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Advance Care Planning Training Manual: Understanding Advance Care Planning

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“In some respects, this century’s scientific and medical advances have made living easier and dying harder.” *Approaching Death: Improving Care at the End of Life.* The Institute of Medicine, Washington, D.C., 1997.

Acknowledgements

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Preface

As healthcare technologies improve and people with many complex diseases live longer, Advance Care Planning, or ACP, is becoming increasingly important. There is considerable evidence that ACP is poorly undertaken, often happening only at the very end of life when crises occur, when life-sustaining treatments have been instituted despite issues of poor prognosis, and when patients are not capable of making decisions about the care they want.

The New Zealand Advance Care Planning Cooperative recognised that healthcare workers need better education in ACP. The Cooperative developed an ACP competency model, and based the original training manual, entitled Advance Care Planning Curriculum Materials, on the curriculum developed by Public Information and Advocacy Work Group of the Canadian Strategy on Palliative and End of Life Care.

Following the publication of the original training manual in 2010, further development of the New Zealand ACP training programme has been undertaken which has influenced the re-writing of the training manual. Developments include a DVD introducing basic concepts of ACP (BASIC level), interactive e-learning modules (LEVEL 1), the revision of the ACP Communication Skills workshop (LEVEL 2) and the development of a workshop facilitators training package (LEVEL 3). A training package for LEVEL 4 has also been developed, which allows for the independent training of LEVEL 3 and of actors for the Level 2 course, within New Zealand. The Ministry of Health has also produced a document entitled, “Advance Care Planning: a Guide for the New Zealand Healthcare Workforce”.

A second manual has been produced entitled “Advance Care Planning Communication Skills Manual”. This contains the advanced communication skills component of ACP delivery, and some of the communication skills content has been transferred to this manual. It is based on the UK Connected® National Communication Skills Training Advanced Communication Skills Handbook and is designed to be used by delegates completing the Level 2 training.

Who this manual is for

This manual is for all health professionals who are involved in ACP delivery or implementation. It is designed to provide an in-depth understanding of what ACP is and how it can be incorporated into healthcare. It should be read in conjunction with the Ministry of Health document: Advance Care Planning, a Guide for the New Zealand Healthcare Workforce (Ministry of Health, 2011) and the National Ethics Advisory Committee document: Ethical Challenges in Advance Care Planning (National Ethics Advisory Committee, 2014).

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Chapter 1: Overview of Advance Care Planning

Introduction

For more information on basic ACP concepts, please refer to the Ministry of Health document, *Advance Care Planning: A Guide for the New Zealand Healthcare Workforce* (2011).

What is Advance Care Planning (ACP)?

Advance Care Planning (ACP) is a process of discussion and shared planning for future healthcare involving patient, those in their whānau or equivalent, and healthcare professionals. It gives people the opportunity to develop and express their preferences for future care based on their values, beliefs, cultures and concerns, hopes and goals, a better understanding of their current and likely future health, and the treatment and care options available to them.

What is an advance care plan?

An advance care plan is an articulation of wishes, preferences, values and goals relevant to all current and future care. An advance care plan is not intended to be used only to direct future medical treatments and procedures when the person loses capacity to make their own decisions (becomes incompetent). It can and should, however, be used to inform decision-making in this situation along with other measures such as discussions with the individual's EPA (where one has been appointed) and with family/whānau. Advance care plans need to be regularly reviewed and updated as and when situations change.

The health professional role

Traditionally, ACP has not been addressed in healthcare training. This training manual has been developed to begin to fill that gap. It recognises the important role of healthcare providers of all disciplines and in all settings in facilitating ACP and of the need to integrate ACP into the care of all patients who would benefit.

There are many benefits to encouraging people to engage in ACP, not only those who are facing a life-threatening condition or those who have a chronic disease, but also people who are young and healthy. If ACP conversations occur before a healthcare crisis, the person has time to consider his or her choices and to talk with loved ones.

The tone of the conversation will be different in different situations; for example a conversation with someone who is facing inoperable cancer may be quite different from a conversation with someone facing a lifetime with diabetes, and a conversation with a person who is currently well would be different again. However the purpose remains the same—to help the person work through feelings and values in the most respectful and appropriate way so that if a time comes when the individual is incapacitated and is unable to make healthcare decisions, there will be a record of what would be important to that person at that time.

This manual focuses on the various elements of how to prepare for and introduce ACP, having the conversation and what to look out for, as well as the implementation of ACP into healthcare practice. There is also an ethical and legal side to ACP that needs to be understood, which will be discussed in Chapter 3.

Talking about Advance Care Planning

For many people, the most important thing about ACP will be to discuss deeply-held values and beliefs, including culturally nuanced beliefs about life and death, with their loved ones and with their doctor, nurse or other members of the healthcare team. Often, the discussion about healthcare choices may be part of a broader discussion that includes, for example, living arrangements, spiritual, wairua or the equivalent care, social contact with family, friends and/or members of the community and what the individual would like to happen after their death.

The value of Advance Care Planning

For **the person**, the process fosters personal resolution and may help to lessen anxiety about what lies ahead.

For the **patient's loved ones**, the benefit is in knowing what choices the patient would likely have made when he or she was capable of making decisions about treatment. Having this knowledge can help avoid disputes among family members because the person's voice has been heard and considered. Finally, there are benefits for families after death; comfort can be obtained from looking back with the knowledge that they were able to acknowledge and honour their family member's wishes. ACP has also been shown to positively affect the grieving process.

For **the healthcare team**, providers generally feel more comfortable providing care that they know is in accordance with the person's wishes and if everyone understands the person's wishes, there is likely to be less anguish and conflict associated with critical decision-making, both for the healthcare team and for the person's loved ones. ACP can help to strengthen the relationship between healthcare workers and the people for whom they care.

Summary

- Advance Care Planning (ACP) is a process of discussion and shared planning for future healthcare involving patient, whānau or equivalent and healthcare professionals.
- It should potentially be incorporated into all aspects of healthcare and undertaken by a variety of different healthcare workers.
- The conversation is individualised and will involve different aspects depending on the person's individual health, needs and preferences.
- There are advantages for the individual, the family/whānau or equivalent, and the healthcare team.

Chapter 2: Advance Care Planning self-awareness

Introduction

Before going ahead and having ACP conversations, there are a number of things to consider in terms of self-awareness. It is important to recognise our own feelings and reactions to such topics that may come up during an ACP conversation, in order to avoid influencing the conversation with our own opinions, values, cultural orientations and beliefs. This chapter explores some of these things.

Engaging in the ACP process

ACP can be difficult to discuss. A person is being asked to think about circumstances when he or she will not be capable of making healthcare decisions. They are being asked to consider such things as their feelings about death and dying, and quality of life, and to potentially discuss these things with loved ones. For some people such a conversation evokes powerful or uncomfortable emotions. For others it brings a sense of relief that things are out in the open.

Before engaging in ACP conversations with individuals, it is a good idea to have engaged in the process ourselves, in order to more fully understand the process in which the individual is being asked to participate. In addition, having engaged in the process ourselves and having a clear understanding of our own personal perspectives and biases helps to maintain integrity, authenticity and credibility. Here are some things to consider:

- How do you feel about ACP?
- How do you feel about death and dying?
- What choices would you make?
- Are you able to talk to your loved ones about your preferences?

How personal experiences and values impact ACP conversations with others

Self-awareness is a process of considering background, cultural identity and practices, where we fit in the world or community, and so on, and how we feel about these things.

Some questions to promote self-awareness include:

- How did I learn from my family about relationships? How does that affect how I deal with family members of patients?
- How does my cultural background influence my values? How does that affect how I approach people from cultural backgrounds different from my own?
- What do I think are appropriate gender roles? How do I communicate with males and females differently?
- How do I handle criticism or anger? In my caring role, how do I deal with people who are being “difficult” or those exhibiting behaviours that are different from mine?

- When I think about death and dying, what words/images come to mind?

It is not necessary to give up personal views or values, only to be aware of them and understand our biases so as to avoid them impacting the conversation.

Using debriefing and self-reflection

Debriefing and self-reflection is a useful way of learning from an experience and of gaining insight into personal feelings and reactions.

Questions might include:

- What am I/are we doing that is working well and what isn't?
- How do I/we know?
- What can I/we do to improve this experience for people engaged in ACP?
- How can we support each other?

Reflection following a negative or difficult experience with a family member, for example, may involve asking:

- How did I react? Was I defensive? Upset? Why did I react the way I did?
- How did my reaction impact the family member?
- How could I have handled that situation differently?
- How did that encounter influence the next ACP conversation?

A reluctance to engage in ACP

If there is a reluctance towards, or avoidance of, ACP conversations it is helpful to reflect on why that might be. Questions might include:

- Am I avoiding these conversations? Why?
- Have I engaged in my own ACP process? What was that experience like for me?
- Are there specific ACP topics or issues that I am uncomfortable with?
- What can I do to become comfortable with ACP?

Self-care

ACP conversations can be challenging and emotionally/psychologically taxing. Experiencing the grief of others can take an emotional toll. It is important to identify support systems and develop coping strategies that are personally effective. Consider:

- What positive support mechanisms work best for me? Am I using them?
- Are there opportunities in my organisation/community (e.g. team social events, stress workshops, wānanga, hui) that I usually avoid? Why?

