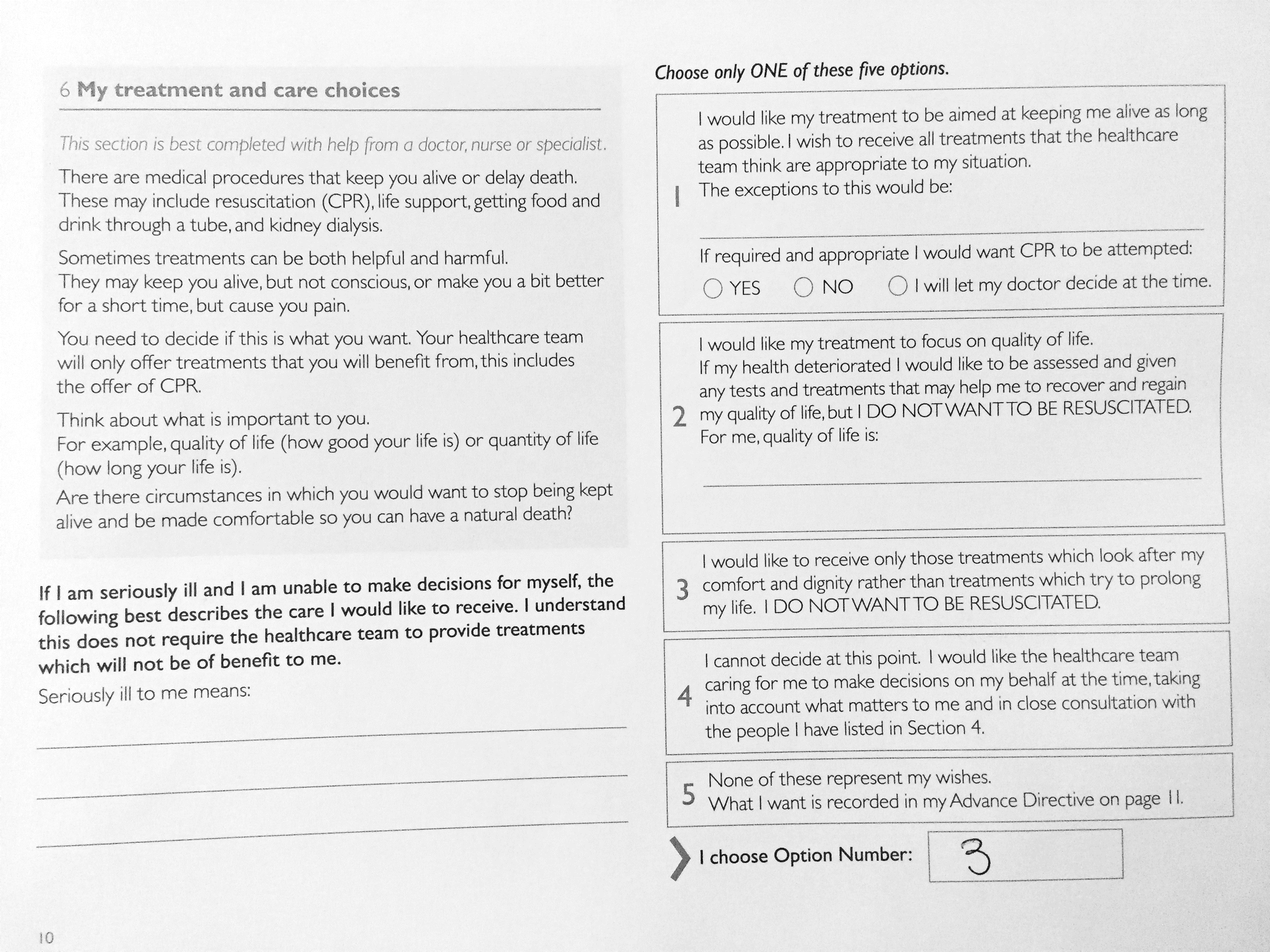
**Section 2** What matters to me – *left blank*. What worries me – *nothing worries me*

**Section 3** This is why I am making an advance care plan - *I am making this plan because I am already very old and cannot last forever. Resuscitation should not be prolonged if brain damage is likely.*

**Section 5** As I am dying: My quality of life means – *left blank.*

In addition, I would like you to: *let the people who are important to me be with me and stop medications and treatments that don’t add to my comfort.* *The place I die is not important to me. I don’t mind where I am cared for.*

**Section 6** Treatment and care choices



**Section 6:** My Advance Directive

|  |  |  |  |
| --- | --- | --- | --- |
| 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* |

**Section 7** After my death – *If my organs and or tissues could be made available or donated I would wish this to happen, glad to give anything useful. I would like to be cremated. For my funeral or tangi I would like simple and short Christian ceremony. I don’t mind what my last resting place is, my daughter can decide.*

**Issues for discussion**

1. Do you think Evan would want life-prolonging measures to be attempted? Why? Why not?

*Ensure group notes the discrepancy between “option 3” where he is refusing life-prolonging measures if he is seriously ill, and the written statements requesting resuscitation in Section 6 advance directive together with the statement in Section 3 where he says “resuscitation should not be prolonged if brain damage likely”.*

*Discussion about limitations to life-prolonging measures may come up.*

1. Does the information in sections 1-5 help with understanding Evan’s wishes? If yes, in what way?

*Promote discussion about the background information providing potentially useful insight into the person, and therefore may help to understand what’s behind his decisions in section 6.*

*E.g. we get the sense he wants input into decision making and some control about what happens to him, and that avoidance of brain damage is important to him so his brain function seems to be important to him. More information could have been helpful, e.g. about what constitutes quality of life for him, and anything else other than avoiding brain damage is important (e.g. is physical function important?)*

1. What aspects of the current plan would you want to clarify and potentially re-write with Evan if you had the opportunity before he became unwell?

*Include:*

* *Quality of life*
* *Clarification of goals of care and treatment in the face of serious illness or injury (the OPTIONS in section 6)*
* *Wording of the specific treatment preferences*

## Reg – Case Study

*Useful for aged care staff, or staff dealing with cognitive impairment.*

**Background**

Reg is a 74 year-old man with late stage dementia, living in a residential dementia unit. His EPA is his wife, Marg. He is mobile, can bathe and dress with prompting, and eats independently. He has limited ability to express himself verbally. He used to walk around the unit most of the day, seemingly content. Recently he has started to lose weight, has become more fatigued. A locum GP ordered blood tests, which indicated anaemia. On obtaining the blood results the locum GP rang the Registered Nurse and asked her to ask the family if they wanted Reg sent to hospital for investigations. This she did, and Reg’s wife said, “yes of course!” ED found nothing acute, and suggested the GP refer him for outpatient investigations. In ED Reg had had to be sedated as he was very distressed.

