

our voice | *Advance
Care
Planning*
tō tātou reo

Advance care planning guide

Planning for the medical treatment and care
you want in the future



Introduction

We all know our lives will end sometime, but most of us put off thinking about it until something happens.

Maybe a friend or relative becomes ill or dies. We might see some dreadful accident reported in the media. Suddenly we are faced with unpleasant thoughts, emotions and fears about the future. We get frightened. The future doesn't look quite so certain. We grieve for – and do our best to support – those who are themselves grieving.

Sometimes that makes us take action, particularly in dealing with financial matters. We might make a will, or get medical or life insurance. We might talk with our whānau/ whānau/ family and friends about what has happened and how it has worried us.

It all becomes much more real if we get a health scare ourselves – whether accident or illness. We may be concerned for ourselves and for our whānau/ families and friends. We worry about what will happen if things get life-threatening. And because our whānau/ family and friends may be upset for us, it sometimes isn't easy to talk to them about what we want as a patient – what medical treatment we would want if the worst happened and our mental and physical abilities were severely damaged.

If we take the time to make plans, it will give them the information they need. If in future we could no longer speak for ourselves,

they could help get us the treatment and care we hope for. They would not have to guess what we want.

We can tell our whānau / whānau/ families and healthcare team what is important to us and what medical procedures we would want if we were very ill or nearing the end of our lives. We might be reassured if we had been able to talk through and record our wishes when still fit and healthy. But too often we wait for trouble to strike before we think about it. This is a natural human approach to end of life. This guide will help you plan for your end-of-life healthcare choices and draw up your own 'advance care plan'. It is just a tool to help you work through the different decisions – a guide and not a test. Also, we suggest you talk it through with a healthcare professional. But most importantly, think about what YOU want. Make sure your closest whānau / whānau/ family and friends understand why you have made these choices, and then they will be happy to carry out your wishes. The time to make an advance care plan is now – whatever your age or state of health.



Using the guide

You may never have reflected on your life or death before. You may want to work on it on your own, or with your closest whānau/ family and friends. You may be comfortable working with a healthcare professional. Or you can talk to your medical support people later. The process has been organised into parts to help you develop your own advance care plan. By working through the planning process, you will end up with a much clearer idea of what types of future healthcare you would prefer. The questions are there to help you, and you can add to them. You can also write things down as you go along (e.g. medical or technical issues you want explained).

This guide will help you work out your values and make future healthcare choices. Going through the process takes time and energy, and it is not easy to do in the middle of a health crisis. The best time to do it is when you are well.

Information Online

If you would like to read further information online about Advance Care Planning, visit www.advancecareplanning.org.nz or email info@advancecareplanning.org.nz

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Advance Care Planning

The development of medical knowledge and tools has dramatically changed medical care –how we can be sustained or mended. These medical breakthroughs have also changed how and where we die.

Think about this:

You have a life-threatening illness or have been in a serious accident. Your mind or body, or both, are badly affected and you were close to death.

What would you want medical treatment to do for you? Keep you comfortable, control your pain and treat any other unpleasant symptoms while allowing a natural death to occur? Or prolong your life with active life-support medical treatments such as surgery, drugs, drips and feeding tubes – even though you have little hope of returning to what you'd consider 'a good life'?

Also consider, when would you want the focus to change from life support to comfort care? And who would you like to have there, to talk to medical staff about what you want?

Advance care planning is about helping you to think and talk about the end of life, and about what treatments and care you might want.

You and your healthcare providers should be working together to ensure that your future care choices make sense. This will then guide your whānau/ family and doctors when you can no longer tell them yourself.

Advance care planning is voluntary – no one can force you to do it.

How do I make an Advance Care Plan?

1. Think about what values and beliefs around end-of-life issues are important to you. What makes life meaningful to you and what situations might make it seem pointless?
2. Talk to health professionals to learn about medical treatments for the very ill or injured. Ask about the benefits and risks of these treatments.
3. Decide at what point you would want your future healthcare to focus on comfort care rather than life-saving measures which may be uncomfortable or unpleasant.
4. Choose what medical care you do or don't want, to honour your values, beliefs and faith.
5. Discuss your choices and wishes with those closest to you, so they know what you would want if the worst should happen.
6. Choose who would you want to speak for you if you could no longer make your own medical decisions, and sign over 'enduring power of attorney' to them.
7. Put your advance care plan in writing and keep a copy in your medical record. It will not be used while you are capable of making your own decisions and speaking for yourself.