- How do I manage to learn from a difficult experience, like a conflict with a patient’s family, without taking it home with me?
- How do I re-energise myself?

Summary

- Personal engagement in ACP helps when supporting consumers through the ACP process.
- Identifying personal feelings and reactions helps to avoid influencing consumers’ preferences.
- Debriefing and self-reflection are useful tools to support learning and the development of insight into personal feelings and reactions.
- ACP conversations can be emotionally draining, therefore self-care is important.
- Refer to the eLearning module entitled, “Considering Advance Care Planning” for more information about self-awareness and personally engaging in the ACP process, available at: www.advancecareplanning.org.nz

Chapter 3: ACP and the Legal Framework

Introduction

The legal framework as it pertains to ACP is described in the Ministry of Health document, “*Advance Care Planning: A Guide for the New Zealand Healthcare Workforce (2011)*”. This chapter expands on some of the concepts, an understanding of which is crucial for the effective implementation of ACP. The National Ethics Advisory Committee document entitled “*Ethical Challenges in Advance Care Planning (2014)*” is also a useful resource which will complement this chapter.

Code of Rights

ACP is consistent with the Code of Disability Consumers’ Rights (the Code), which promotes patient choice and autonomy in planning and receiving health care. Five of the rights within the Code are particularly relevant and applicable to ACP. 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).

Ethical and legal obligations of health care professionals

Healthcare workers need appropriate training to communicate effectively during ACP conversations and to understand the legal and ethical issues involved. This manual is designed to expand knowledge about ACP into all sectors of the healthcare community—to help entrench ACP into routine healthcare practice.

It is important to be aware of concerns about the misuse or misunderstanding of ACPs and/or Advance Directives. The following points reflect some of the issues that have been raised about ACP:

- No one should be pressured into ACP, or the drawing up of a written plan or Advance Directive. It is a person’s right to refuse to engage in ACP and it cannot ethically or legally be made a pre-condition for admission to any facility or institution.
- Consent to treatment must be obtained from a capable adult. The fact that the person has an ACP and/or Advance Directive or has appointed a substitute decision-maker is NOT relevant as long as the person is capable of making his or her own decisions about care.
- If an individual becomes mentally incapable of making healthcare decisions and has left prior documented instructions or preferences about care in the event of incapacity, those instructions or wishes do not necessarily provide consent to or refusal of treatment. Healthcare workers

must be familiar with the legal requirements for obtaining consent to treatment of incapable persons, and with the criteria making an Advance Directive legally binding.

The issue of competence

Mental capacity (or competence) to make healthcare decisions is an issue central to ACP. Only a capable adult can make an Advance Directive, and the directive is only in effect if and when the person becomes incapable. Legally, adults are presumed capable unless proven otherwise.

In general terms competence refers to an individual's ability to perform a particular task at a particular point in time. In this context it relates to an individual's ability to make a decision regarding their own current or future health care – namely, their 'competence at decision-making' or 'decision-making capacity'. Capacity and competence can be used interchangeably although sometimes capacity is referred to as a clinical judgement or assessment and competence as a legal one.

Respect for the intrinsic value and dignity of others means that incapable people must be protected. Declaring a person incapable places large restrictions on their autonomy and is therefore a very serious decision.

Capacity is judged on a task or function specific basis; that is, is the person capable of doing or functioning in relation to making a decision about the particular task or function. Consequently, the nature and content of the task or function, the context and level of risk are all relevant in deciding on capacity. This approach gives us three possible capacity assessment outcomes:

- Full/complete capacity to consent.
- Partial capacity (the person has capacity to consent to or refuse some things, but not others).
- Total incapacity.

A person who occasionally forgets to turn the stove off may still be able to understand what it would mean to go on a breathing machine, be capable of indicating prior wishes, and therefore have full capacity to engage in ACP.

It is important to distinguish between capacity to consent to ACP and capacity to consent to treatment. Capacity is needed in both instances.

Determining if the person is competent

The healthcare worker must use his or her own judgment, based on conversations with the person, to determine whether the person can understand and appreciate the treatment options and consequences. The healthcare worker obtaining a healthcare decision from an individual has the responsibility of determining whether that person is capable or not. If that person has doubts about the individual's competence, they should obtain a second opinion, which may be someone for whom formal capacity assessment is part of their role.

The common law test for capacity centres on a person's ability to **understand** the relevant information and **appreciate** the reasonably foreseeable consequences of a decision.

To understand: a person must be able to grasp and retain the information relevant to the decision at hand. If doubts about the person's ability to understand arise, the following questions must be explored:

- Has the person been given the relevant information in vocabulary appropriate to his or her ability to understand and in a language in which he or she is fluent?
- Has the person been educated about the illness and the treatment alternatives and been given opportunities to ask questions?
- Does the person understand that there are choices, what each alternative involves and its risks, harms, benefits and potential benefits?
- Can the person remember the information long enough to reach a decision?
- Can the person remember the choices made previously and be consistent in decision-making over time?

Note, however, that a person making a decision that the healthcare provider views as irrational does not mean the person is incapable. Equating irrationality and incapacity is a common error.

To appreciate: a person must be able to grasp how a given treatment will affect him or her personally. Some people describe appreciation as the person having an emotional understanding of the events and experiences for that person that will result from the decision.

The point is not whether a decision is reasonable, or what the healthcare professional would have chosen, but whether the person had legal capacity as described above to make the decision.

If a person's understanding or appreciation appears uncertain, healthcare workers may seek to explore further with them or involve someone who is experienced in formally assessing capacity.

Capacity can change over time: delirium, drugs, fatigue, strong emotions (e.g. depression, shock, denial) and underlying illness may render a person incapable; however, the incapacity may only be temporary. Reversible causes must be ruled out, treated and capacity must be reassessed. A person's ability to give informed consent and make healthcare or other decisions may vary from month to month, day to day, or even from decision to decision. For this reason, the process of obtaining consent is on-going, rather than a one-time event. Different treatments may be offered and accepted or refused as health deteriorates or improves, and people can change their minds.

Only a capable adult can document an ACP for him or herself, and an Advance Directive will only come into effect if and when the person becomes incapable. The chapters that follow will include discussion on disagreements about capacity and interpretation of a person's wishes.

Informed Consent

It is the responsibility of the healthcare provider to give the person “material information” to enable that person to make informed healthcare choices. The “material information” is all the information that would be required by a reasonable person in the same circumstances, as expanded by the person’s questions or what the healthcare provider knows the particular person would want to know.

The “material information” needed in order to make informed healthcare choices includes the risks, harms, benefits and potential benefits of the recommended treatment, of its reasonable alternatives, and of no treatment.

Healthcare workers must obtain consent to treatment from a capable adult. The following are prerequisites or elements to a valid consent:

- It must be voluntary.
- The person must be mentally capable to provide the consent.
- It must be informed, in that the person must understand the nature and consequences of the treatment, including its harms, risks, benefits, and potential benefits, and those of any alternative treatments, including no treatment at all.

The three elements—competence, voluntariness and information—sufficient to meet legal requirements are also required from an ethical perspective. Both ethically and legally, a discussion is required regarding the goals of treatment, the nature, purpose, risks/benefits of proposed treatments, and alternatives to the proposed treatments. The benefits and risks of no treatment should be covered as well. The healthcare worker should give reasons for recommending one treatment option over others.

The bioethics literature identifies a mixture of five abilities and conditions to determine capacity to grant informed consent which closely track the legal requirements (Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) 2008:12):

1. Ability to understand information (the informed part) and communicate a decision.
2. Ability to reason (to process information) and deliberate (assess risk/benefits of proposed treatments and alternatives, and comprehend the consequences of accepting or refusing treatment).
3. Ability to choose within a framework of personal goals, values and beliefs.
4. The choice is voluntary (no internal or external coercion).
5. Is capable of sustained co-operation (this last is controversial—not all bioethicists include this capacity).

If the individual has appointed a substitute decision-maker within their ACP or Advance Directive, the substitute cannot give consent on behalf of a capable person. In addition, the ACP or Advance Directive cannot be used in place of consent from a capable person. Prior wishes and substitute decision-makers only become relevant when the person is no longer capable.

Consent is more than a form or a formality

Obtaining consent is a process. A signed consent form is not a replacement for the process of obtaining consent. A signed form will not satisfy legal requirements if all the requirements for obtaining an informed consent were not fulfilled. A form may not satisfy the ethical obligations of the healthcare practitioner.

Different views of individual and family decision-making, and of the importance of individual autonomy, may be encountered. Many people want to make their own decisions about things that are important to their lives, like healthcare. However, some individuals and some cultures (e.g., Māori and Pasifika in NZ) emphasise family or group decision-making by way of consensus over individual decision-making.

Whilst discussing consent to treatment with a capable adult, if the person says he or she wants the family (or cultural equivalent) to decide, an agreement can be made to include family members in the discussion; however the decision belongs to the capable adult. The person may not want to hear about all the risks and benefits and alternatives, and family members may want to discuss them at length, but the consent must ultimately come from the capable person. As noted earlier, the consent is still valid even though the person has waived his or her right to information.

If the capable adult has communication difficulties, it is often tempting to talk with the family instead; however in order to fulfil ethical and legal obligations, it is necessary to attempt to communicate with the person themselves, which may take extra time and resources. For example, there may be a communication device or service that can be utilised, or a professional interpreter may be needed.