**Current situation**

The next day, Marg and her son Paul came into the unit demanding to speak with whoever is in charge, as they wanted Reg sent back to hospital. His condition was stable and he was undistressed.

* They wanted a diagnosis, even if it meant distress for Reg and no change in outcome.
* The Registered Nurse had heard staff saying previously that Reg had said on several occasions that he does not want to live like this and he doesn’t want to “end up like those in there” [hospital level dementia unit]. The Registered Nurse could find no documentation to this effect.

The nurse attempted to discuss with Reg to no avail.

**Issues for discussion**

1. Do the family have a right to demand that Reg be transferred back to hospital?
   1. *Make reference to legal rights of family/EPOA - family have no legal right to demand treatment. That is not to say that it is easy for clinicians in these situations to deal with family demands.*
   2. *Consider ethical issues – right of RN to decline what family are wanting for Reg; hospital already sent him back with no acute treatment needed*
2. Would going back to hospital at this time likely be in Reg’s best interests?
   1. *Consider previous distress in ED;*
   2. *indicators that he may not want his life prolonged (although no written evidence);*
   3. *generally accepted that moderate to severe dementia requires palliative care (White paper 2013, EAPC)*
   4. *What are we trying to achieve?*
3. How would you approach the next part of the conversation with Marg and Paul?
   1. *Explore reasons for wanting hospital investigations*
   2. *Acknowledge wanting to do what’s best for him*
   3. *Explore what they feel his priorities would be (survival/prolongation of life? Comfort/allow nature to take its course)*
4. What might have made this situation easier?
   1. *advance care planning conversations before Reg lost capacity*
   2. *advance care planning conversations with Reg and family prior to this event*

**What really happened?**

The Nurse Practitioner spoke with the family. She asked about what they felt Reg’s priorities would be. They were very clear that he would not want to live like this, that he would hate to end up with even more advanced dementia where he couldn’t feed himself or know his family. They felt his main priority would be to be without pain. When asked what they felt investigations would achieve, they replied, “how can you take care of him if you don’t know what’s wrong with him?” Marg was also receiving pressure from other family members to have a diagnosis and she was worried that they would think she wasn’t doing a good job of caring for him if “nothing was done”. With gentle explanations and clarification, they realised that sending him back to hospital would be distressing for him and that what he would really want would be to stay in the unit surrounded by people he knows, with measures to keep him comfortable. He never did have any further investigations and end of life plans were put in place. A month later he had what appeared to be an acute bowel bleed which ended his life within 24 hours; he remained in the unit, pain and distress were addressed promptly and family were prepared and very grateful for the care he received.

## Sione – case study

*Useful as a basis to discuss cultural aspects of advance care planning.*

**Background**

Sione is a 71 year old Samoan man with Chronic Obstructive Pulmonary Disease who has been living in New Zealand for 8 years due to his health. He and his wife have 6 children, 5 of whom live in Samoa with his wife. He lives with his daughter and her respective family here in NZ. His family in Samoa hold very strong traditional Samoan views on life and his family with whom he lives here in NZ are quite Western in their perspectives and lifestyle.

**Current situation**

One of the advance care planning facilitators was scheduled to give a talk on advance care planning to a Better Breathers group. Usually about 12-15 people attend the group, and there is a mix of genders and cultures, often predominately Pacifica. Pacifica clients frequently attend with a spokesperson.

The Physiotherapist was approached by Sione’s spokesperson – his grand-daughter – prior to the session. She informed her that her grandfather did not want CPR if he was to ‘go down’. At this point Sione does not have a written advance care plan or advance directive.

The Physiotherapist asks the advance care planning facilitator, “So what happens if Sione arrests in the hall today?”

**Issues for discussion**

1. Does Sione’s expressed wish for no CPR constitute a valid advance directive? Why/why not?
   1. *Make reference to legalities re ADs including requirements for validity – get group to name them perhaps*
   2. *Consider difficulties in ascertaining validity – e.g. language barrier; does Sione understand what he has asked for? Has he actually asked for no CPR? Etc.*
   3. *If there is time you might also explore with the group what challenges they might foresee (or have experienced) having family members acting as interpreters?*
2. What legal or other responsibilities does the Physiotherapist have, once she has been given this information?
   1. *Consider code of rights – we have a responsibility to find out and act on people’s preferences and the right to make an AD. Physio needs to enable this*
3. Given the collective decision-making of traditional Samoan culture, would there be a need to involve his family back in Samoa before making a decision about CPR? How does that impact on this situation?
   1. *Make reference to legalities of ADs and code of rights*
   2. *Does the cultural requirements impact on the legal right for someone to make an AD (independently if they wish)?*
4. If Sione did arrest in the hall today, what would your response be?
   1. *No right or wrong answer – let the group tell you what they think.*
   2. *Ask for their rationale.*

**Hone – case study**

*Useful to explore legal framework in the context of Maori whānau.*

**Whānau – support networks and history**  
Hone is a 54 year-old man of Ngāti Kahungungu descent, who lives with his wife Mere and their two adult children. Hone teaches whakairo (Māori carving), at the local kura (school). Both Hone’s parents and his two siblings are deceased.

**Wairua – cultural identity**Both Hone and Mere whakapapa (have genealogy) to the local iwi (tribe) and hold mana on their marae. Hone and his whānau have a fear and distrust of health services, largely due to experiences of racism and perceived lack of care experienced in the past.

**Tinana – physical health and functioning**  
Hone was diagnosed with congestive heart failure 3-years ago. He started the prescribed medications but stopped as they made him feel worse. Hone is registered with a general practice but does not feel a connection with any GP as he sees a different one each time.

When unwell, Hone visits either his acupuncturist or rongoā (traditional Māori medicine) practitioner. He has been seeing his rongoā practitioner more frequently recently, as he has been experiencing increasing fatigue, weakness, leg swelling and shortness of breath. He knows and accepts that his health is deteriorating.