Who decides what treatment you get?

Your doctor considers what treatment to offer you based on:

- your state of health at the time
- the availability of treatment
- the benefit you will get from the treatment, balanced with the risk of possible harm or side-effects.

You then have a choice: agree to have the treatment or refuse it. By completing an advance care plan, you are telling your doctor how you feel and you will have enabled a trusted friend or whānau/ family member to speak for you if you cannot speak for yourself. Your doctors will be clear about what you want.

You will be given pain-relieving and symptom control medicines and treatments when you need them.

You will ALWAYS be entitled to 'comfort care' that respects your body, mind and spirit.



Working out your Advance Care Plan

Part I: Thinking and contemplation

- Has anything happened in your past to influence your feelings about medical treatments?

- Think about a time when someone close to you was very ill or dying. What was positive about it? What do you wish had been done differently?

- What role does spirituality play in your life? How important to you are faith, religion and cultural values around life and death?

- At present, what brings you pleasure and joy? What are you aiming to do with your life from now on?



- Who do you like to spend time with?
- What would you miss most if you couldn't live as you are used to? If you couldn't think, walk or talk normally?
- Do you have any major health problems at the moment? What are they? Will they get worse? How will these affect the rest of your life?
- How do medical treatments you are having affect the way you live now? And how will they affect you in the future?

- What medical problems do you fear you might have in the future?
- What frightens you most about medical treatment?
- What will help you live your life well from now on?
- If you couldn't speak, who could speak for you?
- What would an ideal death look like for you?
- When you are nearing death, what important things would you like your whānau/ family and friends to know and remember (e.g. 'I love ...', 'I forgive ...')?

Part 2: Managing future medical care

You are entitled to a good understanding of your current health status and the possible healthcare issues you could face in the future. You can ask your healthcare team to explain your future medical treatments. Make an appointment with your doctor to have these conversations.

It is important for you to understand what your healthcare providers will provide. When you are in pain or experiencing unpleasant symptoms such as dizziness, nausea and fever, healthcare providers will give you medicines and treatments.

If you reach the point where you no longer want life-saving care, medical treatment and nursing care are always given to keep you comfortable, such as:

- surgery to control pain (such as the repair of a broken hip)
- antibiotics
- pain-relieving medicine and treatments
- medication to ease breathing difficulties

In the case of a serious illness or injury, there are a number of procedures that can prolong life or delay the moment of death. These include cardio-pulmonary resuscitation (CPR), artificial breathing using a machine, tube feeding and artificial hydration (intravenous), and kidney dialysis. Some can be helpful or harmful depending on the situation.

Life-sustaining procedures could be helpful if they:

- prolong life so you can return to the lifestyle you enjoyed before the hospitalisation or one you would be happy with
- restore function (ability to walk, hear, speak, etc.)
- relieve pain and suffering
- are consistent with your religious or cultural beliefs
- support your goals and values.

Life-sustaining procedures could be harmful if they:

- result in more pain and suffering
- damage your body or function
- are mentally or emotionally damaging
- allow you to die without those you want being there

