

Advance Care Planning

A guide for the New Zealand
health care workforce





Photos courtesy of
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The document is endorsed by the National Advance Care Planning Cooperative, the Ministry of Health's Palliative Care Advisory Group and the Palliative Care Council of New Zealand. The document is also endorsed by Age Concern New Zealand and Grey Power New Zealand.

The National Advance Care Planning Cooperative

The effective development and deployment of ACP services in New Zealand will require a national effort to ensure that services best meet the needs of all people living in New Zealand. The National Advance Care Planning Cooperative was formed in June 2010 by clinicians and health care providers across New Zealand to facilitate this effort.

The information in this document reflects the New Zealand Code of Health and Disability Services Consumers' Rights, which 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-\(full\)](http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code-(full))

1 Introduction

Advance Care Planning (ACP) is a concept that was introduced internationally in the late 1980s but has only gained momentum in New Zealand in recent years. ACP assists in the provision of quality health care and treatment and is becoming increasingly important, particularly with the growing range of medical treatment options available and the enhanced recognition of the importance of patient involvement in medical decisions. However, the terminology surrounding the concept of ACP can be confusing for both health care professionals and the public.

This document, *Advance Care Planning: A guide for the New Zealand health care workforce*, was prepared in response to an increasing sector focus on the need for clear and accurate information and guidance regarding ACP in the New Zealand context. The intended audience encompasses providers, funders and planners in all areas of health care. The document is not aimed at the general public. The document provides standardised information about ACP principles and legislation in New Zealand and aims to promote consistency in practice. It will assist in the development of local policies, guidelines and education and training programmes in ACP. Well-implemented ACP policies and pathways will ensure that the treatment and care of each individual are aligned with their personal preferences, values and beliefs. It is also acknowledged that greater use of ACP will assist the community to recognise the limits of modern medicine and the roles that palliative care and ACP have in promoting quality care at the end of life through symptom management, social support, community participation, health and death education, and reducing harm (Kellehear 1999).

A resource aimed specifically at consumers (both patients and their families/whānau) is being produced to complement this document. It will be accessible on the Ministry of Health website by the end of 2011.

What is advance care planning?

Advance care planning is a process of discussion and shared planning for future health care. It is focused on the individual and involves both the person and the health care professionals responsible for their care. It may also involve the person's family/whānau and/or carers if that is the person's wish. The planning process assists the individual to identify their personal beliefs and values and incorporate them into plans for their future health care. ACP provides individuals with the opportunity to develop and express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.

The ACP process may result in the person choosing to write an advance care plan (see below) and/or an advance directive and/or to appoint an enduring power of attorney (EPA). If a person is identified as having strong views or preferences about medical treatments and procedures, they should be advised to consider completing an advance directive. The value of the ACP process, however, lies not solely in these outcomes but in the conversations and the shared understanding that eventuate.

What is an advance care plan?

An advance care plan is the desired outcome of the ACP process (see previous page). Ideally, it is documented rather than verbal and while this might be done on a form designed specifically for that purpose, it can be in any format. It should be accessible to current and future health care providers and to family/whānau members according to the person's wishes. 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.

An advance care plan may itself be regarded as an advance directive and should be consistent with and considered in conjunction with any other advance directive that exists. It should be written in the knowledge that it could have legal authority. Patients should be reassured that their advance care plan will be referred to in future if they are unable to speak for themselves. Advance care plans need to be regularly reviewed and updated as and when situations change.

What issues are discussed in ACP?

The process of ACP is a reflection of society's desire to respect personal autonomy while also holding to the traditional medical values of beneficence (the moral obligation to act for the benefit of others) and non-maleficence (the obligation not to inflict harm on others) (Beauchamp and Childress 2001). The ACP process should empower an individual to make informed decisions about their future care. The content of any discussion should be determined by the individual concerned, and, if they do not wish to engage in ACP or conversations about their future care, this preference should be respected.

ACP discussions cover the:

- person's understanding of their illness and prognosis
- types of care and/or treatments that may be beneficial in the future and their potential availability
- person's preferences for future care and/or treatments
- person's concerns, fears, wishes, goals, values and beliefs
- person's preferred place of care (and how this may affect the treatment options available)
- family/whānau members or others that they would like to be involved in decisions about their care (this may include the appointing of an EPA)
- person's views and understanding about interventions that may be considered or undertaken in an emergency (such as cardiopulmonary resuscitation)
- person's needs for religious, spiritual or other personal support.

On occasions, the ACP process of discussion and planning will clarify that the patient has very specific preferences for their future treatment. These can be communicated in the

advance care plan and/or in an advance directive. An advance directive is a written or oral directive/instruction that enables a person to make choices about possible future health care treatment/s and becomes effective only when the person loses the capacity to make those choices themselves. ACP discussions may also result in a decision to appoint an EPA. Both of these options are covered in detail in Section 6. Any decision to participate in the ACP process and/or use advance care plans and advance directives is entirely voluntary.

It is recommended that ACP discussions be documented, regularly reviewed and, with the patient's agreement, communicated to key people involved in their care.

Those for whom this guide does not apply

People with advanced cognitive impairment including dementia

ACP relies on the patient being competent to share in the planning process and so needs to be considered early in the care of any person for whom the diagnosis of dementia is suspected. A person with advanced dementia will be unable to participate in ACP as outlined in this guide and in this situation, alternative decision-making approaches have to be applied.

Further work is required to develop comprehensive guidelines for ACP in caring for people with dementia. Further resources can be found at the Alzheimers New Zealand website <http://www.alzheimers.org.nz/assets/The-Dementia-Booklet.pdf>

Children and young people

This guide is not intended for ACP for children and young people.

The Starship Children's Hospital in Auckland offers a specialised range of children's services through a multidisciplinary, family-centred approach provided by paediatric-trained workers.

Further information about ACP for children and young people can be obtained from Starship's Palliative Care Team website <http://www.starship.org.nz/palliative-care-team>



2 ACP in New Zealand: Cultural Heritage and Values

New Zealand has its own unique culture and legislation that differentiates ACP policy and practices from those of its international partners in health care. This means that recent frameworks published in countries such as the United Kingdom, Canada and Australia, although excellent resources, cannot be adopted in their totality and used safely in New Zealand.