**Hinengaro – tikanga, mana protection, emotional well-being**Hone has refused to be considered for a heart transplant. He told Mere, “I absolutely do not want a stranger’s heart placed in my chest”. Hone and Mere have made a verbal agreement to always protect each other and be each other’s Enduring Power of Attorney for health and welfare.

**Current Concern**Hone entered the hospital emergency department via ambulance. He is unconscious, following a fall from a tree that he was pruning. He has a head injury and an unstable hip fracture which requires surgery. His wife and children are with him.

The treating clinician has asked Mere and their children what Hone has previously told them about his care and treatment preferences. Their son Matt has taken the role of key whānau spokesperson. He has advised the healthcare team that Hone requested that their whānau decide what was to be done for him if he was unable to speak for himself. Mere says Hone has always been adamant that he doesn’t want ‘anyone cutting him up’.

**Issues for discussion**

1. Can Hone’s reported statements about not wanting surgery, be regarded as a valid advance directive? (He needs surgery to fix his hip fracture.) Why? / Why not?
2. *Ensure exploration of criteria for validity for ADs as relates to this situation*
3. *If it doesn’t come up in feedback, ask: “do you think he meant no surgery for this specific situation (i.e. hip fracture)?” (Last of the validity criteria).*
4. *The group may bring up the fact that even if it was considered a valid AD, to forego surgery for a fractured hip would be problematic in terms of pain, loss of mobility, other complications – which may pose an ethical dilemma. Avoid getting too bogged down in this discussion – acknowledge the concerns and relate to the importance of adequate ACP conversations and clear documentation including specific circumstances for ADs.*
5. If not, who decides whether to proceed with the surgery?
6. *Ensure reference to the decision-making cascade*
7. *In this case, the treating clinician will decide using all the information s/he can find, to determine Hone’s preferences.*
8. What is his whānau’s role in deciding whether to proceed?
9. *Make reference to EPoA: verbally agreeing to have someone be your EPoA does not meet the legal requirements for appointing an EPoA*
10. *Explore collective vs individual decision-making approaches – highlight the constraints in the current law which says only the individual can decide for themselves, and whānau have no legal right to decide – with the exception of an enacted EPoA*
11. *Ultimately, the role of whānau is to inform the medical decision.*

# Appendix Three – Having an advance care planning conversation video transcripts and notes

The facilitation notes and discussion points are meant as a guide. You may not want to bring every detail into each group’s discussion. Points for discussion will, to some extent, depend on the needs of the group. The facilitative skills named in the notes are for the facilitators, who will understand their meaning. Bear in mind that not all groups will have such an understanding of those specific skills, and discussion may need to be more general, using language that the group understands – e.g., what was said, together with the context and the impact may be sufficient in some circumstances.

## Bob – well person, primary care

**Context**

Bob is a 67 year old semi-retired business owner in good health. He has come to his GP practice for a routine ‘well-man’ check-up. The practice nurse knows that his wife has recently died of cancer and is keen to take the opportunity to check in with him, see how he is doing and to explore if this experience has surfaced any thoughts about his own future care preferences.

Bob had been married to his wife Charlotte for 39 years and they have two daughters and more recently three grandchildren. Bob has worked hard to provide for his family over the years and was looking forward to retirement to spend more time with Charlotte and his grandchildren, and to indulge his passions for tramping, hunting and fishing. He is fit and active and finds getting out for a walk or a mountain bike ride a good way to clear his head and order his thoughts.

He is meeting with Jane, one of the practice nurses today after his ‘well man’ check.