Advance Directives

An ACP may include some specific decisions in the form of Advance Directives. As with current decisions, a person making a decision in advance, in the form of an Advance Directive, must be:

- **informed**
- **competent**
- **without undue influence** (the decision must be voluntary).

When the Advance Directive comes to be used, the person must also:

- **have intended it to be used in the current circumstances.**

In the absence of reasonable grounds to doubt validity, an Advance Directive should ordinarily be honoured.

Sometimes an Advance Directive is not specific enough to function as a consent to or refusal of treatment (i.e. a decision) in the presenting situation. However it should still be taken into account when decisions are being made, and may provide direction about what the person may have wanted.

In order to improve specificity, it is desirable to document under what circumstances the decision is to be used. For example the decision may be:

“No renal dialysis”

The circumstances may be:

“Under any circumstances” OR “If I have become dependent on others for basic needs and my doctors believe there is little chance of this being reversed”.

In order to improve confidence in an Advance Directive, and therefore the likelihood that it will be honoured, the healthcare provider who is supporting someone to document an Advance Directive could document and sign that they believe the person to be competent to make the documented decisions, that they were informed and without undue influence.

ACP may contain specific Advance Directives as above; however ACP does not always result in any “decisions” because it is not always possible to anticipate illness or injury. In many instances the person is speculating, or expressing preferences about his or her future care, sometimes in a broad sense.

Enduring Power of Attorney

An Enduring Power of Attorney (EPA) is an authority given by a patient (known as donor or appointing), while they are competent, to another person (known as the attorney) allowing that person to act for the patient once the patient is mentally incompetent.

Under the 2007 amendments to the Protection of Personal and Property Rights (PPPR) Act 1988, a medical certificate stating that the patient is mentally incapable is required before attorneys can act in respect of significant matters.

A significant matter means a matter that has, or is likely to have, a significant effect on the health, wellbeing or enjoyment of life of the person. Examples are decisions about a patient permanently changing residence, entering residential care or undergoing a major medical procedure.

There are two types of EPA:

1. **A personal health and welfare EPA** appoints a person as an attorney to make decisions about an individual’s personal health and welfare on their behalf. Such decisions might include consent to medical or surgical treatment or admission to residential care, or choice of a

residential home. There is one main exception to the decision-making authority: an EPA cannot refuse standard life-sustaining treatment on behalf of the incapable person. Their views can still be considered; however the decision becomes the clinician's.

Only one person can be appointed to be a personal care and welfare attorney. However, one or more successor attorneys can be appointed to act if the authority of a previous attorney lapses.

2. **A property EPA** appoints an attorney to manage and make decisions about a person's property. These decisions might concern investment of assets, expenditure and decisions about sale of property. A property attorney may be given the authority to manage property affairs while an individual still has capacity and to continue to act if the individual is mentally incapable, or they may be given the authority to act only once the individual loses capacity.

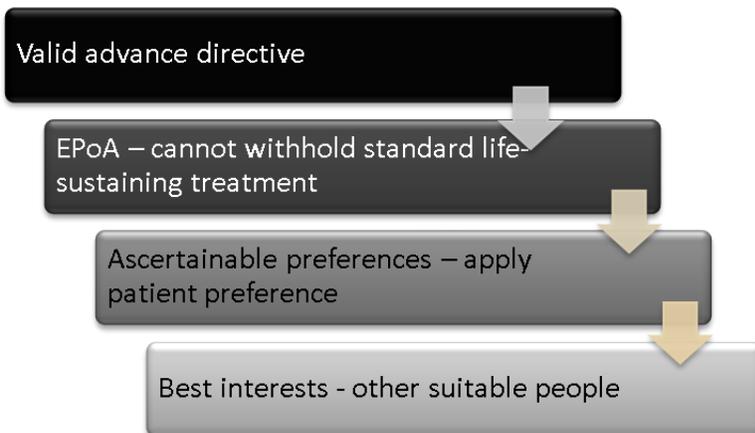
The same person can be both the personal care and welfare attorney and the property attorney. However, a trustee corporation cannot be a personal health and welfare attorney.

An EPA must be organised before an individual loses capacity, otherwise the power will be invalid. In order for it to be valid, it needs to be signed by both the donor and their appointed attorney, with both signatures witnessed independently. An attorney must be at least 18 years old, a New Zealand resident, not bankrupt, legally capable and not subject to a personal or property order.

Although family members may believe they have the right to make decisions on behalf of an incompetent patient because of their relationship with that patient, they do not have this right. Therefore, in the absence of a legally authorised proxy the decision rests with clinicians. The views of family/whānau or equivalent and suitable others are clearly important and should be taken into account; however these individuals do not have legal decision-making authority.

Decision-making for an incapable person

Where a consumer is not competent to make an informed decision about his or her health care, there is a specific order in which alternative measures are taken.



- If there is a valid Advance Directive pertaining to the presenting situation, this is taken as the decision.
- If there is no valid Advance Directive, and there is an EPOA for health and welfare, this person steps into the consumer's shoes and makes a decision on their behalf (with some exception, as noted above). A court-appointed welfare guardian can also consent to care and treatment on the consumer's behalf.
- If there is no valid Advance Directive and no EPOA, healthcare workers look for other ascertainable preferences; this may be in the form of an ACP or clinical records.
- If there is no valid Advance Directive, no EPOA and no ascertainable preferences, the clinician in charge of the care steps into the consumer's shoes and makes a best interest decision on their behalf, taking into account the views of suitable others, and based on best estimates of the consumer's values and preferences. The clinician should believe the decision is consistent with that which the patient would have made if they were able.
- If there are legal or ethical uncertainties surrounding the decision-making process, relevant people should be contacted for support and advice; for example a hospital's legal department.

Summary

- Healthcare workers have legal and ethical obligations regarding informed consent and refusal of treatments, both in the present, and in advance.
- A person must be competent in order to make an informed consent or refusal of treatment, and this competence may vary from day to day or from decision to decision.
- An ACP may contain Advance Directives, which are advance consents or refusals of specific treatments.
- If an Advance Directive meets the four criteria for validity, legally it should ordinarily be honoured.
- If there is no valid Advance Directive, an EPOA or a clinician may make healthcare decisions on the incapable individual's behalf, under certain conditions.
- Refer to the eLearning module on the legal framework entitled "Changing Outcomes" available at:
www.advancecareplanning.org.nz
- More information regarding the New Zealand Code of Health and Disability Services Consumers' Rights is accessible online at:
<http://www.hdc.org.nz/the-act--code/the-code-of-rights> and
<http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code> (full)

Chapter 4: How to Initiate the Conversation

This chapter discusses how to prepare for an ACP conversation and how to introduce the conversation in a sensitive way. The general approach will be influenced by the person's state of health.

The document entitled "Advance Care Planning: a guide for the New Zealand Healthcare workforce" (Ministry of Health, 2011) also contains some information on initiating an ACP conversation.

When to initiate an ACP conversation

A prevailing myth is that only people who are near the end of life, such as the elderly or people receiving palliative care, should engage in ACP. The fact is that conversations are much better conducted before the end of life is near, when the individual has time and peace of mind to think about the goals of care and to talk openly about wishes and concerns with family or close friends and with healthcare workers who can provide information and support.

Although people of any age can benefit from ACP, it becomes a priority if healthcare workers would not be surprised if the individual were to die within the next 12 months, bearing in mind that engagement in ACP is voluntary. The opportunity should be offered in a way and at a time that is most meaningful to the individual; their personal choice to engage in ACP or not, should be respected.

In the primary health environment, for example, ACP might be offered to a healthy person during a routine medical or wellness check. In hospital, ACP might be initiated during discharge planning, with a request to the GP to continue the conversation. In residential aged care, ACP might be initiated as part of the routine care planning process in the first few weeks of admission.

The person's emotional state needs to be taken into account when considering the timing of initiating ACP. For example the meeting at which the person learns of a life threatening illness is often not the best time to initiate an ACP conversation. The person will likely be shocked and emotionally upset, and usually neither the person nor the family members who are with them will be able to digest further information. If urgent decisions need to be made, a focussed discussion about certain aspects of ACP may occur; however a more comprehensive conversation is likely best left for another time.

Who should initiate and facilitate ACP conversations

The most appropriate person to initiate or facilitate an ACP conversation will depend on the circumstances. One of the great benefits of healthcare teams is that there is access to a variety of different expertise and information. A doctor may have the best information about treatment options, whilst a nurse may know the individual's needs and preferences better than other members of the team. A social worker or spiritual care advisor may have the closest contact with the individual. The ACP process may be initiated by one healthcare worker and continued by others.

In different settings, the person who is best suited to initiating ACP may be different. In a long-term care facility, for example, it may be the nursing director who is in the best position to take the lead. If the person is in hospital, it may be a social worker or a doctor.

Factors to consider when initiating ACP conversations

The patient's understanding

Before ACP is introduced, it is important that the patient understands its relevance so that the conversation can be placed in context. Reaching this level of understanding may involve exploring the patient's understanding of their prognosis and general health issues before introducing ACP.

The environment

Whatever the setting or circumstance, efforts should be made to have ACP conversations in an appropriate environment. Consider the following:

- A non-threatening environment.
- Ensure privacy and making people comfortable (e.g., adequate seating, familiar environment if possible).
- Set aside adequate time for the discussion.
- Prevent interruptions.