New Zealand is a multicultural society, and ACP, like all areas of health care, needs to be sufficiently flexible to be culturally appropriate for all individuals in our society. There are differing cultural practices around dying and death that also need to be acknowledged and respected in ACP practices. Health care professionals must be sensitive to different cultural perspectives on how decisions are made and by whom, because there are differing views of autonomy, beliefs and values and how these elements are respected.

Fundamental to all health approaches in New Zealand is the firm commitment to the cultural considerations of our heritage and to honouring Te Tiriti o Waitangi. The concept and practice of ACP, in its purpose and intent of empowering an individual and their family/whānau to participate in their own health care, are closely aligned within Te Whare Tapa Whā (the Māori health model described below) and the Whānau Ora strategy to promote a model of care that builds upon Māori values, aspirations and intent.

Māori health: Te Whare Tapa Whā

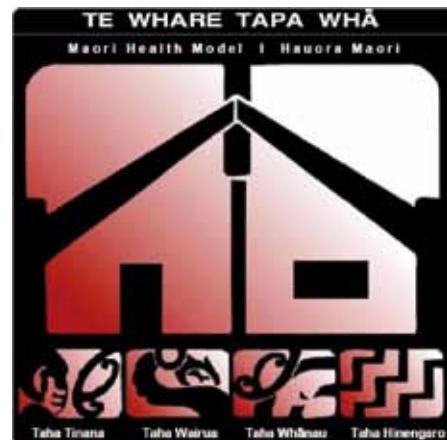
With its strong foundations and four equal sides, the symbol of the wharenui illustrates the four dimensions of Māori wellbeing. Should one of the four dimensions be missing or in some way damaged, a person or a collective may become ‘unbalanced’ and subsequently unwell.

For many Māori, modern health services fail to recognise taha wairua (the spiritual dimension). In a traditional Māori approach, the inclusion of the wairua, the role of the whānau (family) and the balance of the hinengaro (mind) are as important as the physical manifestations of illness.

Further, Whānau Ora is a model developed by Māori to achieve equitable health and improve broader development outcomes. The model is premised upon Māori values, aspirations and intent. However, this effective model can improve the health and wellbeing of other populations as well, especially high-need population groups.

Additionally, the concept of ACP aligns with the Pacific health model of care that supports Pacific peoples who are receiving care in the community and ‘by Pacific for Pacific’.

Further resources need to be developed with health service providers with the aim of aligning ACP principles and practices within specific cultural frameworks and models for health care.



3 ACP and the Code of Rights

The medico-legal framework in New Zealand includes features that are different to other jurisdictions and that are relevant to the implementation of ACP. The Code of Health and Disability Consumers' Rights (the Code) promotes patient choice and autonomy in planning and receiving health care. ACP is consistent with this approach and facilitates clinical decision-making and the provision of health care services that respect the rights and preferences of individuals.

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).

Right 3: Dignity and independence

'Every consumer has the right to have services provided in a manner that respects the dignity and independence of the individual.'

Right 4: Services of an appropriate standard

'Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.'

The phrase 'optimises the quality of life' is defined in the Code as meaning to take a holistic view of the needs of the patient to achieve the best possible outcome in the circumstances. By taking account of the person's views and values, ACP facilitates the delivery of services of an appropriate standard for that person.

Right 5: Effective communication

'Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.'

The care environment should enable the patient and the health care provider to communicate openly, honestly and effectively, in a private setting with minimal distractions and the time available to have a meaningful discussion.

Right 6: Be fully informed

'Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive . . .'

When making a choice about the place of care, as well as treatment procedures, the patient needs to understand the options available, including full details of any assessment of the expected risks, side effects, benefits and costs of each option.

Right 7: Make an informed choice and give informed consent

Right 7 of the Code is fundamental to ACP, including Right 7(4), which outlines the approach to decision-making in incompetent patients.

- Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent . . . (Right 7[1])
- Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent. (Right 7[2])
- Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent to the extent appropriate to his or her level of competence. (Right 7[3])
- Every consumer may use an advance directive in accordance with the common law. (Right 7[5])
- Every consumer has the right to refuse services and to withdraw consent to services. (Right 7[7]).

ACP requires an individual to be able to make an informed choice about their future health care. Making such a choice requires the capacity/competence to make decisions and both the Code and the Protection of Personal and Property Rights Act 1988 require a presumption of competence. This issue is discussed more fully in Section 6.



4 The Advance Care Planning Process

The value of ACP

The introduction of ACP as a key component of health care is integral to achieving high-quality care and should be regarded as part of the role of all health care practitioners and services. There is a growing public expectation that an individual's wishes for medical treatment, including end-of-life care, will be respected, even if a progressive disease has affected their decision-making capacity.

ACP differs from more general health care planning in that it is based around an anticipated deterioration in the health of an individual. ACP includes a focus on the person's wishes and preferences for the time when they lose capacity to make decisions. It also encourages discussion around end-of-life care, a subject that is generally not considered part of routine care planning and one that can be avoided.

ACP discussions are likely to encompass rich conversations that go beyond the issue of resuscitation and may include meanings and fears around illness and dying, preferences for after death care, and spirituality (Simon et al 2008). The process can facilitate valid expressions of wishes that would not have been known without these conversations. ACP discussions should be ongoing and should not be regarded as a single consultation or viewed only in regard to the signing of legal documents.

In essence, effective ACP has the following outcomes.

It **encourages conversations** about what is important for a person, providing them with the opportunity to discuss their hopes and expectations, as well as their fears and anxieties about their future health and about death and dying. ACP allows a person with a life-limiting condition to plan in advance for appropriate care at end of life (Hudson and O'Connor 2007).

It **helps a person achieve a sense of control** as their illness progresses and death approaches. It reassures the patient that others are aware of their values, goals, priorities and expectations for the final phase of their life. Central to ACP is the opportunity, knowledge, appropriate advice and support for the person to plan their future medical care, including end-of-life experience and treatment (Lyon 2007).