| **Who** | **Script** | **Facilitation comments** |
| --- | --- | --- |
| **Discussion**  **points** | Ask the group how they might start the conversation.  What strategies or skills might be important at the beginning of the conversation? | |
|  | **Part One** | **01:52 mins** |
| Nurse | Bob thanks for popping in to see me today, I know you've been through with Karen having your well man check. And I thought this was probably an opportunity for us to have a bit of a catch-up. Because there’s been quite a lot going on for you in the last few months hasn’t there? | *Valuing Bob’s time.*  *Re-connecting.*  *Agenda-setting.*  *Permission/offer to talk about recent happenings* |
| Bob | Yeah, yeah, I mean Charlotte and, you know that business, and 2 daughters having to look after her, that sort of thing, and yeah, bit of a hard time. | *CUE: daughters having to look after her*  *CUE: bit of a hard time* |
| Nurse | It sounds like it’s been a really hard time for you. | *Empathy* |
| Bob | Yeah. |  |
| Nurse | How are you feeling about things? | *Open question re above* |
| Bob | Oh not too bad, a few adjustments, you know, yeah (sigh). Daughter’s getting back on track after having to put a whole lot of time into her, mmm. | *CUE: reference to daughters having spent a lot of time looking after Charlotte* |
| Nurse | So there’s been an awful lot going on for all of you hasn’t there and – I'm guessing it’s been a pretty tough road to hoe the last wee while? | *Empathy*  *Educated Guess* |
| Bob | Yeah. |  |
| Nurse | Yeah. |  |
| Bob | Yeah, but I'm fortunate that I don’t have to go to work every day and I can choose my time and everything else like that. But yeah you can’t sort of, you have to restrict some of your activities and I like to get out and about, so yeah. Now I can get back to it I suppose, yeah. |  |
| Nurse | Yeah absolutely. You mentioned a little bit about your daughters and things being a bit tough for them? | *Responding to CUE about daughters* |
| Bob | Yeah well I mean I had to rely on them to sort of provide most of the care. I mean it was 24 hour in the end and so I was sort of a bit in the background because I'm not quite as good at that as they are. But it was pretty hard on them, you know and their families, you know they’ve got young kids, so yeah. Sort of wondered if I could have done a bit more here and there, yeah. | *CUES: Reliant on daughters to care for Charlotte*  *Could he have done more?* |
| Nurse | It’s hard knowing quite where to sit in some of those situations isn’t it? | *Empathy* |
| Bob | Yeah, yeah, well – |  |
| Nurse | Tough. | *Empathy* |
| Bob | Yeah. |  |
| **Discussion**  **points** | * *How was the conversation initiated?* * *Let Bob know she knows the reason he came to see Dr and reference to recent death of his wife (so both start on same page)* * *How did the nurse communicate empathy?*   *‘It sounds like it’s been a really tough time for you’*   * *What was the impact of this?*   *Bob felt heard, that the nurse cares, he engaged in the conversation*   * *What were some of the cues that Bob gave?*   + *Daughters having to look after Charlotte; bit of a hard time; he was reliant on daughters to care for Charlotte* * *Were any responded to?*    + *‘You mentioned a little bit about your daughters and things being tough for them’* * *What is the relevance of the conversation so far regarding advance care planning?*   + *Recent bereavement, family, setting the scene* * *Where would you go next in this conversation?*   + *Allow group to come up with suggestions. Acknowledge all suggestions – there are no right or wrong answers.*   + *If needing to prompt, ask ‘what are some of the ways we might start to talk about his preferences for the future?’ Again, acknowledge all ideas.* | |
|  | **Part Two** | **02:49 mins** |
| Nurse | Bob I'm wondering today and I'm not sure how it feels for you, and whether it feels like it might be the time to start these conversations … but often we find people, when they’ve had the experiences, and the things that have happened like recently for you with Charlotte’s death, that sometimes it gets them thinking about the things that they might want for themselves if something was to change and happen with their health in the future. I'm wondering whether that might be something you want to chat to me about today, if there have been things that have been sort of percolating, or happening and thinking about for you around what you might like? | *Agenda-setting*  *Negotiation*  *Tentative* |
| Bob | Well I'm pretty fit and healthy I, you know I don’t have any immediate worries or anything else like that. But I mean my older brother he keeled over on the golf course, you know with a heart attack and, you know they resuscitated him. But (sigh) he had pretty severe brain damage and he only lasted a week and yeah, so, it does make you think when something like that happens to somebody pretty close to you like that, yeah, yeah. | *Picked up on the concept straight away*  *CUE: brother’s death* |
| Nurse | What sort of things did it make you think about in particular? | *Exploring thoughts with open directive question* |
| Bob | Well, you know I mean if that happened to me, well I certainly wouldn't want to be still alive if I had severe brain damage, I wouldn't see the point in that. If there wasn’t any quality of life, if couldn't get out and about, enjoy my friends and, you know the family, and probably more so than … I mean they're more important than ever now, the grandkids and all that sort of thing. If I couldn't do something, you know actively with them, and help here and there, well (sigh) I don’t think there’d be a lot of point in carrying on, yeah. | *Described Quality of Life, and what he wouldn’t want.*  *CUE: family more important than ever now* |
| Nurse | So that sense for you that it’s really important to still be part of that, part of your family, being active, and being out and about I heard you mention as well? | *Reflection* |
| Bob | Yeah, oh yeah, well I'm pretty active outdoors, you know out tramping and, you know the occasional hunting trip, things like that with some of my mates. | *Gave more info in response to reflection* |
| Nurse | The great Kiwi outdoorsman, absolutely – | *Reflection* |
| Bob | Yeah, yeah, yeah, yeah, yeah, yeah. |  |
| Nurse | I sense maybe if some of those things were more restricted that that would be feeling quite different for you and – | *Reflection*  *Clarification* |
| Bob | Yeah it would, it certainly would change my outlook on life because it’s been part of my life, you know right from when I was a youth. So yeah I'd miss that and it would, you know I don’t know what I'd replace it with, you know, yeah, yeah. | *Gave more info in response to reflection* |
| Nurse | So that’s really helpful for me to know that for you being able to be out and about, to be able to be active, to be able to be still, you know interacting with the outdoors, is a really important thing for you in your life. And if you couldn't do that at this stage you're not quite sure how it would feel going forward, is that, have I captured that right? | *Validating what he has shared*  *Internal summary*  *Clarification* |
| Bob | Yeah, yeah, yeah, yeah, I mean that would be, you know I would think I'm having a lesser standard of life than what I'd been having previously and yeah it would colour my thinking – |  |
| Nurse | Colour your thinking a little bit? | *Reflection* |
| Bob | Yeah. |  |