In a GP's practice, privacy should not be an issue; however allowing time for the discussion can be a challenge. In a hospital ward, finding private space may require some planning ahead. Preventing interruptions will be a challenge in most settings because of cell phones, pagers and so on.

Support services and devices

Appropriate supports may include professional interpretation services, or the presence of Kaumatua, Kuia or cultural elders which will need to be arranged ahead of time. Avoid using family or community members as interpreters, if at all possible, as their own views of the situation may colour their translation of the conversation; they may not understand medical terms and pass along inaccurate information to the person. Professional interpreters should have the necessary knowledge and objectivity.

Some people with disabilities are highly functioning cognitively, but cannot adequately communicate verbally. Do not assume that someone who has difficulty communicating does not understand, or has nothing to say. Find out what supports they need to make communication possible. Appropriate supports may include interveners for the deaf-blind or computer devices that create speech, for example.

Cultural considerations

Find out if there are cultural considerations for which arrangements can be made. For example, beyond desiring the inclusion of Elders or community members in the ACP process, people from some cultural backgrounds are reluctant to talk about their care or share intimate details of their lives with professionals of the opposite sex. If possible, the person facilitating the ACP conversation should be someone with whom the consumer can communicate comfortably.

Some people have a culture whereby the individual makes their own decisions, and others have a culture whereby family/whānau or equivalent make decisions as a group. Although legally and ethically in New Zealand it is the individual's decision that is important, the function of the wider family or community group in that decision-making process should be respected, if that is important to the individual.

Who should be present

Some people may prefer to meet one-on-one with a healthcare worker and no one else for all or part of the conversation. Others may want to have one or more family members or perhaps a close friend or Elder as mentioned with them. The person should be given the choice.

That also applies to inclusion of members of the healthcare team. Some people will be comfortable meeting with several people (e.g., nurse, social worker, spiritual/wairua care advisor and doctor), while others will find being faced with a team of people overwhelming.

Time for reflection

People need time to assimilate, reflect on and discuss the various elements of ACP, and as such the conversation may take place over several encounters.

Being prepared with appropriate information

Before engaging in an ACP conversation, an adequate awareness of the individual's state of health, course of illness and relevant medical facts (if appropriate) is important. Having to flip through documentation during the conversation is distracting and can impact on credibility and trust.

Creating an opening for discussion

After the above considerations have been addressed, an opening for discussing ACP is needed. All conversations should involve simple and clear language with technical terminology avoided as much as possible. The person should be reassured that ACP is an opportunity to clarify their priorities and wishes for their future care and to plan accordingly. ACP encourages them to focus on what is important to them to talk about the future if they wish (including death and dying) and to feel in control of their future care.

A healthy person

To encourage a healthy person to think about ACP, an opening might be:

“You are in excellent health and taking good care of yourself. Now is a good time to think about future healthcare planning; we call this Advance Care Planning. Is that something you’ve ever thought about?”

If the person has an ACP and/or Advance directive, the conversation can focus on what it says, when it was made, whether it reflects current wishes or needs updating, whether it names a substitute decision-maker, and whether the person has discussed the contents with loved ones. A copy should be placed in the person’s clinical record.

If the person is not familiar with ACP, they can be encouraged to consider it by raising awareness of why it might be important. For example:

“You never know what can happen in life. For example if an accident left you without the capacity to make your own healthcare decisions, what would you want to have happen? Who would you want to make decisions for you? What would be important to you? Advance Care Planning deals with those kinds of questions.”

Having take-home material available will help inform the person and encourage a conversation after the person has given ACP some thought. For example:

“I have a workbook/leaflet here that you may like to read and give some thought to. On your next visit, we can have a conversation about this, if you like. You may want to write down any questions or thoughts you have and bring them with you. You can ask someone close to you to sit in if you wish. I would like to help you with this, but remember, if you really don’t want to talk about it, that’s okay too.”

Someone who has a serious illness

Once the patient’s understanding of their current health is determined, you might introduce the subject by saying:

“We’ve talked about your health not being so good recently, and we know that there is a possibility that your health may change at some point in the future. I’m wondering if you’d like to consider having a conversation about what would be important to you if your health does change, and if you were ever too unwell to talk to us about your wishes. Is this something you have thought about at all?”

If, as noted above with a healthy person, the person has an ACP or Advance Directive, the conversation can focus on what it says, when it was made, whether it reflects current wishes, or needs updating, whether it names a substitute decision-maker, and whether the person has discussed the contents with loved ones. A copy should be placed in the person’s clinical record.

If the person has not engaged in ACP, having something to give the person and family members to read would be helpful.

“A conversation like this would give us an opportunity to talk about what might be ahead of you and what care and treatments might be required and available to you, and it will give you the opportunity to have some choice in what happens if you couldn’t speak for yourself at the time. It is also often helpful for family members to hear what’s important to you. Are you feeling up to having this conversation? I can set something up if you like. You can choose who you want to be with you.”

Summary

- People of all ages and states of health may benefit from ACP.
- Initiating ACP before the person become unwell or nearing end of life is preferable.
- ACP can be initiated by various members of the healthcare team.
- Ascertaining the person’s understanding of their current state of health should be considered prior to, or as part of, the initiation of the conversation.
- The environment, support services, the person’s cultural needs, who should be present, and being adequately prepared, need to be taken into account when initiating ACP.
- For additional information on cultural considerations it may be helpful to read the “Asian Health Support Services Guidelines for Advance Care Planning” available at:
<http://ecald.vps2.netpotential.co.nz/Resources/Resources-Publications/ID/946/Advance-Care-Planning--Guidelines-for-working-with-Asian-patients-and-their-families-2012>
- For additional information on initiating ACP, refer to the eLearning module entitled “Talking about Advance Care Planning” at:
www.advacecareplanning.org.nz

Chapter 5: Having the Conversation

This chapter looks at the potential content of ACP conversations, having done the preparation, and scheduled the time and place to begin a conversation.

More detail about specific communication behaviours is addressed during the Level 2 training, and in the accompanying Advance Care Planning Communication Skills manual.

The points below pertain to conversations with individuals in different states of health. Some points may be more relevant to conversations with a healthy person; some relate to someone who is very ill or dying; others could apply to any conversation with a patient.

Important considerations

Taking notes

There may be a great deal of information shared during ACP conversations, therefore it is advisable to take notes in order to capture all the important information for documentation purposes, and so that future conversations can build on, rather than repeat, what has already been discussed. It is courteous to explain the reason for that to the people present.

The person or family member may want to take notes too. They may also have brought their own questions in writing. Make sure those questions are dealt with as part of the ACP conversation.

In some cases it may be appropriate to make an audio or video recording of the conversation, if that is the person's wish. This may be useful if an important family member cannot be present, for example, or if the people present are unable to make notes.

Hearing the person's voice

Everyone is unique, influenced by experience, life circumstances, family, society, culture, and belief systems. The choices that a person makes in ACP will be based not just on medical options, risks and benefits, but also on personal values such as what makes life worth living and previous experiences with death and dying. While medical facts are taken into account, the ways in which they are interpreted, and the importance placed on different risks and benefits, are deeply personal.

It is important to go into ACP conversations without preconceived assumptions or predictions about what people will or should feel or believe. For instance, someone who is severely disabled may consider that they have a very good quality of life; whereas someone who is reasonably functional may consider that they have a very poor quality of life. It is helpful to try to understand their viewpoints as an individual.

Encourage the person to explain how they see things, and why certain things are important to them. For some people this may be the first time they have had the opportunity to explore their feelings about what is most important to them in life and how they feel about death and dying. They may even be surprised at the feelings that come up for them. Listening without judgement and helping them to articulate their individual preferences by gaining some understanding of what is behind these preferences, will help to ensure that it is the person's voice that comes through in the ACP.

Active listening

A person can be encouraged to continue talking by using minimal prompts such as nodding, or giving verbal encouragement such as "mmm...go on". Acknowledging and reflecting back to them what they have shared will let them know they have been heard, and this will also provide encouragement to continue and help them to know that their views and feelings are valued.

Exploring values and beliefs

Exploring values and beliefs about quality of life and dying well often forms part of an ACP conversation. One way of broaching this might be:

"It's one of the hardest and yet one of the most important questions we can ask ourselves. What makes life worth living? What matters most to you?" Or "What are the things you value most in your life?"

"What does quality of life mean to you?" Or "What makes up quality of life for you? Can you think of a situation in which you would consider you would have no quality of life?"

Depending on the person's response, further exploration may be appropriate.

Someone may fear confusion and dependence; others may not worry about these things. People may fear pain, or breathlessness, or some medical treatments. Older people often worry about being "a burden" to family members.

Again, acknowledging their perspectives without judgement or a need to 'fix' anything, will help to most accurately capture what is important to that person.

Involving family/whānau or the equivalent

Family/whānau or equivalent may or may not be present, either because the person has chosen to have the conversation without them, or because they cannot be there. It may be that they find it difficult to discuss ACP wishes and preferences with them; they may need support to have that conversation, and this should be offered. Having written resources to give to family members may help. The family group may wish to meet without the healthcare worker in the first instance, or after an initial discussion together. Either way, the person should be supported to engage in the most appropriate process for them, in line with their preferences.

Conflict within a family group can occur at times, and this is discussed in Chapter 6.