It **engages others**, including family/whānau and caregivers, in the ACP process to help them understand the person's wishes and to support them through the process. A greater engagement of others places those others in a better position to actively participate in decision-making when the person can no longer make decisions themselves. If a person wishes someone else to make decisions on their behalf should they lose capacity then this wish should be included in any ACP discussions and documents and consideration given to appointing that person as an enduring power of attorney (see Section 6).

It **reassures the person** that discussions and plans can change over time and in particular if circumstances change. ACP is an ongoing process that allows plans and documents to be reviewed regularly and as necessary.

Deciding when to have the conversation

Ideally, all people who have an advanced life-limiting illness or condition should be given the opportunity to discuss their prognosis and end-of-life issues. However, it may be difficult to know when it is the right time to have those discussions. The health care professional may consider raising the topic of ACP if they can answer 'No' to the question, 'Would I be surprised if this patient were to die within the next 12 months?'

The patient or their family/whānau, at this vulnerable time, may trust that the health care professional has the knowledge and skill to assist them. It is important that health care professionals empower the patient and/or their family/whānau by taking positive steps to involve them in discussions and decisions.

However, ACP discussions can occur at any time, not necessarily only when a person has been diagnosed with a life-limiting illness. If a person is well, discussions are likely to focus on what they would want should they have an unanticipated sudden illness or accident. Such discussions would generally be prompted by a specific patient request but could also be recommended by health care professionals or family/whānau members who recognise that a person has care preferences that differ from the mainstream.

Other occasions when it might be appropriate to begin discussing ACP include when a:

- patient or their family/whānau/carer enquires about palliative care
- patient has been hospitalised recently for a severe progressive illness or condition or has required repeated admissions for a serious condition
- patient says they want to forego life-sustaining treatment
- patient expresses a wish to die.

Some patients will prompt the ACP discussion themselves, but many will expect health care professionals to initiate these discussions, and many patients welcome the opportunity to discuss end-of-life care in advance. However, not everyone will choose to participate in ACP.

ACP is most easily accomplished when a patient is in a stable state of health or when they have had time to adjust to a new illness. Sometimes, however, discussions have to take place when the clinical situation is unstable.

It is important for health care professionals who are intending to start an ACP discussion with a patient to be well prepared. Preparation involves reviewing all of the patient's information and setting aside sufficient time to allow the ACP conversation to develop. Ideally, they should be caring for the patient and should be able to discuss the patient's specific prognostic information in clear, simple terms. They should use an open question style of dialogue and try to avoid following a rigid, prescriptive method of interviewing. They should have communication skills that are appropriate for ACP discussions as well as knowledge of the legal framework so that any formal documentation can be completed if required. Where ACP is part of a health care professional's role, competence-based training should be available and accessed.

Explaining the process and getting started

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. 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.

The following points may assist with this process of explanation.

- Ask the patient what they understand about their current situation and what they think might happen in future. It is useful to know what they have been told by other health care professionals and have learnt from other sources, like the Internet.
- Ask about past experiences with illness either their own or others.
- Elicit and clarify concerns, expectations and fears about the future in relation to their health care.
- Identify any gaps in their understanding by describing what ACP is and what the rationale is for having ACP conversations. They should be made aware that they are able to change their goals and preferences at any time and make changes to their document as and when they wish.
- Describe possible scenarios and/or ask them if they would like to write down in a letter how they would like such scenarios to be handled for their situation. Such a letter may be a tool for developing a formal advance directive if the patient subsequently chooses to prepare one.

Patients may need time for reflection and discussion after they have received this information. Health care professionals must be sensitive to different cultural perspectives on illness, death and dying and on how end-of-life decisions are to be made, and by whom. It is important that they do not make any assumptions about the information needs of a patient based on their cultural background; these needs should be clarified with the patient directly.

ACP conversations should take place in an environment that:

- is non-threatening
- offers privacy, quietness, space and time for reflection
- is familiar to the patient so that they feel comfortable
- is well-lit and well-ventilated
- has sufficient seating for all the participants.

Involving the right people

A multidisciplinary approach involving the patient's family/whānau to ACP is recommended. Such an approach involves a partnership of the primary and secondary health care professionals who are caring for an individual, including doctors, nurses, allied health care professionals and, in many instances the person's family/whānau.

In most cultures, and for most individuals, interpersonal relationships are hugely significant and contribute to the way in which decisions are made. Individuals and their health care professionals should identify the family/whānau and significant others who the person wishes to be involved in ACP discussions. Their role may be to simply listen, taking notes or asking questions for clarification. At any time, a person may ask or defer to family/whānau or others to help make decisions.

All decisions are made within the cultural context of the individual and therefore the extent to which decision-making is shared will vary. Shared decision-making may be the cultural norm and health care professionals should acknowledge and respect such practices. It is important for family/whānau to be aware of the person's preferences as it is possible that they will be involved in decision-making should the individual lose the capacity to make their own decisions sometime in the future.

An individual who wants to plan their future care may not always want to discuss their plans with a health care or legal professional, although such discussions should be encouraged. They may simply write down or tell another person their wishes. However, plans made separately from discussions with health care professionals are likely to be less informed and might be more difficult to honour, especially if they are contested. Although ACP discussions, advance care plans and advance directives may be completed orally, there are advantages to having written documents.

Documenting the discussions

Ideally ACP discussions will result in an agreed plan. Individuals need to be made aware that a key factor in the success of ACP is recording and sharing the plan with appropriate others. ACP information, like all health information, cannot ordinarily be shared without the agreement of the individual concerned. However, it should be explained to the patient that the effectiveness of ACP relies on the appropriate sharing of any plan developed. Although it is possible for ACP discussions to result in oral agreements only, there are advantages to having written documents. Individuals should, however, still be encouraged to participate in discussions even if they initially or ultimately choose not to document a plan or are unable to make any definitive decisions.