| **Discussion**  **points** | *Did the nurse bring up advance care planning? [Yes]*   * + *How did she do that? [I’m wondering … after experiences … sometimes it gets them thinking about things they might want for themselves…]*     - *She was tentative*     - *She made it relevant to him by linking this conversation to his experience with Charlotte*     - *She asked permission/negotiated proceeding [I'm wondering whether that might be something you want to chat to me about today …]*   + *Was advance care planning named? Does that matter at this stage? [No … the important thing is that it is relevant to him … naming it can come later]*   *How did she move through the conversation?*   * + *Explored CUE- brother’s death [What sort of things did it make you think about in particular?]*   + *She reflected back to him what he had shared [So that sense for you … part of your family…]*   + *Internal summary and clarification [for you being able to be out and about … outdoors … important to you … have I captured that right?]*   *What was the impact of following the cue, reflecting back what he had said, summarising and asking if she had got it right?*   * + *He shared more. He gave us information about what quality of life means to him (without being specifically asked).*   *So we’ve learnt a bit about what Quality of Life means to him, and something of what he would not want. How might you move forward?*   * + *Allow the group to come up with suggestions.*   + *If needing to prompt, suggest:*   *‘Would you want to move the conversation towards end of life preferences for example? How might we do that?’[Pick up on when he talked of Charlotte’s end of life]*   * *Or other open question linked to something he has previously said?* | |
|  | **Part Three** | **01:38 mins** |
| Nurse | And I know that you sort of mentioned a wee while ago in this conversation about Charlotte and how tough it was with the girls looking after her. If things were to change and meant you needed increased support and care, and maybe even thinking about sort of as things were coming closer to the end of your life, have you thought about what you might like in that situation? | *Open question related to what he has shared already.*  *Exploring End of Life preferences* |
| Bob | Mmm, well I certainly wouldn't wanna be kept alive artificially, you know I mean yeah. If I can’t have, you know make my own decisions and, you know choose when I wanna go out and things like this. And if I couldn't get out and about (sigh) I wouldn't be too happy about it, yeah. |  |
| Nurse | So that’s definitely feeling important … | *Acknowledgement* |
| Bob | Yeah. |  |
| Nurse | What about where you might wanna be in terms of your care? | *Exploring further* |
| Bob | Well I wouldn't wanna have to be reliant on my daughters again, I think they’ve done enough, you know caring for the family. And I'd rather go into somewhere like a Hospice or somewhere like that where, you know you've got professionals looking after you. And your family are your family, and your friends can come and see you and yeah, that’s a pretty good sort of a place to be from what I've seen with people, friends that I've had in there, yeah. |  |
| Nurse | So that sense for you that actually if things did deteriorate with your health and you were needing that increasing care it would be important for you be having your daughters to be your daughters – | *Reflection*  *Clarification*  *↓* |
| Bob | Yeah. |  |
| Nurse | And your friends to be your friends – |  |
| Bob | Oh yeah. |  |
| Nurse | Not the people that are taking care of you? |  |
| Bob | Yeah, yeah. |  |
| Nurse | That would be okay to be kinda left to the experts? |  |
| Bob | Yeah. Yeah, yeah, certainly, yeah. |  |
| Nurse | Yeah. Okay. |  |
| **Discussion**  **points** | *So how did nurse bring up End of Life? [You mentioned … Charlotte and how tough … girls looking after her … If … you needed increased support and care … have you thought about what you might like …]*   * + *Open question linked to what he had shared earlier*   *What was the effect?*   * + *He shared something of what he wouldn’t want at the end of his life*   *What else have we learned?*   * + *He wouldn’t want his daughters to have to care for him … he’d rather be somewhere where family can be family …*   *What did the nurse do to elicit this information?*   * + *Acknowledged what he said [so that’s …important]*   + *Open question [what about where you might wanna be…]*     - *This works because the questions have been linked to what he has shared, and he understands the relevance to him … the same question might not be so effective, without this ‘groundwork’*   *Where would you go next?*   * + *Allow group to come up with suggestions.*   + *If needing to prompt, ask ‘what else would you want to try to cover in this conversation?’ OR*   + *‘If you wanted to start to wrap up the conversation, how might we do that?’* | |
|  | **Part Four** | **01:25 mins** |
| Nurse | That’s really important information, thank you so much Bob, a really great chance to start thinking about these things and for me to hear where you're up to with some of this thinking – | *Acknowledgement* |
| Bob | Yeah. |  |
| Nurse | And I wonder if it’s something that we might be able to pick up a conversation again in the future a little bit more about this. Because I think given the experience you've been through with Charlotte and the experience with your brother, and the thinking that you've clearly been doing about some of this, it might be the opportunity to create something we call an advance care planning document. Have you heard of that before? | *Negotiating further conversation*  *Introduce the words advance care planning and concept of a documented plan*  *Find out knowledge of advance care planning – open question* |
| Bob | No, no I haven't, but I, yeah being a businessperson I know that you've gotta plan for things and if you don’t they jump on top of you when you least expect it, yeah. | *He gets it*  *Agrees important* |
| Nurse | Absolutely, and I guess this is a chance to put down some of those things on paper, those things that you've talked about that are important for you, and why they're important for you. So that we’ve got some guidance in the future about how we might care for you and look after you if something did happen with your health that meant you weren't the person that could tell us those things anymore | *Explanation of advance care planning* |
| Bob | Yeah, yeah, well that’s the problem, if you can’t communicate your wishes you're gonna get all sorts of things foisted onto you aren't you, yeah, things you don’t want? | *Hearing her* |
| Nurse | Absolutely and this is a chance for you to say what you do want, what you wouldn't want so that we have a real clear sense of the care that we give you. | *Expands explanation* |
| Bob | Yeah. |  |
| Nurse | Something that you'd be interested in talking a little – bit more about – | *Negotiation* |
| Bob | Yeah I think so, yeah. |  |
| Nurse | Okay well let’s set up a time and we can have a bit more of a detailed discussion about that in the future? | *Planning* |
| Bob | Great. |  |
| Nurse | Thank you. |  |
| Bob | Okay. |  |
| **Discussion points** | * *Does he understand advance care planning? How do we know?*   + *Yes*   + *‘I know that you gotta plan for things’*   + *‘yeah, well that’s the problem, if you can’t communicate your wishes…’* * *Would the explanation have been as effective at the beginning of the conversation? Why?/Why not? (Why does it work now?)*    + *Done the ground work*   + *Linked explanation to what he has shared in order to make it relevant to him*   + *He has been heard (reflection, empathy => shared more info)* * *You may like to get the group to list what Bob has shared in terms of preferences (depending on how time is going and needs of group)* * *Get the group to summarise the communication tools that the nurse used to gather information from Bob about his preferences* | |