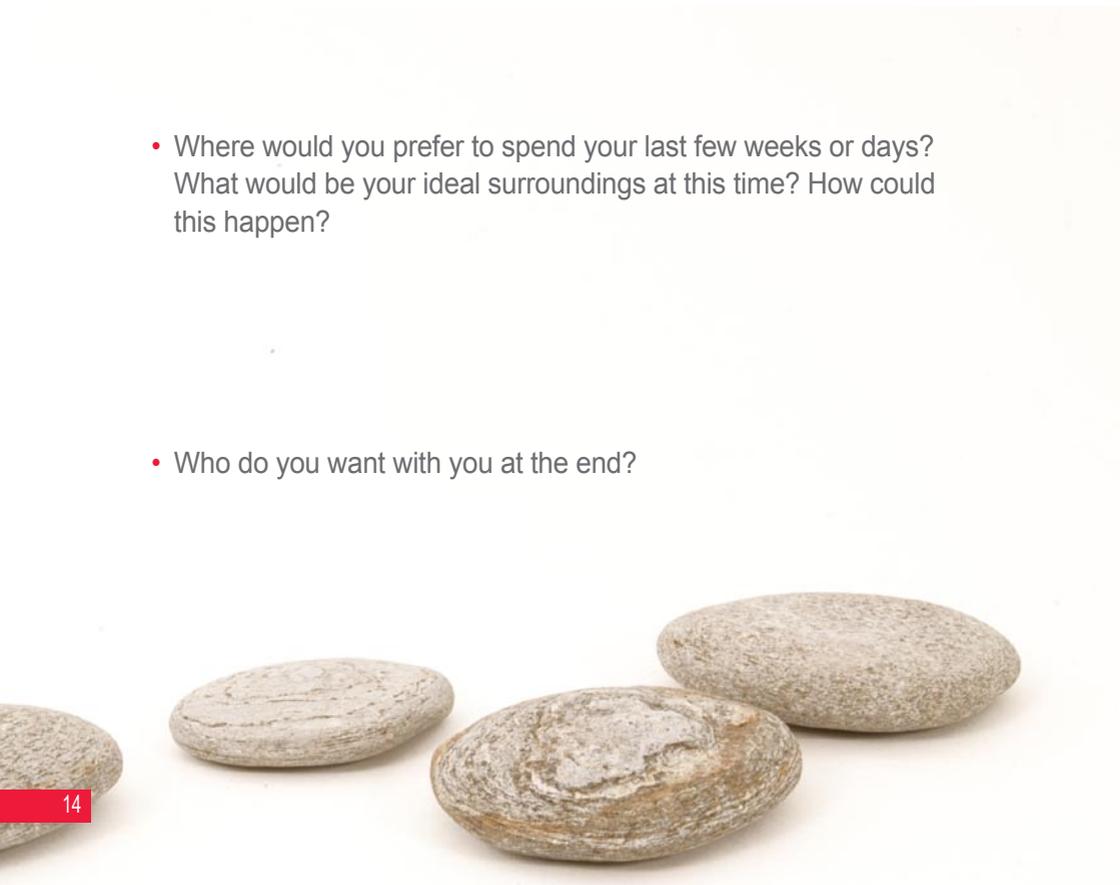
Often treatments are both helpful and harmful. For example, it might be possible to prolong life but not restore awareness; or restore functions such as walking, but with great pain. You need to weigh this up against your values and personal goals.

Consider in what circumstances you would want the goal of medical care to switch from prolonging life to comfort care. The latter focusses on physical comfort, pain relief and caring support for you and your whānau/ family. For example, would you want your life prolonged if you had little chance of recovery or a return of speech, walking or thinking?

We assume you will always want medical relief for pain and distress.

Part 3: Managing the end of life

- When you think about dying, what situations worry you? For example, do you worry about being alone or struggling to breathe?
- What do you need to do before you die? For example, would you contact old friends or whānau/ family you have lost touch with? Make amends for things you regret?
- Where would you prefer to spend your last few weeks or days? What would be your ideal surroundings at this time? How could this happen?
- Who do you want with you at the end?



- When you are nearing death, what do you want or NOT want? For example, how do you feel about food and drink if you are not hungry or thirsty?
- What kind of spiritual care do you want at the end of your life? Is there a favourite priest, minister of religion or kaumatua you would like to have present? Would you like prayers at your bedside? Or none? Do these things matter to you?





Organ & Tissue Donation

Sometimes when people are very ill, the only way they can recover or lead an active, normal life is to receive an organ or tissue transplant. Most commonly, organs and tissues are donated by people who have died. Organ Donation New Zealand and health professionals throughout New Zealand work together to ensure that the person donating and the whānau/ family are treated with respect and dignity throughout the donation process.

Over 1 million people have indicated their wish to donate organs on their driver licence. Only a small number of people, however, will die in circumstances that makes it possible for organs to be donated for transplantation. People who die at the scene of an accident or die from heart attacks, for example, cannot donate organs for transplantation. This is because once the heart stops and there is a period of time when the organs have no blood and oxygen supply, the organs will not be suitable for donation.