The impact of culture and religion

When working cross-culturally, particularly in a bicultural treaty responsive and rich multicultural society such as ours it is important to be aware of how personal beliefs, values and culture affect our attitudes and behaviour. The assistance of clergy or an elder, or someone with the same cultural background with whom the person can comfortably communicate, may be required. Understanding a religion or culture takes more than an open mind.

Beliefs about life and death vary considerably, and will affect how individuals would want to be treated, and what would be important to them, in the event of serious illness or when they are approaching the end of their life. Certain belief systems may impact an individual's desire or ability to engage in ACP. If the person seems uncomfortable with the ACP process but hasn't said why, it might be appropriate to explore this, to try to gain an understanding of what might be behind their discomfort.

Documentation

All ACP conversations should be documented in the clinical record so that other relevant health care professionals can continue the ACP process if appropriate, and so that important information is available to inform future decision-making. Details may include, for example, decisions about goals of treatment, treatment plans, questions or concerns raised by the person and perhaps the need for emotional psycho-social supports, as well as a plan for continuing the process.

Documentation may also include a copy of an ACP document, where one is completed with the individual.

Documentation and sharing of information from an ACP conversation is dealt with in more detail in Chapter 7.

Advance Care Planning as a process

As has been discussed, ACP is a process rather than a one-time event. ACP may involve one or more conversations over time before an individual is ready to make any decisions or define goals or preferences. There may be many conversations over the remainder of the person's lifetime, because as health or circumstances change, so may their preferences or decisions. People need to know that they can change their minds at any time (if they remain competent to do so) about the preferences they have articulated or decisions they have made.

The person with a known health condition

One way of opening up an ACP conversation with a person with a known health condition, is to ask what they understand about their condition, what he or she expects to happen, and how they feel about it. In other words, to explore their knowledge, understanding and feelings about their situation *before* offering explanations – your explanations are more likely to make sense to them, and they are likely to retain more of what you say.

A person may know a lot or very little about their own illness and its possible trajectory over time. Some people are avid researchers and want to know everything that could happen and what the odds are of various outcomes; others may be much less interested, preferring to live day-to-day and face events when they happen. Using pictorial representations of disease trajectories and asking the person to indicate where they think they are on the line, might be one way of finding out their understanding.

As well as their understanding of their current condition, it is useful to know how they feel about it, and how it impacts their views on life and death. A person may be fatalistic, or optimistic or somewhere in between. They may be angry, or sad, or have other strong emotions relating to their condition and likely prognosis.

Possible ways of starting the conversation include:

“Perhaps the best place to start this conversation is with how you are feeling right now.”

“What is the effect of this illness on your life?”

“What do you expect to happen down the road?”

Other questions that could be helpful include:

“What do you think has caused your problem/symptoms/illness?”

“How severe is the problem from your point of view?”

“What kind of treatment do you believe is best?”

There is an opportunity to validate understanding, fill in gaps or correct misunderstandings about medical facts, after having listened to the person.

This conversation is not just about getting the medical facts clarified. It is about exploring how the person feels about the illness and what may happen in future, particularly when they may no longer be able to decide what kind of treatments they want or don't want.

It may be appropriate to explore further by asking:

“What worries you most about your illness as time goes on?”

“Is there something you are especially afraid will happen?”

At this point it may be appropriate to explain possible treatments that the person may be offered in the future, what these treatments entail, and the potential benefits and risks. Or it may be an opportunity to reassure them about something that is very unlikely to happen.

If the person has directed that they do not want to go to the ICU, or if they are in a long-term care facility and they don't want to be taken to an emergency department, you can help the person clarify

the implications. For example, are they aware that in certain circumstances, not going to the ICU will mean that their life will not be able to be preserved?

Explaining life-sustaining treatment

An ACP conversation often involves talking about life sustaining treatments to some extent, whether it be regarding antibiotics for a life-threatening infection, or intubation and ventilation in an ICU. For someone who is terminally ill, this part of the conversation may be a simple and straightforward discussion, as any life-sustaining treatment that may be offered is likely to be very limited. For someone who is currently well, or in a situation where all possible life-sustaining treatments may be offered at some point in the future, the person may require detail about the various options that may be offered; this may require involving a healthcare worker with relevant knowledge and experience with such treatments.

It is important to bear in mind that not everyone would be offered all available life-sustaining treatments; therefore the healthcare worker having this conversation needs to be aware of such limitations for the individual, or involve someone who is. There is no value in assisting a person to decide if they would want intubation and ventilation, if this would never be offered to them, for example. If the person expresses a wish for something that would not be offered, there may need to be a conversation about treatment limitations in their situation, and why certain interventions are not an option for them. This may mean involving someone else with the appropriate expertise.

However involved the conversation about life-sustaining treatments is, the role of the healthcare team in the context of ACP is to help the person understand what is involved and the implications of various options, in order for them to make informed choices; also to interpret and document their wishes in a way that is useful to the healthcare team that may be treating that person in the future.

As with other aspects of ACP, a person's preferences regarding life-sustaining treatment will be based on their values, beliefs and goals. For some people, life is precious under any conditions and there is no way they would plan ahead to limit life-saving treatment. For others, there will be concerns about unduly prolonging their lives when death is imminent or when life as they value it will no longer be possible. Even people with similar states of health may vary greatly in what life-sustaining treatment they would want. For example a person with end stage lung disease, with very limited life-sustaining treatment options, may prefer to have all treatments available to them to preserve their life under any circumstances; another person with the same illness may prefer no interventions that may prolong their life, including antibiotics.

Misconceptions about life-sustaining treatments are common. With television full of hospital-based shows, many people have received a distorted view of the possible risks and benefits. On television, hearts are commonly restarted after cardiac arrest in people who are very ill, and patients on the brink of death are restored quickly to robust health after administration of some miraculous cure. Part of an ACP conversation may involve correcting misconceptions. It is therefore important to find out what their understanding is.

The person's goals

Before launching into a conversation about life-sustaining treatments, it is useful to first find out what the person's goals are in terms of care and treatment in various circumstances. You might start with:

“Do you foresee any circumstances when you would not want to be kept alive by artificial means?”

“We have all heard of cases where a person is kept alive for a long time with breathing and feeding tubes. What would you want to happen in those circumstances?”

Some people may feel that having their life sustained under certain conditions is interfering with the natural course of dying, while others may feel the opposite—that not trying to save someone, regardless of the person's quality of life, is to disregard the sanctity of life.

It may be that a person makes no decisions about specific life-sustaining treatments; they may prefer to make a broad statement regarding their goals in certain situations, and leave the healthcare team to decide what treatments fit with those goals at the time. For example:

“I do not want any interventions given with the intention of preserving my life if I am mentally impaired to the point of being unable to recognise my wife and this is not expected to improve.” Or

“I would want all available treatments to preserve my life as long as recovery with quality of life is reasonably expected. Quality of life for me is being able to recognise my wife and being able to communicate.”

Someone with a terminal illness, for example, who feels they have an unacceptable quality of life and this is not expected to improve may choose:

“No treatments of any kind to be given with the intention of sustaining my life, under any circumstances including for potentially reversible conditions.”

Where a person dies, or is cared for before they die, is important to some people, and this may have implications regarding life-sustaining treatments. For example if a person wishes to remain in their residential care facility, there will be limitations to the types of life-sustaining treatment available to them. Receiving ICU treatment for a potentially fatal condition may compromise a person's strong wish to die at home.

Life support

“Life support” is a fairly well-known term, but most people do not know what it involves, nor do they know what going to an ICU implies in terms of the severity of illness. Many people are unaware that life support measures may not be appropriate for all people and in all circumstances.

If life-support measures might be an option for the individual at some point in the future, the first thing to do is find out what they know. Rather than asking whether he or she would want to go on life support or would want “everything done”, you might start with:

“Can you tell me what you understand about life support? Have you had any experience with ICU? Lots of people only know ICU through what they see on television.”

The level of detail the person wants to know will vary by individual and by state of health. Gauge how much they want to know by their responses and questions. One introductory explanation might be:

“When we talk about life support, we are talking about two broad categories of treatment: the ventilator or breathing machine and powerful drugs to support heart and blood pressure. The ICU is the place in a hospital where they use these machines and drugs to treat seriously ill people who could not survive without them. And sometimes these machines and drugs are not enough to keep people alive.”

“Life support can prolong life and potentially restore people to the same quality of life as before. But life support is not a cure, so if there is an underlying illness, like cancer or heart disease, the person will still have that illness when they come out of the ICU. They may be weaker than they were before.”

If further explanation is required, a healthcare worker with the appropriate expertise may need to be involved, for example an ICU nurse.

Time-limited trials

Someone having an ACP conversation may want to know if life sustaining treatment is an all-or-nothing scenario. It may be appropriate for life-sustaining treatments to be trialled, and if treatment goals are not met, the anticipated benefits do not occur, or if the burdens are greater than the benefits, the treatment can be withdrawn.

The advantage of time-limited trials is that they may allow a person to achieve a specific goal (e.g., live until the first grandchild is born or until the family has time to gather at the bedside) or allow the family to feel that they have tried “everything” even in the face of slim odds.

The disadvantage is that it may be harder emotionally to stop life-sustaining treatments than to start them. While, ethically and legally, withholding and withdrawing treatments are considered equivalent, in practice they may feel very different.