ACP discussions should be documented in the patient's notes as having taken place. The record should include the content of the discussion and the plan developed. This level of documentation is in keeping with the obligation on health care professionals to keep full and accurate records of all discussions with patients. The actual plan can be documented on forms specifically designed for that purpose or written within the patient's records or correspondence. The patient should be provided with the opportunity to confirm the accuracy of the record and any disagreements noted. With the patient's understanding and permission, all relevant health care professionals should be made aware that ACP discussions have taken place and should have access, if required, to any plan produced.

Recording information and sharing it with primary and secondary care providers and members of multidisciplinary teams is important to maximise the benefits of ACP. There should be locally agreed policies and mechanisms for safe and secure document storage. For example, it may be decided that the patient will hold the original document, while an electronic or hard copy is also available within the patient's clinical records in both primary and secondary care settings.

There also needs to be appropriate access as required for other health care providers such as after-hours and ambulance services. These issues need to be addressed at a local level. Mechanisms developed will need to balance patient privacy with access and sharing in order to maximise the effectiveness of ACP.

Any ACP record should be subject to review and, if necessary, revision. This possibility and the reasons why it may be needed should be made clear during the ACP discussions. Review may be instigated by the individual or the health care professional, as part of a regular process, or it can be triggered by a change in circumstances. Processes that ensure review and revision also need to be developed. A record of who has copies of ACP documentation will facilitate future updating and review.

There is no requirement at this time in New Zealand to register or lodge advance care plans and advance care directives with anyone.



5 The Role of ACP in Health Care Decisions

Ideally, the majority of health care decisions are made by patients and clinicians together, although the decision remains fundamentally the individual patient's to make, provided they are competent. Decisions made by patients should be valid – that is, based on adequate information, made by individuals who are competent to make them and made free from coercion. Where incompetence means the patient is unable to make a decision or the decision is invalid for other reasons, clinicians should follow the approach to decision-making as outlined in Right 7(4) of the Code of Health and Disability Consumers' Rights (see below). Decisions made on behalf of incompetent patients are some of the most difficult decisions health care professionals have to make.

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.

Competence is a continuum and fluctuates. Patients should always be involved in decisions that concern them to the maximum extent possible (Code of Health and Disability Services Consumers' Rights Right 7(3) and PPPR Act 1988 18A (2) and (3)). This requires that the health care professional actively seeks the input of the patient into discussion and decisions, regardless of their competence or lack of competence.

At a minimum, decision-making capacity requires understanding and communication, reasoning and deliberation, and a set of values or concept of good (Buchanan and Brock 1989, p 23).

A more detailed list of requirements would be:

- awareness or consciousness of the need to decide or take action
- ability to communicate choices and preferences
- ability to receive, recall and comprehend relevant information
- ability to foresee likely consequences
- ability to work with or think about information in minimally rational ways
- ability to recognise the relevance of the information to their own situation
- ability to make decisions of sufficient stability to be implemented.

Right 7(4) states:

Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where –

- (a) It is in the best interests of the consumer; and
- (b) Reasonable steps have been taken to ascertain the views of the consumer; and

(c) Either, –

- (i) If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of services is consistent with the informed choice the consumer would make if he or she were competent; or
- (ii) If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

Essentially, where a patient is not competent for any reason and where time permits, the first consideration is whether or not there is another person legally entitled to give consent on behalf of the patient – that is, a legally authorised proxy or substitute decision-maker. In New Zealand a person who fits this definition will be either an individual with enduring power of attorney (EPA) or a court-appointed welfare guardian. Where such a person exists services may be provided with that person's consent. 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 and suitable others are clearly important and should be taken into account, but these individuals do not have decision-making authority.

Clinicians making decisions on behalf of incompetent patients must follow the approach outlined in Right 7(4) where the primary principle is the person's best interests. They must take reasonable steps to ascertain the patient's views and, where they can establish these views, make a decision that they believe would be in keeping with the choice the patient would make if they were able. Reasonable steps to ascertain the views of the patient include enquiring about whether they had specifically expressed their wishes earlier, which clearly would include any wishes expressed during ACP discussions and in an advance care plan, or an advance directive. Where they cannot ascertain any such views, clinicians should take into account the views of suitable others but then have to make treatment decisions based at best on estimates of the patient's values and preferences. This process can place a significant burden on both clinicians' and on family members.

In summary – for incompetent patients without a legally authorised proxy decision-maker the final decision reached represents a substituted judgement made by the clinician on behalf of the patient. It should be based on a 'best interests' determination which is informed by the combination of clinical judgements, the patient's views and values where they are known, and the views of others. The clinician should believe the decision is consistent with that which the patient would have made if they were able.

The role of enduring power of attorney

Enduring power of attorney (EPA) is an authority given by a patient (known as donor, 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 EPAs for property and EPAs for personal care and welfare.

There are two types of EPA.

1. A **personal care and welfare EPA** appoints a person as an attorney to make decisions about an individual's personal care and welfare on their behalf. Such decisions might include agreement to medical or surgical treatment or admission to residential care or choice of a residential home. 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 care 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 20 years old, a New Zealand resident, not bankrupt, legally capable and not subject to a personal or property order.

EPA witnessing

The donor's signature agreeing to the EPA will need to be witnessed by a lawyer, a qualified legal executive or an authorised officer or employee of a trustee corporation who is independent of the attorney (or attorneys) and any successor attorneys who are appointed by the person with the EPA. The donor's attorney(s) will also need to sign the EPA, and someone other than the donor or the witness to the donor's signature must witness the attorney's signature.

The donor's witness will need to complete a certificate confirming that they have explained the effects and implications of the EPA to the donor before the donor signed it. This witness must also advise the donor of all matters set out in the notes to the EPA form, as well as other matters, such as the donor's right to suspend or revoke the EPA or the right to appoint more than one attorney or a trustee corporation in the case of a property EPA.

The certificate will need to state that the witness had no reason to suspect that the donor was mentally incapable when the donor signed the EPA and that the witness is independent of the appointed attorneys (or that one of the exceptions to independence applies). The certificate will need to be attached to the EPA.