## Gladys – post stroke, Residential Aged Care

**Context**

79 year old lady who was living with her husband, Rex, in a Retirement Village townhouse until 2 months ago when she had a stroke. Following treatment in hospital with several weeks of rehabilitation, she has been admitted to an Aged Residential Care facility where she has been for 3 weeks. She walks with a frame, has some right-sided deficit so requires help with showering and dressing and cutting up her food. This conversation is part of the process of developing Gladys’s long-term care plan. The nurse having the conversation today has provided Gladys with the written information and they have had an introductory conversation about Advance Care Planning. Gladys did not want her husband present during this initial conversation.

| **Who** | **Script** | **Facilitation comments** |
| --- | --- | --- |
| **Discussion**  **points** | Ask the group how they might start the conversation.  What strategies or skills might be important at the beginning of this conversation?  *Get ideas from the group. Refer to the list we have made if necessary, and to what worked for the conversation with Bob.* | |
|  | **Part One** | **02:02 mins** |
| Nurse | Gladys thanks for making the time to come and see me today and to catch up – | *Valuing Gladys’s time* |
| Gladys | It’s okay. |  |
| Nurse | How are you going? | *Open question* |
| Gladys | Not bad, not bad. I'm not enjoying it, you know, the hospital people are lovely, you know and they try to entertain you and things. And worrying about my husband Rex because he’s on his own, and I do most of the stuff at home. And I don’t know whether he’ll remember to do anything, you know, and he suffers a lot from arthritis. So I always have to watch out for him when we go out, like you know because he tends not to look where he’s going, so he trips up. And if I'm not there I'm worried that he’ll have a fall somewhere and break something, and you know I just, you know. And I miss being with him. | *CUE: Worried about Rex*  *CUE: Miss being with Rex*  *Minimal prompts from nurse … ok … nodding*  *Allow to ‘vent’* |
| Nurse | You've had some big changes haven't you Gladys in the last few weeks? | *Acknowledgement of Gladys’s situation* |
| Gladys | Yes, yes I have coz, you know I'm used to being busy in the village, I get involved in a lot of things there, you know. I, I do the gift table there and organise getting the money, and delivering the gifts, but who’s gonna do it if I'm not there? Because nobody else seems to want to do anything like that, you know and I dunno – | *CUE: Missing identity of being a member of the village? Not feeling useful anymore?* |
| Nurse | Gladys it’s been a huge change for you hasn’t it – | *Empathy* |
| Gladys | Yes |  |
| Nurse | Since you had that stroke, now you've ended up needing more care and so that’s why you're here with us. And it sounds like you've been very active and busy in your life – | *Acknowledgement of current situation and past life* |
| Gladys | Yeah. |  |
| Nurse | And that’s, you're not able to do those things anymore – | *Reflection* |
| Gladys | This is right, I mean I make my own birthday cards and Christmas cards, and now I can’t do that – | *CUE: Feeling useless?* |
| Nurse | You can’t do anything – | *Reflection* |
| Gladys | Coz I'm right-handed, you know I don’t know who’s gonna do the cooking when I, you know I am going to get back home aren't I? | *CUE: getting back home* |
| **Discussion points** | * *How was the conversation initiated?*    + *Thanking Gladys for her time – valuing her*   + *Open question “how are you going?”*     - *Need to find out if she is in a space to be able to have this conversation*     - *What she says may be a starting point for discussion* * *What cues did she give us?*    + *Worried about and missing Rex*   + *Missing her identity as a member of the village? [used to being busy and involved in the village]*   + *Feeling useless? [used to do the gift table]; [I make my own … cards … now I can’t…]* * *What does it sound like is happening for Gladys?*    + *Grieving for her past life* * *How did Carla respond?*   + *Acknowledgement [you’ve had some big changes..]*   + *Reflection [you’re not able to do those things any more…]*   + *Summary of current situation [since you had that stroke … needing more care … been active and busy…]* * *How would you respond to Gladys’s last question?*   + *Allow group to come up with suggestions and then say “let’s see how Carla responds”.* | |
|  | **Part Two** | **01:04 mins** |
| Nurse | Gladys you know we need to see how things go, it sounds like being at home with Rex is something that’s really important to you – | *Honesty; tentative*  *Acknowledgement of importance of being at home* |
| Gladys | Ooh yes I can't, I can’t even begin to imagine not being there with him, you know, and I worry about him being on his own all the time, he’ll be so lonely. I might not get back home again, I just – | *Affirms importance*  *CUE: worried about Rex (2nd time)*  *CUE: thought about not getting back home* |
| Nurse | You’ve obviously thought about that? | *Exploring thoughts of not getting back home* |
| Gladys | I have a lot. |  |
| Nurse | What if you couldn’t get back home. | *Prompting disclosure about that* |
| Gladys | Exactly. I worry that, you know I know he could get meals delivered, what’s he gonna do all day on his own? I mean we do everything together always. | *CUE: Worried about Rex (3rd time)*  *CUE: being together (2nd time)* |
| Nurse | Do you know maybe that’s something that we can follow up with him – | *Negotiate following up Rex’s needs (attempting to ‘park’ Rex)* |
| Gladys | Oh that would be good. |  |
| Nurse | Yeah. And make sure that his needs are taken care of as well – | *As above* |
| Gladys | Yes. Yeah that would be lovely. |  |
| Nurse | So leave that with me and I’ll let you know how we’ve got on and what’s happening – | *As above* |
| Gladys | Oh that would be great, yeah I would appreciate that. |  |
| Nurse | Alright we can do that, that’s not a problem. | *Reassurance* |
| **Discussion points** | * *How did Carla respond to ‘I am going to get back home aren’t I?’?*   + *Tentative [see how you go…]*   + *Honest [not just saying what she wants to hear]*   + *Acknowledgement that being at home is important to her* * *What was the impact?*   + *Gladys expanded on her thoughts around this*   + *More cues – worried about Rex (2nd time); not getting back home* * *How did Carla use what Gladys said to explore the possibility of not getting back home?*   + *‘You’ve obviously thought about that?’*   + *‘What if you couldn’t get back home’* * *How did Carla try to move the conversation on?*   + *Acknowledge the importance of Rex’s wellbeing*   + *Offer a solution – attempt to ‘park’ Gladys’s worries about Rex* * *Where would you go next?*   + *Allow the group to come up with ideas and acknowledge them.*   + *If needing to prompt, ask, ‘what kind of things would you want to discuss with Gladys, in terms of the future?’*   + *‘Let’s see what Carla does’* | |
|  | **Part Three** | **01:03 mins** |
| Nurse | So Gladys just going back to thinking about what’s important to you, what you're saying to me is if you could get back on your feet – | *Steering the conversation*  *Acknowledgement of what’s important* |
| Gladys | Oh yes. |  |
| Nurse | And get back home that would be your ideal – | *Acknowledgement* |
| Gladys | Yeah, ooh yes definitely and get back to a normal life again. Am I gonna be able to do things that I used to do, or am I going to be unable to? See at the moment I can’t shower or dress myself properly, I can’t expect my husband Rex to do it can I? | *More scattered thoughts*  *CUE: wants to get back to a normal life again – unrealistic?* |
| Nurse | No, so I guess that’s – why you're with us so we can help you with those things – | *Acknowledgement of reality* |
| Gladys | Yeah. |  |
| Nurse | So getting back on your feet is important to you – |  |
| Gladys | Oh yes, yeah. |  |
| Nurse | But Gladys have you thought, I know you don’t want to consider this scenario – | *Warning shot of difficult question, linked with what’s been said* |
| Gladys | Right. |  |
| Nurse | But what about if things didn't quite get back to how you'd like? | *Exploring thoughts and feelings if home not possible – attempting to re-align Gladys’s reality* |
| Gladys | I don’t wanna think about it actually, I've never had any real problems and this has really thrown me. The thought of having another stroke scares the hell out of me. | *CUE: Thrown me*  *CUE: scared of another stroke* |