The dying process

ACP conversations often include a discussion about dying. Some people may have fears about the dying process; some people may fear being dead. Many people have misconceptions about the dying process. ACP conversations are opportunities to talk about a person’s understanding of the dying process, what they might be worried about, and what would be important to them at that time.

There are many different beliefs around death and dying. For example some people believe that to withhold or withdraw artificial hydration or nutritional support constitutes euthanasia or assisted suicide. The alternative and more common view, however, is that artificial nutrition and hydration are medical treatments just like any other, and consequently are subject to the same ethical and legal rules about withdrawing them as other treatments. It is often helpful, when discussing the withdrawal or withholding of treatments, to keep the discussion in the context of the person's values and goals; in other words what they would like the healthcare team to try to achieve for them.

Cardio-Pulmonary Resuscitation (CPR)

A discussion of CPR in the event of cardiac arrest is also often part of an ACP conversation. The term 'resuscitation' can refer to other interventions as well as CPR, and often people mistakenly believe it to mean 'no treatment'. Therefore it is important to be clear that the discussion refers to if the person's heart stops; interventions in other situations would be a different discussion.

It is also important to know whether there are any treatment limitations for that person; for example, would CPR be medically appropriate for them in all or any circumstances? There is no value in helping a person to decide whether they would want CPR, if it would never be medically appropriate (for example for someone with end stage heart failure living in the community). Similarly, if the person's primary goal is to be kept comfortable and to allow the dying process to occur naturally, there is no value in having a discussion about CPR. Instead, the conversation would include clarification that the person understands the implications of their choices, or of the severity of their illness.

There are four general categories where CPR can be viewed as a treatment option:

- People who are likely to benefit.
- People for whom benefit is uncertain.
- People for whom benefit is unlikely.
- People who will almost certainly not benefit—the person will either not recover due to underlying illness or will never be able to experience any benefit.

As with life support, many people have misconceptions about what is involved in CPR and its likelihood of success, as what is portrayed in television shows is often unrealistic. As previously, start with finding out what the person understands.

"What about CPR? Do you know what it is? Have any of your healthcare team talked to you about it before?"

It is not the role of the healthcare provider to discourage use of CPR, but it is important to be realistic about the severity of the illness that can lead to a cardiac arrest, and what is involved in resuscitation, so that the person can make informed choices. For example people are often unaware of the risks of neurological damage, multi-organ damage, or the need for life support afterwards. CPR may worsen the patient's overall health. The underlying state of health of the person affects the chances of CPR being

successful. The level of detail provided will depend on the person's state of health and desire for information. An example of a fairly detailed explanation is as follows:

"If your heart was to stop, you would die. A medical team or emergency paramedic team could do chest compressions and use electric shocks to try and restart your heart. Even with CPR, unfortunately, the blood flow to your body is not as good as if your heart was still beating. The longer it takes to restart your heart, the more damage will occur, particularly to the brain. The sicker you are before, the less likely your heart will be able to be restarted at all. If it is restarted, you are likely to have to have a breathing tube and be on life support afterwards."

If the person you are talking to is living in his or her own home and does not want CPR to be performed, the decision should be communicated with others living in the same house, and if there is a Do Not Resuscitate order, it should be readily accessible.

In some institutions, if no order has been signed, the default is to perform CPR in the event of a witnessed cardiac arrest. Most health care professionals would try to resuscitate if the person had not specifically rejected CPR.

In hospital, there may be a tendency to think that a patient with a DNR order has given up and so should the medical team. That is an incorrect and inappropriate assumption. It does not mean that the patient has given up hope of quality of life or even, depending on the situation, of cure. It may simply mean the person recognises the severity of illness and the gravity of the situation in which CPR would be needed and understands chances of successful resuscitation are uncertain or low and does not wish to undergo CPR.

Interpretation of a person's preferences and decisions

One of the roles of health care professionals is to interpret, and help the person to articulate, their preferences and decisions in such a way as to be meaningful to clinicians treating them. A person may say something like "I never want to be a vegetable – if I'm ever like that, switch me off." This statement may mean different things to different people, therefore it is important to clarify. You might respond with:

"What would being a vegetable look like to you?" And then "And what do you mean by 'switch you off'?"

Summary

- Explore the person's perspectives, statements, or wishes.
- Find out their understanding and feelings before giving them information.
- Listen carefully to what they are saying.
- Explore if, when and how they wish to involve loved ones.
- Take cultural, spiritual and religious beliefs into consideration.
- Documentation and the appropriate sharing of information are essential.

- Talking about life-sustaining treatments is often part of an ACP conversation.
- The level of detail of a discussion about life-sustaining treatments will vary from person to person depending on their state of health, their preferences and goals.
- As health care professionals we need to interpret and help the person articulate their preferences.
- ACP is a process not a one-time event.

Chapter 6: Conflict: Prevention and Management

ACP may, at times, involve some conflict either within families or between consumers and the healthcare team. Usually the conflict can be easily and simply resolved with appropriate communication before it becomes a significant issue. This chapter discusses the prevention and early intervention of conflict. Strategies for managing more complex conflict can be found in the ACP Communication Skills Manual.

Conflict may arise in different situations and involve different parties. Perhaps a capable person and his or her family disagree about engaging in ACP. Or a capable person has a preference for future care that his or her substitute decision-maker does not feel able to honour. Perhaps a capable person or the family wants something that the healthcare team does not think is appropriate care, or members of the healthcare team disagree over the interpretation of an incapable person's wishes.

It is not possible to avoid all conflict. Recognising that is important. Where possible, however, health care professionals should try to reduce the likelihood of disputes, prevent the escalation of disagreements in the early stages, and promote the resolution of conflicts.

Prevention of conflict

The source of many disagreements between health care professionals and consumers is miscommunication in the form of inconsistent information. This can be minimised by having processes in place to ensure effective transfer of information.

Sometimes miscommunication is in the form of poorly delivered information. Clear and unambiguous communication is important. Effective communication involves finding out the person's perspectives/concerns/understanding, listening carefully, speaking clearly in plain language free of medical jargon and euphemisms, and pausing often to clarify what you have heard and to check what the person has understood.

How the person perceives the healthcare worker will impact on how they receive information. Consider the following:

- Do I seem empathic or impersonal?
- Am I at the same level as the people I am talking to or do I tend to stand while they are seated (or lying down)?
- Am I usually rushed or distracted or am I invested in this conversation and the time it will take?
- Do I really listen when people talk about their lives and emotions (as well as their illness and treatment)?

If the person perceives they are being heard, and that their concerns and perspectives are important, they are more likely to effectively receive information from the healthcare worker. If the person engaged in ACP is facing a life-threatening illness, they and their family may be experiencing significant

emotions or stress; if they feel this is acknowledged by the healthcare worker, again information may be more effectively received.

Managing different preferences

Consider the example of a person whose health status is deteriorating quickly and who is weighing healthcare options as part of ACP. They may have been told that certain treatments are not an option at this point, and why. If the person is in disagreement about the treatment plan, getting impatient or pushing an opinion more aggressively may turn confusion into anger. To prevent this, it is useful to try to understand the reason for the resistance.

Discovering the reason for the disagreement

Some things to consider:

- Have I given the information that the person needs in order to understand the risks/benefits of future care in a way that is meaningful to them? If not, it may be appropriate to try again.
- Have I given the information that a reasonable person would need to understand these risks/benefits?
- Have I explored their understanding first, before giving the information?
- Is there something they are afraid of?
- Do they know that I have heard their difficulty? If they have a perspective or concerns that they feel you haven't heard, they are less likely to be fully able to engage with what you are explaining.
- Is this the best time to be having this part of the conversation: are they able to concentrate on this conversation right now or are they distracted? Are the appropriate people present/not present?
- Am I listening more to the family or to other professionals than to the capable person?
- Am I feeling a certain way because the request for care is being presented in a certain way?
- There may be spiritual, cultural or other reasons why this person does not agree with the view of the healthcare team. A capable adult has the right to plan in advance for a future incapability and to give instructions about treatment. The healthcare provider should explain options, but is not the decision-maker.

Preventing escalation

If the conflict is not resolving, seek appropriate support in order to prevent escalation. Here are some examples:

- A colleague from a different discipline may be helpful in providing additional information or clarity for either the health professional or the patient.
- A spiritual or cultural advisor may provide emotional support for the patient who has underlying fears, enabling them to move forward with conflict resolution.

- A bioethicist may help to resolve conflict of opinions about appropriate treatment between colleagues.

If a disagreement is escalating, it may be necessary for someone with the appropriate skills to mediate. Mediation strategies are discussed in the ACP Communication Skills Manual.

When the person's request is unable to be met

Although a person has the right to give instructions, he or she does not have the right to insist on healthcare that is not medically indicated. For example, a patient cannot force a surgeon to try and remove a tumour if the surgeon feels that the surgery is impossible or futile. They may, of course, request a second opinion and that request should be honoured if time and resources permit.

At times the conversations where a person is told that their requests cannot be met are difficult, and involve ensuring that the person feels that their choices and their reasons have been heard. Strategies for managing such conversations are addressed in the ACP Communication Skills Manual.

Family/ whānau (or equivalent) dynamics

Even the most amiable family relationships can dissolve under the strain of a situation that disrupts the family system. Avoid labelling families who are having a hard time dealing with advance care planning issues, as “dysfunctional” or “difficult”.