Many more people can donate tissues for transplantation as tissue donation is not restricted to those who die in an intensive care unit from a non-survivable brain injury. Those who die in hospital or at home can be considered for tissue donation. Tissue donation, including eyes (corneas and sclera), heart valves and skin donated can be facilitated up to 48 hours following death. Corneal transplantation will restore sight, heart valve transplantation can save the lives on newborn babies and skin transplantation can prevent death for patients with severe burns.

If you would like your organs and/or tissues to be donated please tell your whānau/ family and include this information in your advance care plan. For more information go to www.donor.co.nz or call **0800 4 DONOR (0800 436 667)**.

Part 4: Talking things through

Once you have thought about what you want, meet your healthcare provider to clarify any medical questions or issues.

If you have a faith tradition, you may also want to talk to your priest, minister (or nursing home chaplain) or kaumatua about your choices.

Then talk with your friends and relatives about your plans, including any wish to complete an advance care plan.

If you want to appoint someone as your enduring power of attorney, you will need to discuss your choices with them so they understand what you want and why.

These may not be easy conversations. Pick a time when you feel comfortable to deal with it – and don't expect to answer all their questions in one go.

Part 5: Taking action – drawing up a plan

Think about getting a healthcare professional to help you write up your advance care plan.

You should keep a copy. Keep it somewhere that you and those who live with you know – for example with your enduring power of attorney document, will and other important documents.

Give copies to:

- your healthcare professionals
- the person you chose/ nominated to speak on your behalf
- members of your whānau/ family and/or friends
- your minister, priest, kaumatua – the nursing home manager if you live in one.

Make sure to let all these people know if you change the plan, so they can keep up to date with your life changes and health status.



Frequently asked questions

Can I change my Advance Care Plan?

You can change your advance care plan whenever and as often as you wish, as long as you are competent (see page 17 for more information about competence). Looking at your plan is especially important if any aspect of your life or health status has changed.

Keep it close to you and up to date.

How can I appoint someone else to make decisions for me?

You can appoint someone as enduring power of attorney. This person should be involved in most decisions about your care if you can no longer make decisions for yourself. They may be a close whānau/ family member, a friend or anyone else you choose. For more information, contact your solicitor or Public Trust (contact details below).

When you legally appoint somebody to make decisions for you under an enduring power of attorney, it is important that they know your wishes, feelings and values. This will help them make the best decisions on your behalf. It is a good idea if you include them in any discussions about your future treatment options.

If you do not give someone enduring power of attorney, you can name someone to speak for you. Then, if you cannot make a decision for yourself, a health professional would consult this person. But if you have a named person only rather than someone with enduring power of attorney, they cannot make decisions for you. They can only provide information about your wishes, feelings and values, which will help the healthcare professionals act in your best interests.

The Public Trust

The Public Trust is available to provide legal and financial advice.

National Freephone: 0800 371 471

or visit the website at <http://www.publictrust.co.nz/life-events/becoming-a-whānau/family/enduring-power-of-attorney/what-is-an-epa.html>

Community Law Centres Nationwide

Community law centres around New Zealand provide a range of community legal services. These include free advice, representation, information and education.

Contact by Telephone:

North Island:

Auckland: 09 275 4310

Gisborne: 06 868 3392

Hamilton: 07 839 0770

Hastings: 06 878 4868

Taranaki: 0800 LAWTRUST (529 878)

Wairarapa: 06 377 4134

Wellington: 04 499 2928

Whangarei: 09 437 0185

South Island:

Canterbury: 03 366 6870

Dunedin: 03 474 1922

Marlborough: 03 577 9919

Nelson Bays: 0800 246 146

Ngai Tahu Maori Law Centre 03 477 0855

Southland: 03 214 3180

or visit <http://www.communitylaw.org.nz> for access to free information brochures.

What happens in an emergency when my advance care plan and decision-makers are not available?

In emergencies, there may not be time to locate and consult the detailed instructions in your plan. Your health professional may begin life-saving treatments but then stop these if they learn that it is not what you want.

When am I 'competent' to make medical treatment choices?

You are competent if you can:

- understand the basic medical problem
- understand what the treatment is for, the benefits and risks, the alternatives, and what would happen if you did not get the treatment?
- weigh up the information
- show that you can recall the information
- tell the doctor (with words and/or actions) what your choice is.