| **Discussion points** | * *What did Carla do to keep the conversation on track?*   + *Acknowledgement of what’s important*   + *Acknowledgement of the reality – gentle, tentative*   + *Explored ‘if home not possible’ – thoughts and feelings* * *How was the question of not getting back home opened up?* * *When Gladys says, ‘I don’t want to think about it’ would you take that at face value and move away from that topic? Why?/Why not?*   + *She has previously says she is worried about not getting back home*   + *It sounds like it’s a possibility she may not – so should we offer the opportunity to talk about it?* * *How would you respond to Gladys’s last statement?*   + *Allow the group to come up with ideas*   + *‘Let’s see where Carla goes next’* | |
|  | **Part Four** | **01:15 mins** |
| Nurse | I wonder whether it would be really helpful for all of us to start thinking about those things that would be important to you and to Rex if your health did change? Because one of the things that you've said is that stroke happened out of the blue – | *Tentative negotiation to discuss if health did change (linked with previous statement)* |
| Gladys | Yes it did. |  |
| Nurse | You were well and you're worried about what happens if it happened again – | *Reflection*  *Acknowledgement of worry* |
| Gladys | Yes. |  |
| Nurse | If you had another stroke – part of taking away, or at least easing some of that worry – is about making some plans around those things. | *Relate worry of another stroke with concept of advance care planning* |
| Gladys | Oh what sort of plans can I make? | *Engagement – asking about it* |
| Nurse | Well thinking about how you would want us to respond if you were very unwell, if something happened. How you'd want to be cared for if you couldn't speak to us and tell us | *Explanation* |
| Gladys | Oh if you, I don’t want, if I had another stroke and I got worse and couldn't talk or anything, I just wouldn't wanna be here. Because I think Rex would, it would upset him even more and I couldn't bear the thought of him just watching me like that, that would be horrible. It would be like looking at a vegetable, I don’t wanna be like that; I couldn't cope with that. | *CUE: What she would want if he had another stroke*  *CUE: worried about Rex seeing her even more sick*  *CUE: Vegetable* |
| **Discussion points** | * *How did Carla start to explore getting more unwell?*   + *Link to Gladys’s worry about another stroke*   + *Introduced the idea of making plans for if that happened (linking fear of another stroke with advance care planning)* * *What was Gladys’s response to this suggestion of making plans?*   + *She asked what sort of plans – she is engaged*   + *When she heard the explanation, she started talking about what would be important to her – she sees the relevance for her* * *What information did we get from her?*    + *Being able to talk is important to her*   + *Worried about Rex seeing her very sick*   + *She wouldn’t want to be a ‘vegetable’* * *How would you respond to that last set of statements?*    + *Allow the group to come up with suggestions*   + *If needing to prompt, ask ‘what do we think she means by being a vegetable? Do we need to check this out?’* | |
|  | **Part Five** | **01:29 mins** |
| Nurse | You wouldn't want to be a vegetable? | *Explore what she means by repeating her words back to her* |
| Gladys | No. |  |
| Nurse | Is that what you're saying? |  |
| Gladys | No. I couldn't bear the thought, I would want somebody to pull the plug, the thought of just lying there not being able to do anything, or being with Rex, or, I just. I mean what would there be for me? I mean if I'm going to like just lying there day in and day out what is the point? |  |
| Nurse | Okay so am I right … help me to understand what you mean by that. So if you were not able to do anything for yourself? | *Clarification of meaning of vegetable using reflection with a questioning tone* |
| Gladys | Exactly. |  |
| Nurse | And not able to interact with people? |  |
| Gladys | Yeah I couldn't cope with that and as I say I'd want either to have another stroke and that’s it, finished, you know. I don’t want anybody to try and resuscitate me, or try and do anything because I couldn't cope with that, and I don’t think Rex could, it wouldn't be fair. | *CUE: Resuscitation*  *CUE: Rex couldn’t cope [with her being a ‘vegetable’]* |
| Nurse | Alright so if you were ever in that situation then what you're saying to me is that you wouldn't want us to try and pull you out of that so that you – could exist. | *Reflection*  *Clarification of what she means by above statement* |
| Gladys | No, no, no, no. I mean what sort of a life would I have and what life would Rex have? It would be worse than if I went suddenly, that would be it, you know. I mean oh I can’t even begin to think about that. | *Affirmation* |
| Nurse | Do you know that’s really helpful for us to know that, because everyone likes different things. | *Validating disclosure* |
| **Discussion points** | * *What did we learn in this section?*   + *She doesn’t want to be left in a situation where she is ‘just lying in a bed’, unable to do anything for herself*   + *She doesn’t want Rex to have to see her like that*   + *She would rather die suddenly* * *What did Carla do to enable this disclosure?*   + *Explore and clarify her meaning of being a vegetable*   + *Reflection [‘so if you were ever in that situation …’]*   + *Validate disclosure [‘really helpful for us to know that …’]* * *What is needed now? How might you facilitate that?*   + *Allow group to come up with ideas*   + *If needing to prompt, ask, ‘what is one of the things we can do if someone has shared quite a bit of information with us?’* | |
|  | **Part Six** | **01:45 mins** |
| Nurse | Can I just summarise what I've heard from you – about what’s important, coz I wonder whether we might, if you're agreeable, if I can write some of these things down – | *Summary*  *Tentative negotiation of documenting* |
| Gladys | Yeah sure. |  |
| Nurse | So that we’re all on the same page – coz you shared some valuable information – | *Validating importance of disclosure* |
| Gladys | Yeah, no, that would be good. |  |
| Nurse | So the things that are important to you are, you're worried about Rex – | *Summary…* |
| Gladys | Oh yes. |  |
| Nurse | And, and he’s the most important person in your life? |  |
| Gladys | He is, he is, I mean I don’t have any other family you see – |  |
| Nurse | You really want to be together, yeah, you really, if you possibly could you'd want to get back on your feet and back into your cottage? |  |
| Gladys | Yeah, yeah. Yes I do, I do. |  |
| Nurse | And you want to get back into what you were doing in the village with – the crafts table |  |
| Gladys | Yeah I do. because I love socialising with, we’ve made a lot of friends in the village, you know. And I organise street parties so that we can all coz, you know neighbours, we’re all busy. And so I try to organise a street party every now and again so that we can all sit down together for a change. | *Expands on the things that are important* |
| Nurse | So being part of that village is – really important to you? | *Acknowledgement* |
| Gladys | Yes exactly. It’s wonderful there, you know. |  |
| Nurse | And what else you've shared with me is if you had another stroke – or something equally as serious and you were not expected to recover – then you wouldn't want to be here? | *More summary* |
| Gladys | No I don’t want anybody to make an effort to try and bring me back because I can’t see me, if I had another stroke, or anything like that, I'd be worse than I am now. And I just couldn't cope with that. | *Calmer?* |
| Nurse | Okay. And what you couldn’t cope with is the, not being able to do anything for yourself – | *Summary continued* |
| Gladys | Exactly. |  |
| Nurse | And not being able to interact with people? |  |
|  | Exactly, you know and I don’t want Rex having to do things for me because I don’t think he’d be able to. |  |
| **Discussion points** | * *Discuss the impact of the summary*   + *Clarification of wishes and what’s important to her*   + *More information (and probably more to follow…)*   + *The summary was in several parts, because Gladys was clarifying and adding information as we went* * *Gladys appeared a little calmer during the summary – any thoughts about why?*   + *She felt heard:*   + *Acknowledgement*   + *Picking up of cues and questions linked to the cues*   + *Acknowledgement of the importance of Rex* | |