There can be disputes among family members about carrying out what a loved one has requested; for example, if the person has specified that they want to die at home - which family members will be there to look after the person? Who will learn how to give injections? Does everyone understand what kind of care will not be given—ventilation, intubation, and so on?

It is important to focus on the current situation, the person's needs and the decisions at hand, rather than past disputes. It is also important that all people involved feel that their perspectives have been heard and taken into account, and that the healthcare worker is not taking sides.

Sometimes grief and distress about a loved one's illness can turn into anger towards health care professionals. They may try to interfere with delivery of medical care, make excessive demands on staff time, and see everything as a crisis. Sometimes when someone is dying, family members refuse to acknowledge it. They may pretend their loved one is getting better or demand procedures to “cure” the person. They may avoid the person. Family members may argue amongst themselves at the bedside or pass on inaccurate information to other family members.

The healthcare team's challenge is to understand these behaviours and help the family in their coping and adaptation where possible. The first step to understanding these behaviours is to listen, not only to what is being said, but also to what is not being said, and to the motivation and the emotion underlying the words. The next step is to acknowledge and validate what is being said and to show empathy. A shared understanding and ability to negotiate a way forward may then be possible.

The healthcare team must assess its own strengths and limitations in the resolution of family conflict. If the situation is beyond the capacity of the team, seek help from a skilled mediator.

When family members want to speak for a capable person

Sometimes for cultural or other reasons, families may try to stand between the healthcare team and a capable person. The family may ask the person not be told about a diagnosis and not be consulted on options for care as the disease progresses, for example.

A person is not required to engage in ACP, however is entitled to be informed about his or her medical condition, and to be given the opportunity for ACP. It is not usually acceptable to talk to family members instead of the capable person. A conversation with the capable person should occur in the first instance, in order to establish what they want to know about their state of health, how much detail they want about their condition and likely progression, and who they want the information to be shared with. Most people want to be informed directly about their condition; however, in some cultures it is the family that receive this information – the capable person should be consulted in the first instance to ensure this is their wish, and if it is, this should be respected.

The family can ask to be present for this conversation; however who attends is up to the individual. If there is a problem with communication because of language for example, make arrangements within the healthcare team to solve it (for example a professional interpreter may be required for the conversation or a communication device for a person who has difficulty speaking or hearing).

Similarly, if the family objects to wishes that the person makes as part of his or her ACP, the healthcare team's obligation is to respect the wishes of the individual.

Summary

- Clear and consistent communication from the team will often avoid conflict.
- An ability to see the world as it occurs for the patient and family, will likely result in the building of trusting relationships, and conflict is more likely to be avoided.
- If the goals of care are agreed upon, conflict is less likely.
- If the person feels that their perspectives have been heard, they are more likely to effectively receive the perspectives of the healthcare team.
- Mediation may occasionally be required if conflict begins to escalate.
- For further training in advanced communication skills related to ACP, consider a Level 2 course; more details available at: www.advancecareplanning.org.nz

Chapter 7: Documentation and the sharing of information

There may be many different forms of ACP documentation, depending on the context of the conversation. If an ACP conversation has occurred with a healthcare worker, at the very least there needs to be reference to the conversation and main points covered, documented in the clinical record.

If the ACP conversation was an initiation of the process with the provision of written information, the documentation may be very brief. If the ACP conversation was comprehensive, involving care and treatment preferences and so on, the documentation will be more comprehensive.

Documentation may also be different in different healthcare settings. The important thing is that this information is available to the relevant people if that person ever becomes incapable.

The ACP document

If a comprehensive conversation, or series of conversations, has taken place, and the person has expressed values, goals and preferences, for example, it would be appropriate to suggest to the person that these be recorded on the specific ACP document. In that way the person can have a copy, they can share it with relevant family/whānau, and a copy can also go in the clinical record and appropriately shared with relevant health care professionals (with the person's permission). When completing an ACP document, the person needs to be aware that it can be altered at any time by them if they remain capable of making their own healthcare decisions.

The completion of an ACP document might be done by the person themselves, or it might involve one or more health care professionals. It is strongly suggested that the Advance Directives section, if this is completed, be done with a healthcare worker with relevant knowledge of care and treatment options as relates to the individual.

The clearer and unambiguous the statements within the ACP document (or within the clinical documentation), the more likely they will be interpreted as the person has intended. As discussed previously, one of the roles of the healthcare worker is to interpret the person's statements and to ensure that what is written will be meaningful to the treating healthcare team if the information is required in the future. Some things to consider:

- Quality of life means different things to different people and therefore needs to be defined by the individual in their ACP.
- "Being a vegetable" and other such phrases also mean different things to different people and need to be defined.
- Different people may have different interpretations of what "severe" dementia or "severe" illness means, for example. The parameters need defining.

Articulating Advance Directives

If an ACP document includes Advance Directives, these need to be articulated in such a way as to minimise ambiguity and define the circumstances in which a decision should apply. Here are some examples that might have been written by someone with an advancing neurological disease:

I would / would not want:	In these circumstances:
<i>I would not want artificial hydration or nutritional support</i>	<i>If the ability to eat or drink by mouth is compromised or absent and this is irreversible</i>
<i>I would not want to be intubated</i>	<i>Under any circumstances</i>
<i>I would want reversible conditions, such as treatable infections, to be treated with a view to preserving my life</i>	<i>If I have quality of life or this is expected to return with treatment. For me quality of life means being able to communicate, feed myself and toilet myself without assistance</i>

Defining quality of life may, instead, be documented in a previous section of the ACP, when defining what makes life meaningful for the person, for example.

As mentioned previously, the healthcare worker assisting a person to define Advance Directives should ensure that the person understands the implications of what they are documenting. In the above example, the person needs to understand that refusing ventilation could result in their life ending sooner than it otherwise would, as ventilation might, in theory, be offered for a potentially reversible episode.

Sharing ACP information

The appropriate sharing of ACP information is important for two main reasons. Firstly, ACP is a process and there may be more than one healthcare worker involved in the process; in order to prevent unnecessary repetition, or beginning the process all over again, relevant information needs to be passed on.

Secondly, the information needs to be available to the relevant people if the person with an ACP becomes incapable, in order that appropriate decisions can be made about their care and treatment.

There are many challenges to the appropriate sharing and access to ACP information and documents, not least of all because there are many healthcare settings throughout the country with different, and evolving, systems and processes, and communication between them is not always effective. Whatever systems or processes are in place, there are some important considerations:

- Documentation related to the ACP process of an individual needs to be available to others who may also be involved in the process with that person. Therefore it might make sense to keep all ACP-related documentation in the one place within the clinical record, and to share appropriate information about the process with relevant others involved in that person's care (with their permission).
- Sharing appropriate information about an individual's ACP process might be in the form of hospital discharge summaries, clinic letters or referral letters, for example.
- A completed ACP document is ultimately the property of the person it pertains to; however a copy should ideally be kept in relevant clinical records in order that the people who might need the information have ready access to it when it is required.
- Appropriate places to keep copies of a person's ACP (with their permission) include hospital notes/electronic patient management system to which health care professionals in the Emergency Department have ready access and know where to obtain it; the person's primary care/General Practice notes/electronic patient management system; residential care home notes; community nursing notes; EPOA and/or others who may be involved in care and treatment decision-making.
- If a person with an ACP document transfers from one healthcare setting to another, their ACP document should accompany them; for example residential care home to public hospital, or from one care home to another.
- A person is entitled to change their preferences and the contents of their ACP document; therefore provision needs to be made to ensure that the copy being held on record is the latest version. This can present challenges if there is no central repository, and it may be advisable for the person with an ACP document to be responsible for keeping a record of who has a copy, and ensuring that they each have the latest version.

Reviewing ACP documentation

As already discussed, a capable person may review and alter their ACP at any time. However if health care professionals have been involved in the process, it would be appropriate to offer a review of their preferences or ACP document at certain points in their life or illness trajectory. For example:

- Following a significant life event such as marriage/civil union or divorce/separation.
- Following a significant medical diagnosis.
- When a major change in health occurs.
- When the end of life may be approaching.

Summary

- There may be many different forms of ACP documentation, including clinical notes or a specific ACP document.
- Documentation should be clear, and useful to the healthcare team.

- An ACP document may contain Advance Directives, which need to be as unambiguous as possible, and need to define the circumstances for which they are intended.
- It is important that ACP documentation is appropriately shared, which can present challenges.
- ACP documentation can be amended by the capable person at any time; health care professionals should also offer to review an ACP document with a capable person at appropriate times.

Chapter 8: Building Organisational Capacity for ACP

Healthcare organisations and institutions should have a commitment to ACP as part of quality care strategies and effective resource management. This chapter focuses on building organisational capacity for ACP through policy and staff development.

Building capacity

Building capacity for ACP will require:

- the commitment of people in positions of authority (e.g., CEOs, Administrators, Ethics Committees, Boards) to provide leadership and demonstrate their support for ACP
- identification of leaders and champions throughout the organisation, particularly among front-line health care professionals
- a policy development process that builds consensus
- resources to provide educational opportunities and tools for staff
- removal of barriers to learning (for example time allotted for training, internal marketing of ACP programs and policies)
- inclusion of ACP in the orientation of all new employees
- creation of incentives through clear performance expectations and performance review
- recognition of outstanding contributions to development of ACP in the organisation,
- integration and codifying of new learning and experience into practice
- on-going feedback and review of practices in order to seek ways to improve quality and performance.