The witness process has been introduced to prevent people from signing EPAs under pressure from or influence of their attorneys. It ensures that the people signing EPAs know what authority they are giving to their attorneys.

Effecting an EPA

For an EPA for personal care and welfare to come into effect, a medical practitioner must assess a patient (the donor) as being mentally incapable of any one of the following:

- making a decision about a matter relating to his or her personal care and welfare
- understanding the nature of decisions about matters relating to his or her personal care and welfare
- foreseeing the consequences of decisions about matters relating to his or her personal care and welfare or of any failure to make such decisions.

NB: It is important to note that in some cases, the person's capacity to communicate decisions about matters relating to his or her personal care or welfare may change according to health status, for example, the unconscious patient.

In this context this means that the person:

(a) lacks the capacity—

- (i) to make a decision about a matter relating to his or her personal care and welfare; or
- (ii) to understand the nature of decisions about matters relating to his or her personal care and welfare; or
- (iii) to foresee the consequences of decisions about matters relating to his or her personal care and welfare or of any failure to make such decisions; or

(b) lacks the capacity to communicate decisions about matters relating to his or her personal care and welfare.

Limits to an EPA

Although an EPA is authorised to give consent for many treatments on behalf of the incompetent patient there are some limits to this and also limits to the authority of a person with an EPA to refuse treatments. The legislation states that a person with an EPA cannot refuse consent to the administration of any standard medical treatment or procedure intended to save a person's life or to prevent serious damage to their health (sections 18(1) and 98(4) PPPR Act 1988).

If the treatment is not standard in the circumstances, it may be possible for a person with an EPA to legally refuse consent. However, this limitation means that an advance directive remains the best way for an individual to express their wish to refuse a particular treatment in the future, especially if the treatment may be considered standard and/or is potentially lifesaving.

Given the formal legal processes required in appointing an EPA there are significant costs involved. Individuals should be made aware of such costs if considering this option.

The role of the advance directive

Advance directives are defined in the Code as written or oral directives in which a patient makes a choice about a future health care procedure, and this choice is intended to be effective only when the patient is no longer competent. For this reason, advance directives are also, though less frequently, referred to as 'living wills'.

Right 7(5) of the Code gives every individual the legal right to use an advance directive in accordance with common law and health care providers are obliged to take account of advance directives when deciding which services to provide to an incompetent patient. Individuals with an EPA are also required to have regard to any advance directive.

Advance directives and advance care plans can be modified or revoked by the individual at any time, while they are still competent.

The scope of advance directives

Advance directives have tended to be used as a mechanism allowing individuals to indicate refusal of or consent to a particular treatment or procedure at a future time when they have become incompetent and therefore are unable to provide current consent or refusal.

Negative advance directives (also known as anticipatory refusals) indicate a refusal of treatment and, where valid, have the same authority as a valid and current refusal of treatment. If a patient has made a valid advance directive specifying that they do not wish to receive certain treatment in certain circumstances, and those circumstances have arisen, then that treatment should not be provided, irrespective of whether health care providers consider that the treatment would be in the patient's best interest.

As discussed above, there are limits to the authority of a person with an EPA to refuse treatments, in particular to refuse any standard medical treatment or procedure intended to save life or to prevent serious damage to health (section 98(4) PPPR Act 1988). Therefore, an advance directive remains the best way for an individual to express their wish to refuse a particular treatment in the future, especially if the treatment may be considered standard and/ or is potentially lifesaving.

Advance directives indicating a positive preference for, desire to receive, or consent to receive a particular treatment do not, however, have the same legal weight as an advance directive indicating treatment refusal. A patient's desire, wish, request or expectation to receive a particular treatment does not establish a duty on the health care provider to provide it. There is no right to receive a particular treatment where the treatment is not offered or available. Where a treatment or procedure is not indicated and/or would offer no benefit the individual's wishes would not take priority over the clinical decision. Advance directives stating positive preferences may be most useful in those circumstances where there is clinical uncertainty. The individual's wishes can then be taken into account along with clinical judgements in deciding the course of action that is in the individual's best interests.

An advance directive can also be used to document wishes and preferences other than refusal of or consent to particular medical treatment or procedures. For example, an individual might wish to specify:

- personal beliefs and values as informed by their cultural identity or religion and how they would impact on care and treatment decisions
- particular conditions or states that they would find unacceptable
- the existence and name of a legally authorised substitute decision-maker (a person with an EPA)
- the name of a person that the individual would choose to have represent them in discussions with clinicians about treatment options
- other non-medical aspects of care that are important to the individual during their dying phase.

The legal status of advance directives

The legal authority of an advance directive rests with its validity, which should be established before it is honoured or given effect. There are four legal criteria that an advance directive needs to meet, as follows.

1. The individual was competent to make the particular decision, when the decision was made.
2. The decision was made free from undue influence.
3. The individual intended the directive or choice to apply to the present circumstances – this criterion is likely to incorporate the requirement that the individual was sufficiently informed at the time of making the advance directive.
4. The existence and validity of the advance directive must be clearly established.

Unless there are reasonable grounds to doubt one of these four criteria, a clinician should ordinarily give effect to an advance directive and should not provide services that would contradict it. For positive treatment preferences the advance directive should be considered but it cannot require the clinician to provide treatment or services the patient, if competent, could not choose or expect to receive.

Effective ACP does not necessarily require a patient to complete a written advance directive. The reflective discussions and open communication of ACP will help health care professionals and family/whānau prepare for and make decisions that respect the individual and their preferences at a time when they can no longer speak for themselves. The patient may have chosen to verbally communicate specific wishes or appoint an EPA and these actions can be extremely helpful to later decision-making.

There is no doubt, however, that a documented advance directive or advance care plan arising from a well-informed discussion involving both the individual and the health care professional(s) is more likely to meet the criteria for validity than an unrecorded oral directive or plan, or an advance directive drafted either by the individual on their own or as a legal document in isolation from health care professionals.

In the New Zealand context it is likely but as yet legally untested that a written advance care plan would constitute an advance directive for legal purposes. If there is uncertainty about the validity of an advance directive or the applicability of an advance care plan, then the health care provider concerned should discuss the case with colleagues and/or seek legal advice.