My children/spouse do not agree with my carefully chosen healthcare wishes. What can I do?

If you have discussed your healthcare choices and last wishes with your doctor and whānau/ family, this situation is less likely to arise.

If there is a disagreement, you should consider choosing someone else to hold your enduring power of attorney.



Legal Issues

Your rights as a patient are set out in the New Zealand Code of Consumer Rights. Under the code, your 'advance directives' and plans do not need to be formal written documents. And they can include any treatments, not just life-sustaining treatments.

Your right to refuse treatment is set out in the New Zealand Bill of Rights Act (section 11). If a healthcare provider violated this right, they would be guilty of a criminal offence.

A person cannot demand a specific treatment.

An advance directive, to be legally binding, must meet certain criteria.

First, you must be competent at the time you make the directive. You are competent if you can receive and understand information, think about it, draw a conclusion or come to a decision, and then can communicate that. You are considered competent unless it can be shown not to be true.

Second, any decision you make to refuse treatment you must do freely, without undue influence, or limiting pressure, from anyone else.

Third, when you made the 'advance directive', you must have intended that your refusal or consent to treatment would apply in the current situation. You should have had enough information when you made the directive, and the directive must still make sense in the current situation. If this contains any doubt, the medical team will make treatment decisions that they believe are in your best interests.

Other important rights you are entitled to:

- privacy
- services that consider your needs, values and beliefs
- services which respect your dignity and independence
- effective communication
- information you need for making an informed choice.



Glossary of terms

Below are some definitions of key words and terms used in this booklet.

Advance care plans (sometimes including advance directives) are instructions made while you are still capable. They describe what kind of care you would want (or not want) if you were unable to speak for yourself. You cannot make an advance care plan for someone else.

Advance directive is an instruction on what medical care or treatment a person does or does not want in specific future circumstances. Any treatment refusals are legally binding on the healthcare team treating the person who can no longer communicate the refusal.

Antibiotics are drugs that are used to fight bacterial infections.

Artificial nutrition refers to giving food through tubes to a person who cannot eat/ swallow; tubes can be used temporarily or permanently.

Cardiopulmonary resuscitation (CPR) refers to medical procedures used to restart a patient's heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping on the chest to electric shocks that restart the heart.

Dementia is a physical disease that affects the brain and causes a progressive decline in mental function.

Dialysis is a medical procedure that cleans your blood when your kidneys can no longer do so.

End-of-life care refers to the healthcare provided at the end of a person's life. This type of care focuses on patients living the way they choose during their last weeks and the type of care provided until the time of death.

Enduring power of attorney (medical) is a legal document that allows you to appoint another person to make healthcare decisions on your behalf. It only becomes effective once you can no longer make healthcare decisions for yourself. This appointment must be in writing, and signed and witnessed by a justice of the peace (JP). This legal document does NOT allow the appointed person to withhold or withdraw treatment.

Feeding tube is a way to feed someone who can no longer swallow food. It is a small plastic tube that carries liquid food, which is inserted through the nose or directly into the stomach or intestines.

Healthcare provider (or professional) describes a person licensed, certified or registered in New Zealand to provide healthcare. It includes for example doctors, nurses, social workers and physiotherapists.

Informed consent refers to the permission you give to healthcare providers to allow medical investigations and/or treatments. Healthcare providers will give detailed explanations of the investigations/treatments and their risks before you are asked for consent.

Intravenous (IV) is a way to give a person fluids or medicine. A hollow needle, attached to a narrow tube, is placed in a vein in the hand, the arm or another place.

Life support with medical interventions refers to medical or surgical procedures including for example tube feeding, breathing machines, kidney dialysis, some medications and CPR where the intention is to support and/or continue life.

Symptoms are the things that you experience which can indicate that you are unwell, such as pain, vomiting, loss of appetite and high fever.

Terminal illness means an incurable medical condition caused by injury or disease. These are conditions where life support can sometimes prolong life or the dying process but not prevent death.

Ventilator is a machine that helps people breathe when they cannot do it on their own. The machine is connected to the person either using a facemask or a tube in to either their windpipe or through their mouth/ nose/ neck.





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