Policy and quality assurance

Healthcare organisations should have specific policies to ensure that:

- All patients or residents are offered ACP conversations, which may or may not result in the completion of a specific ACP document.
- No one is pressured or required to have an ACP and/or Advance Directive for any reason.
- If an individual wants to engage in ACP, he or she receives encouragement and assistance.
- ACP preferences are respected.
- A copy of a person's written ACP and/or Advance Directive (where this exists) is put in the clinical record, is easily accessible and appropriately shared with members of the healthcare team
- Verbal wishes and preferences are also documented in the clinical record and are easily accessible.
- Staff are informed of organisational policies on ACP.
- Staff are appropriately trained, and training includes the legal framework.

Policies and processes should promote ACP as part of everyday practice and as far as possible, ACP processes should be incorporated into existing organisational processes. It is also important to ensure that existing policies do not conflict with ACP.

Policies should include:

- Information on different cultures that may assist health care professionals to understand how a family of a particular culture may make decisions
- Educational materials and resources, translated as appropriate, for persons engaged in ACP and their families
- A process of review of ACP for individuals which is not based solely on a time interval, but on assessing changing needs
- A process for broad dissemination strategies so that all staff and as many patients/residents as possible are aware of the organisation's ACP policies
- Links with related organisational policies and procedures.

Quality assurance processes are required in order to measure the impact of ACP. Processes may include keeping records of numbers of ACP conversations and completed documents, evaluating patient/family satisfaction, reviewing numbers and content of complaints, and numbers of staff undertaking ACP Level 1 and Level 2 training.

Staff development

An ACP policy without education of staff will have little impact. An organisation that promotes a culture of learning will benefit enormously from the experiences of those who learn about ACP and pass their learning on to others. ACP should be a routine aspect of staff education and can be incorporated into compulsory training days, clinical training sessions, journal clubs, and so on.

ACP champions could be identified; they could be responsible for raising awareness of ACP within their department or across the organisation, for ensuring ACP resources are available, and for encouraging and prompting ACP conversations. They may be in a position to support others to have ACP conversations, and to promote the appropriate sharing of ACP documentation with other agencies.

Summary

- Involve front-line staff in ACP policy development and gain the support of senior administration and clinical leaders.
- Ensure ACP policies comply with the voluntary nature of ACP. Recognise ACP as a process, and promote the value of the conversations rather than focus on the completion of ACP documents.
- Ensure other organisational policies do not conflict with ACP.
- Provide ACP education for all appropriate staff, and ensure relevant orientation to ACP for new staff.

Chapter 9: Developing ACP skills

Having ACP conversations

Keep a Reflective ACP log

Keeping a reflective log will help you reflect on the conversations you are having, and to develop your skills with regard to having ACP conversations. Here is a suggested format:

- Date and basic demographics – sex, age, ethnic group
- What benefits to the conversation did you identify?
- What went well?
- What did not go so well? Why might that have been?
- Anything to try differently next time?

You might like to use an Excel spread sheet, or a journal or diary – choose a format that works for you. The more time-consuming and the more arduous it feels, the less likely you are to do it.

Education and training

There are now a number of New Zealand resources and training opportunities to assist health professionals in understanding and developing skills in ACP.

Basic Level DVD

This introduces ACP concepts. Available at www.advancecareplanning.org.nz

Level 1 eLearning modules

There are four modules available at www.advancecareplanning.org.nz

1. Considering your own future health care
Learning Outcomes:
 - You have thought about, talked about and planned for your own future care
 - You are able to help someone else consider Advance Care Planning
2. Talking about ACP with your patients
Learning Outcomes:
 - You are able to recognise your own barriers to having ACP conversations and how to overcome them
 - You are able to recall useful conversation starters
 - You are able to explain how to respond appropriately to patients during ACP conversations

- You know what to do at the end of a conversation
 - You will make plans to raise ACP with your patients
3. eLearning module: Changing the outcomes of future health care
- Learning Outcomes:
- You are able to define key terms – decision making competence; valid consent; Advance Directive; Enduring Power of Attorney (EPOA)
 - You are able to explain how an ACP can influence a clinician’s decisions and change a patient’s outcomes
 - You are able to determine who has the legal right to make healthcare decisions for an incapable patient
4. eLearning module: Clarifying ACP processes in your organisation
- Learning Outcomes:
- You will have reinforced how you can encourage your patients to think about, and talk about ACP matters
 - Clarified how you will capture and store your patients ACP conversations and plans.

Level 1A ACP One Day Workshop

This is an optional one day interactive workshop with a focus on more in-depth exploration of ACP in practice. It is not necessary to complete this before attending a Level 2 course. For more information or to apply see www.advancecareplanning.org.nz

Level 2 ACP Communication Skills course

This is a two day course **with** a focus on the communication skills required to have the more complex ACP conversations, and to manage difficult reactions and barriers. For more information or to apply see www.advancecareplanning.org.nz

Advanced ACP training in New Zealand

Intermittently the following training is offered:

- Level 3 Facilitator (those who deliver the Level 2 course)
- Level 3A Mentor (to support those undertaking Level 3 Facilitator training)
- Level 4 Trainer (the clinical leads for the programme who work on the programme content and train the Level 3A Mentors, the Level 3 Facilitators and the professional actors who work on the course).

If you are interested in receiving further information on these training options when they are next offered please contact www.advancecareplanning.org.nz

Chapter 10: Resources

Written resources for health care professionals

Advance Care Planning: A Guide for New Zealand Healthcare Workforce

This is a Ministry of Health document which outlines important information for health care professionals regarding ACP processes and practice in the New Zealand context. This manual expands on the information contained in this document.

Ethical Challenges in Advance Care Planning

This is a document produced by the National Ethics Advisory Committee. It aims to explore ethical challenges that health professionals face in ACP, and to provide practical assistance to help ensure good outcomes for consumers and health care professionals from the ACP process.

Advance Care Planning Communication Skills Manual

This outlines communication skills and strategies for the more complex ACP conversations, and for addressing strong emotions and other challenges in difficult conversations. It is designed as a resource for those who have completed the Level 2 training.

ACP information and documents for consumers

These are available to the general public at: www.advancecareplanning.org.nz

References

Ministry of Health (2011). *Advance Care Planning: A Guide for the New Zealand Healthcare Workforce*. Wellington: Ministry of Health.

National Ethics Advisory Committee (2014). *Ethical Challenges in Advance Care Planning*. Wellington: Ministry of Health.

Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) (2008) Facilitating Advance Care Planning: An Interprofessional Educational Program Curriculum Materials. Retrieved from http://www.advancecareplanning.ca/media/48650/acp%20curriculum%20module_2008.pdf

Appendix One: New Zealand ACP Competency Training model

The following diagramme summarises the ACP training available through the national programme.

Summary of New Zealand ACP Communication Training – Levels Basic to 4			
Module number	Level	Short description of course content	Applicable healthcare workforce
Module 12 Theory & practical supported teaching of L3 & actor training. Leadership & management skill development.	Level 4	A minimum of 32 days training over 12-24 months. Leadership & management of the training team including development of mentorship skills, leading the research application of the programme, ensuring quality assurance processes are followed etc.	2 - 4 Trainers nationally
Module 11 2 days theory & supported mentorship provision	Level 3A	Level 3 Mentor: A minimum of 2 days training & supported mentorship provision over 6 months/until competencies met.	4 - 6 Mentors nationally
Module 10 4 days theory & supported co-facilitation	Level 3	Level 3 Facilitator: A minimum of 17 days training over 4-6 months. Supported co-facilitation over a minimum of 4 courses/until competencies met.	10 - 12 Facilitators nationally
Module 9 Clinical practice	Level 2	Level 2 Practitioner: Completion of 10 ACP conversations (clinical practice).	Senior healthcare professionals. Aiming for 5% of the workforce by 2022.
Module 8 2 days ACP communication skills training (experiential & didactic learning)		Application of ACP knowledge & skills. Advance communication skills training. Applying communication skills to initiating & facilitating ACP conversations, translating what is important into care & treatment preferences. Role play of individual clinical scenarios with professional actors.	
Module 7 Reading / eLearning		Communication theory Pre-course reading for L2 Practitioner training	
Module 6 One day classroom based	Level 1A	A one day workshop consolidating Level 1 competencies & focussing on how to hear & document the patient's voice.	Optional model
Module 5 Self-directed learning / eLearning	Level 1	Clarifying ACP process: Developing organisational ACP policy, procedures & processes	Healthcare workers who work with patients & their families/whanau. Aiming for 45% of the workforce by 2022.
Module 4 Self-directed learning / eLearning		Changing outcomes: Critical understanding of AD's, EPOA & ACP application & implementation.	
Module 3 Self-directed learning / eLearning		Talking about ACP: Basic communication skill development	
Module 2 Self-directed learning / eLearning		Considering ACP: Completing your own ACP & reflection on how this feels	
Module 1 Film	Basic	What is ACP, the benefits of ACP, why is it important & where to get more information	Everyone who works in healthcare

Programme underpinned by evidence based methodology & materials/resources, quality assurance processes, evaluation & continuous quality improvement cycles.