Advance directive templates

In New Zealand, there is no standard format for advance directives. However, two sources of assistance worth noting are the:

- New Zealand Medical Association, whose website offers information and sample forms patients can use <http://nzma.org.nz/patients-guide/advance-directive>
- Mental Health Commission, which has produced a sample advance directive for people with mental illness.



6 Barriers to ACP in Clinical Practice

It is important to recognise that there may be barriers to effective ACP in the health care sector and wider community. These barriers include the following.

- Time constraints on health care professionals may influence their ability to initiate ACP discussions and may impact on the quality of any discussions because ACP requires preparation and planning by the clinical team. It is important to recognise that discussions should take place in appropriate settings, with sufficient time to confirm a patient's knowledge and consider the choices.
- The patient, family/whānau or health care professionals may feel uncomfortable talking about end-of-life issues. Communication difficulties between patients and their health care providers are well known and well documented. This restriction on communication is exacerbated when the topic to be discussed is considered to be delivering bad news. Studies have shown that the quality of end-of-life and ACP discussions between patients and their health care providers are predominantly poor. An anonymous survey of district nurses in the United Kingdom identified that 70 percent had difficulty dealing with the subject of death and dying and that an equal percentage had purposefully blocked patients from talking about it (Curtis et al 2001; Carline et al 2003; Gooding 2004). Further studies have also confirmed that what a patient wants to discuss and what is actually discussed in end-of-life discussions often differ (Street and Ottmann 2006; Lyon 2007). There is no New Zealand evidence available about this area.
- Patients who are not aware of their right to actively participate in treatment decision-making or who prefer their doctors to lead the medical decision-making may be less inclined or less willing to engage in the ACP process. Likewise, instances of clinical paternalism mean that some health care professionals may not see the need for instigating ACP.
- Patients may be fearful about being unable to change their minds once treatment preferences are documented. It is therefore always important to explain to the patient that they have the right to change their mind about treatment preferences at any time while they are still competent. The health care professional plays a crucial role in empowering the patient to review and revise the patient's ACP to ensure that the patient's wishes remain current and up to date.
- People may not know anything about ACP and advance directives, or the medical implications of their documented preferences.
- Health care professionals may not know of or understand the legal and ethical frameworks for patient and clinician decision-making, including the roles of ACP, EPAs and advance directives.
- Facing a progressive terminal illness will of course always be a new experience for the individual but their family/whānau may also not have experienced the process of caring for a loved one who is dying. In such circumstances they will have limited awareness of what lies ahead and may not appreciate the benefits that can arise from ACP. They need health care professionals who are willing and competent to engage them in difficult discussions and who can describe with compassion what they have witnessed in their professional roles to help their patients prepare for what is to come (Gawande 2010).

For more detailed clinical guidelines on the issue of communicating prognosis and end-of-life issues, see the document developed by the researchers Clayton et al (2007).

7 People Requiring Special Considerations

This section identifies individuals and groups for whom special considerations must be made in the ACP process, such as those with communication difficulties and those with mild cognitive impairment. It provides some guidance to optimising communication and decision-making in these groups. As with all difficult conversations it is important to have patience and to take and give as much time as is necessary to communicate all relevant matters effectively. Highlighted under each subheading below are specific tools and techniques that can be employed to ensure effective communication with the identified group.

Effective ACP depends on the person being able to communicate with health care professionals and to make choices and decisions about their future health care. For some individuals and groups ACP will therefore present particular challenges and for others of course it will simply not be possible. Where an individual is completely unable to participate in ACP, alternative decision-making approaches have to be applied.

Where the individual has impaired competence or decision-making capacity, and/or where there are communication difficulties, health care professionals will need to carefully consider their approach to ACP. The first consideration must be to ensure everything possible is done to maximise the ability of the individual to participate; the second must focus on whether or not the individual even with maximum support has sufficient capacity to make plans and decisions for the future and to accurately communicate them.

People with mild cognitive impairment

ACP relies on the patient being competent to share in the planning process and so needs to be considered early in the care of any person for whom the diagnosis of dementia is suspected. A person with dementia does not necessarily lack capacity, however, it should be anticipated that their capacity will fluctuate and decline over time. ACP can help the person with early dementia feel valued and respected and, of course, ensure that their values, beliefs and preferences for care can be honoured appropriately. When a person with dementia finds that their mental abilities are declining, they often feel vulnerable and in need of reassurance and support.

The people closest to them (including their main caregivers, health care professionals, friends and family/whānau) need to do everything they can to help the person with dementia retain their sense of identity and feeling of self-worth. ACP provides an invaluable opportunity to respect the person and their preferences and to reduce or prevent some of the difficult decisions which would otherwise need to be made in the future.

People with intellectual impairments

When having ACP discussions with a person who has an intellectual impairment, make all explanations clearly and concisely and use plain language. Be patient; take and give as much time as is necessary to communicate all relevant matters effectively.

The visually impaired person

A person who is visually impaired is usually verbal and may have heightened other senses, such as hearing and smell.

Try to arrange for the ACP discussion to take place as far away from distracting background noise as possible, and explain any noises, including writing and paper noises, and any odours that might be related to the space.

The Deaf person

A Deaf person may need a sign language interpreter and a support person to accompany them to any ACP discussion. An interpreter provides the Deaf person with the information, and the support person helps the deaf person find understanding of or meaning to the words.

Focus on the relationship with the Deaf person (rather than the interpreter). Speak clearly and distinctly at a moderate speed but without exaggeration. Ask the Deaf person to repeat things if you are unable to understand their speech, and use drawings, writing and gestures to assist in the discussion.

Make sure lighting levels are adequate. Don't stand in front of a bright light source because this puts your face in shadow and makes lip reading difficult. Try to limit visual or noise background distractions – if necessary move to a quiet place.

Studies have shown (Con 2007) that at end of life, the ability to sign decreases as the dying person weakens. ACP discussions need to occur early to ensure that the Deaf person can still communicate their desires and opinions.