# Appendix Four – Case scenarios for practice sessions

***Advance care planning conversation practice session***

**CASE 1**

* 72 year old retired barber/hairdresser
* COPD, CHF, diabetes, infected leg ulcers, obese
* Just been referred for home oxygen
* three hospitalisations this year (2 for exacerbation of COPD & 1 for CHF)
* Mobility limited to around the house
* Married and lives with spouse. Adult children do not live locally.
* **Setting:** GP practice or hospital.
  + **Note:** if hospital, consumer came in for a COPD exacerbation and improved with treatment; now feeling somewhat better and able to engage in conversation.

**CASE 2**

76 year old retired cook.

Stage 4 lung cancer, hypertension

Currently four weeks through a six-week course of palliative chemotherapy

One recent hospital admission for dehydration secondary to post chemo nausea and vomiting

Lives alone

Domestic assistance for vacuuming 1x week

Daughter and grandchildren help out with shopping the weeks she is feeling more unwell with chemo

**Setting:** Home visit by district nurse or community palliative care team to assess symptom control.

***Advance care planning documentation practice session***

**CASE 1 - documentation**

72 year old retired barber/hairdresser

COPD,CHF, diabetes, infected leg ulcers, obese

Just been referred for home oxygen

Three hospitalisations this year (2 for exacerbation of COPD & 1 for CHF)

Mobility limited to around the house

Married and lives with spouse. Adult children do not live locally.

**Setting:** GP practice or hospital.

* + **Note:** if hospital, consumer came in for a COPD exacerbation and improved with treatment; now feeling somewhat better and able to engage in conversation.

**Narrative**

“What does seriously ill look like to me? Being too sick to say what I want and not being able to breath.

If I get that sick again? Well, I’d want you to fix me up, of course! Phone an ambulance, bring me into hospital … I can’t stay at home when I am like that. I’m too sick – I can’t breathe!

The Dr said I came within an hour of dying last time I was in hospital. Just proves what I’ve always known – that I am a fighter and I don’t give up in a hurry! That last admission they talked about CPR and Intensive Care. They said jumping on my chest would be a waste of time with all that is going on with my heart and my lungs. After they explained it to me, I agreed! Sounds like a terrible thing to go through for no benefit. It does make me even more determined to keep going with everything else though, especially if they think it was going to help and get me fixed up again. Including antibiotics and that BiPAP machine.”

*Would there be a point, do you think, where you would want us to stop trying to save*

*you, and concentrate more on keeping you comfortable?*

“The only exception to this would be if my brain started to go…. I couldn’t imagine not recognising my family… spending my days lying in a bed with my mouth open dribbling all day long. No thank you!

Or if I couldn’t get back home … they’re not gonna put me in one of them homes – shoot me if that ever happens! Couldn’t bear it, to be gaga, dribbling my food, staring at the walls...”

**CASE 2 - documentation**

76 year old retired cook.

Stage 4 lung cancer, hypertension

Currently four weeks through a six week course of palliative chemotherapy

One recent hospital admission for dehydration secondary to post chemo nausea and vomiting

Lives alone

Domestic assistance for vacuuming 1x week

Daughter and grandchildren help out with shopping the weeks she is feeling more unwell with chemo

**Setting:** Home visit by district nurse or community palliative care team to assess symptom control.

“I am going to die from this damn thing. The cancer is going to kill me but at the moment I am doing OK - I still have my independence. I am proud of my attitude. I am not going to give into it without a fight.

I’m currently having chemotherapy. This means I am travelling in and out to hospital 2-3 times a week. It is limiting my social life and the chemo leaves me feeling pretty drained. I am looking forward to the chemo finishing so I can start getting involved in activities outside the hospital. I am keen to start going to a euchre group around the corner and get back to my weekly aqua-aerobics.

If my health is going down the tubes because of progression of my cancer and there is no possibility of recovery then please keep me comfortable and let me die. I am very clear I don't want to be kept alive hooked up to machines if there is no hope. It is important to me that my kids don't see me moaning and groaning and dying in pain. I recently watched my best friend die and it was horrible to see her in so much pain. I don't want that for myself. Please give me enough pain relief to keep me comfortable.

But if I am in an accident or have some other sudden health event and doctors believe my life can be saved and/or extended with good quality of life (in other words if they can make me well enough to return home again and keep living independently) then YES I would want interventions. They’re the experts and they know what my body could cope with, given it’s so full of cancer.”

**CASE 3**

84 year old retired school teacher

Parkinson’s disease; medication no longer working as well; cognitively intact

Two hospitalisations this year; one with an ICU stay due to complications from hip surgery after a fall

Worsening balance issues and several falls at home

Spouse deceased

Lives in Granny Flat on daughter’s property

Two other kids live locally; multiple grandchildren

**Setting:** GP Practice or home visit; you know the person very well.

**Narrative**

“Look … I’m deteriorating, there’s no hiding that. My daughter is having to do more and more for me, and I’m becoming a burden. She says I’m not. But I don’t want her to be looking after me. Especially when I can’t take myself to the toilet … ah no … I don’t want her to have to nurse me. I would rather go into the old people’s home. I don’t want to go back to hospital. No point. They can’t fix this … what’s the point in trying to keep this old body alive, just so I can deteriorate further? No … that’s not for me. I’d like to just go to sleep and not wake up.”

*Are you saying that if you become more unwell, even if there was something that could be*

*done to improve things, to keep you going, you wouldn’t want us to try?*

“No! Please … just let me go. I don’t want to get to the point where I’m just stuck in bed, can’t move, can’t speak, lost my marbles. No … last time I was in hospital they prodded and poked me … tubes everywhere, no privacy, so noisy … and so much fuss! I never want to go through that again. They wanted to give me a feeding tube, because I’m having trouble swallowing solid food now – but I told them no – it won’t achieve anything, except keep this broken body going – and I don’t want that.”

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1. [↑](#footnote-ref-1)