The Deaf blind person

A Deaf blind person may need to have a tactile sign language interpreter and a support person with them at any ACP discussion. The discussion may need extra time and resources to ensure that all points are expressed clearly, understood fully and that the conversations are meaningful.

People with physical impairments

Most people with physical impairments are able to converse normally. However, it is common for them to be ignored in favour of their support person this should not be allowed to happen.

People with speech impairments

It is critical that ACP discussions with a person with a speech impairment are not conducted in a noisy, public place; talk in a private, quiet area wherever possible and do not speak for the person or attempt to finish their sentences. Concentrate on what the person is saying. Ask them to repeat what they said if you did not understand something and then repeat it back to confirm that you have understood them correctly. Consider writing as an alternative means of communicating if you are having difficulty understanding what the patient is saying. Ask questions that require only short answers, or a nod of the head, when appropriate.

8 Key Elements of the ACP process

- A key factor in effective ACP is starting and continuing discussions about what a patient values in life and believes to be important for their end of life.
- The ACP process is voluntary and should not occur as a result of external pressure.
- Discussions usually focus on medical treatment preferences but may include other matters, such as spiritual or interpersonal issues.
- Family/whānau and caregivers should be included in ACP discussions if that is the person's wish.
- It is recommended that discussions be ongoing, documented, regularly reviewed and, with the patient's agreement, communicated to key people involved in that person's care.
- Discussions should take place in appropriate settings, with sufficient time to confirm a patient's knowledge and consider the choices.
- All health care professionals should be open to any ACP discussion instigated by their patients.
- Health care professionals will need to have the appropriate training to communicate effectively during ACP discussions and to understand the legal or ethical issues involved.
- ACP requires that the person has the capacity to discuss and understand the options available to them and ideally to make a plan outlining choices and decisions about their future care.
- The individual, their family, caregivers and whānau, and health care professionals should expect ongoing discussions that will allow the person to make their choices known as death approaches.
- When an individual is unable to make their own decisions an ACP discussion, advance care plan or an advance directive can assist clinicians, a person with an EPA and family/whānau to reach a decision that prioritises the person's best interests.
- One result of the ACP process may be to appoint an EPA and/or complete an advance care plan or an advance directive.
- There will be individuals, such as those with physical disabilities and mild cognitive or intellectual impairment, for whom the process of ACP requires special considerations.
- There are other individuals, such as those with advanced intellectual or cognitive impairment, including dementia, for whom ACP as outlined in this guide does not apply. Other approaches to advance decision-making need to be considered in these people.
- Clinical decision-making ultimately comes down to a concerted effort on behalf of all health care professionals to make the best decisions they can in conjunction with or on behalf of each individual patient. Such decisions will take into account each person's unique personal and social situation and their individual wishes, beliefs and values for future care.



Glossary

Advance care plan	An advance care plan is the desired outcome of the ACP process. Ideally, it is documented rather than verbal and while this might be done on a form designed specifically for that purpose, it can be in any format. It should be accessible to current and future health care providers and to family/whānau members according to the person's wishes. An advance care plan is an articulation of wishes, preferences, values and goals relevant to all current and future care. It 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). An advance care plan can and should, however, be used to inform decision-making in this situation along with other measures such as discussions with the individual with an EPA (where one has been appointed) and with family/whānau.
Advance care planning (ACP)	<p>Advance care planning (ACP) is a process of discussion and shared planning for future health care. ACP is focused on the individual and involves both the person and the health care professionals responsible for their care. ACP may also involve the person's family/whānau and/or carers if that is the person's wish. The planning process assists the individual to identify their personal beliefs and values and incorporate them into plans for their future health care. ACP provides individuals with the opportunity to develop and express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.</p> <p>The ACP process may result in the person choosing to write an advance care plan (see below) and/or an advance directive and/or to appoint an enduring power of attorney (EPA). If a person is identified as having strong views or preferences about medical treatments and procedures, they should be advised to consider completing an advance directive. The value of the ACP process, however, lies not solely in these outcomes but in the conversations and the shared understanding that eventuate.</p>
Advance directive	<p>Instructions that consent to, or refuse, specified medical treatment or procedure in the future.</p> <p>Advance directives are defined in the Code of Health and Disability Services Consumers' Rights (the Code) as written or oral directives in which the patient makes a choice about a possible future health care procedure, and this choice is intended to be effective only when the patient is no longer competent. For this reason, advance directives are also, though less frequently, referred to as 'living wills'.</p> <p>Right 7(5) of the Code gives every consumer the legal right to use an advance directive in accordance with common law.</p>

Assessment	A service provider's systematic and ongoing collection of information about a patient to form an understanding of the patient's needs. A clinical assessment forms the basis for developing a diagnosis and an individualised treatment and support plan (eg advance care plan) with the patient, their family/whānau and significant others.
Capacity/competence	In general terms, an individual's ability to perform a particular task at a particular point in time. In the context of ACP, this relates to an individual's ability to make a decision regarding their own health care (that is, competence at decision-making or decision-making capacity). At a minimum, decision-making capacity requires the ability to understand and communicate, to reason and deliberate, and the possession of a set of values (Buchanan and Brock 1989).
Community	The people living in a particular area, or people who are considered as a unit because of a common nationality, occupation, culture, belief, interest or experience.
Culture	The shared attitudes, beliefs, values, experiences and/or practices of groups in society.
End-of-life care	End-of-life care is simply acknowledged to be the provision of supportive and palliative care in response to the assessed needs of patient and family/whānau during the last phase of life.
End stage	The final period or phase in the course of a progressive disease, leading to a patient's death.
Enduring power of attorney (EPA)	An authority given by a patient, while they are competent, to another person, in order for that person to act for the welfare of the patient only once the patient is mentally incompetent. Under new legislation (2007), a medical certificate that the patient is mentally incapable is required before a person with an EPA can act in respect of certain matters. Note there are two types of EPA (property; and personal care and welfare).
Family	For the purposes of this document, and in recognition of the collaborative nature of health care, a person or people who has/ have a close, ongoing, personal relationship with a patient. Such a person or people may or may not include the immediate biological family of the patient and may include other relatives, a partner (including same-sex and de facto partners), a friend or a 'person responsible' according to any wishes expressed by the patient. See also whānau.
Goals	In this context, a person's personal goals at the time they participate in advance care planning, for example, spending more time with family and friends.

Health care practitioner/ professional	A practitioner of a particular health profession, such as a doctor, dentist, physiotherapist, midwife, optometrist or pharmacist, licensed, certified or registered in New Zealand to provide health care.
Informed consent	The permission a patient gives to a health care provider to allow medical assessment and/or treatments.
Life-limiting conditions	Conditions for which curative treatment may be feasible but can fail, conditions where premature death is inevitable, or progressive conditions without curative treatment options.
Palliative approach	An approach that improves the quality of life of patients and their families/whānau facing the problems associated with life-limiting illnesses and conditions. It involves active, holistic care, including managing pain and other symptoms and providing psychological, social and spiritual support.
Palliative care	<p>Palliative care is care for people of all ages with a life-limiting illness which aims to:</p> <ol style="list-style-type: none"> 1. optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs 2. support the individual's family, whānau, and other caregivers where needed, through the illness and after death. <p>Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life. It should be available wherever the person may be.</p> <p>Palliative care should be provided by all health care professionals, supported where necessary, by specialist palliative care services.</p> <p>Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities (Palliative Care Working Party, Ministry of Health 2007).</p>

Supportive care	Supportive care helps the patient and their family/ whānau to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. Supportive care is given equal priority alongside diagnosis and treatment (National Council for Palliative Care UK).
Whānau	Kuia, koroua, pakeke, rangatahi, tamariki. The use of the term whānau in this document is not limited to traditional definitions, but recognises the wide diversity of families represented within Māori communities. It is up to each whānau and each individual to define for themselves who their whānau is.
Whānau Ora	Strategy or model through which Māori families achieve their maximum health and wellbeing.



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Further information

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Appendix 1: The National Advance Care Planning Cooperative

Vision

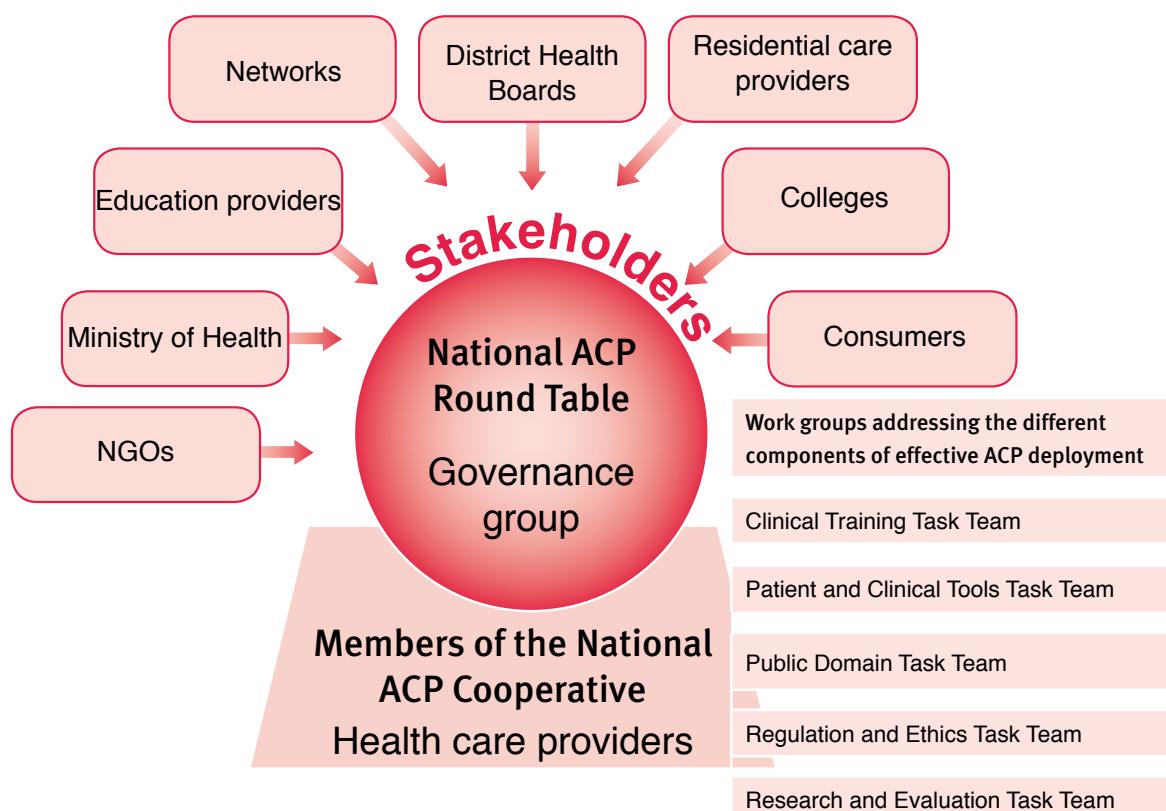
All people in New Zealand will have access to comprehensive, structured and effective advance care planning.

Mission

The Cooperative will work together to develop a common understanding, framework and direction for ACP in *all* areas of health, for *our* communities. The Cooperative will work with government and non-governmental agencies, to advance its aims and objectives within the current legal and ethical context in a manner that is coordinated, evidence-based and outcomes focused.

Key priorities are to encourage:

- consistent language and documentation in regards to ACP
- public engagement and education with ACP
- staff training in ACP and communication
- cultural appropriateness.



National ACP Cooperative structure (as at November 2010)

Goals

- To fully engage the community (public and private organisations, non-government organisations, networks and the general public) in the design and implementation of ACP.
- To develop training for health care workers.
- To grow and support a group of ACP-trained clinicians.
- To create and control consistency in ACP documentation and messaging and to actively seek to obtain a national mandate for universal documentation over time.
- To influence research on issues related to ACP.
- To develop funding and resource proposals.
- To provide input into and impetus for IT integration in relation to ACP.

