

# *Guide to dying*



*... your way.*

# Do it your way

Nobody gets off this planet alive. Dying is part of living but we rarely think about death, especially our own, until or unless we have to.

This guide is designed to do just that: to encourage you to think deeply about what you do and don't want for yourself if worse comes to worst, and to help you put your affairs in order to increase the likelihood of achieving the death you choose, rather than leaving it all to chance. Thinking things through when you are calm, able to research the issues and able to tell the relevant people what you want, is much better than making decisions in a crisis.

When thinking about dying, it's easy to forget that you may be in a situation where you are unable to speak for yourself, unable to communicate what you do and don't want – for example, after a head injury, stroke or heart attack – or you may be suffering from Alzheimer's disease, dementia or other health issues that could alter your quality of life.

An **Advance Directive (AD)** is literally specifying what you do and don't want, written down, witnessed and signed. Your **Agent** is the person you have chosen to speak for you if and when necessary. Someone who knows and understands you and is prepared to argue for what you want.

Your completed **Advance Directive** acts as an important guide for your **Agent** who will communicate your choices. This is extremely helpful for the medical team who may not be familiar with your case, but want to provide the best care possible. It is also very helpful for your family members who otherwise may not agree with one another as to the best course of action.

This document is designed to help you through the process of creating your own **AD**. A form is included, plus some suggestions to help you choose your **Agent** and to provide advice for them.

At the end of this document you will find a Membership Application Form for the End-of-Life Choice Society of New Zealand, Inc. If you are interested in joining the campaign to support all end-of-life options including assisted dying for those with a terminal illness or irrecoverable condition, then please consider joining our organisation.

Knowing that you have done everything you can to make sure you die the way you choose, there will be considerable peace of mind for you and those who care about you.

Fill out your **Advance Directive** while you can. Don't leave it to chance.

# Guide to dying . . . your way

## Why do I need to know about this?

Many people make an **Advance Directive** in the expectation that it will be fully observed by medical staff, but this is not always the case. Planning ahead to use the law to your best advantage could make all the difference between a peaceful death and a distressing one, not just for you but for your family. There are two important elements:

An **Advance Directive** (a form is at the end of this guide)

An **Agent** (someone you trust to ensure the wishes you have expressed in your **AD** are carried out)

## What is an Advance Directive?

These are instructions you give, verbally or in writing, to your medical team so they know how you wish to be treated at some future time when you are no longer competent. The instructions indicate your choices regarding your future healthcare wishes. You decide in advance of an event whether to receive certain medical treatments and services, or to receive them for a time and then subsequently withdraw consent to receive them when your health deteriorates to a certain stage, or to refuse them altogether at the outset.

## Who should have an Advance Directive?

Anyone who wants to make decisions about his/her end-of-life treatment should have an **Advance Directive**. It would be a mistake to limit the usefulness of the **AD** to the elderly or to those with terminal illness. Incapacity can strike anyone at any time. For example, an accident or a heart attack could create the need for an **Advance Directive** in a young, apparently healthy person.

## Is an Advance Directive compulsory?

No, it is not. In the absence of an **Advance Directive**, medical staff will make their own decisions. These may or may not be what you would want. If you are competent, you can make your decisions as and when the need arises. The **AD** protects you when you cannot speak for yourself (for instance, if you have a stroke, accident or advanced terminal condition), and helps those caring for you to understand your wishes. Many people choose to complete an **Advance Directive** at the same time they complete their will, and keep the documents together for easy access and as a reminder to review them periodically to insure they reflect current wishes.

## Is an Advance Directive a legal document?

Yes, provided it is clear, witnessed and the requests you make are lawful. However, its legality can be over-ridden by other, competing legal requirements. For example, your **Advance Directive** might say that under certain circumstances you do not wish resuscitation, but your ambulance crew (first responders) may resuscitate you anyway. The problem for the Ambulance Officer is to evaluate an **AD** in an extreme emergency situation, and they may not want to take the risk of not resuscitating you, when they are unsure of your wishes.

## **What is the standard position of medical staff – for instance, in hospital?**

This will be to treat the patient. That is, to employ procedures and processes or to use medications and treatments with the intention of correcting the problem or improving the problem or sustaining life. In most situations this is exactly the right response, but in some situations the patient may feel it is not. These may include terminal situations, situations of advanced and continuing degeneration or situations of irreversible damage likely to leave the patient with an extremely low quality of life even if recovery is possible.

This inclination to treat and to prolong life is deeply embedded in medical practice and custom. It is helpful to medical staff if your AD indicates your wishes to the contrary.

## **What is the standard position of medical staff within palliative care / hospices?**

Palliative care staff specialise in caring for a dying patient and their family. In palliative care, there is no intention to "cure" the patient. Instead, efforts are directed towards making the patient's last days/weeks/months as comfortable and pain-free as possible. Hospice/palliative care in New Zealand is of a very high standard and many terminally ill patients and their families benefit greatly from this special kind of care. Patients receive care and comfort through procedures, medications and treatments. However, there are still options and choices within palliative care that may result in prolonging or shortening life even if this is unintentional. Your **Advance Directive** will tell Hospice/Palliative Care staff which options you prefer, even when you cannot speak for yourself.

## **Why is an *Advance Directive* sometimes not followed as intended?**

Reasons include:

- Medical staff do not know of the **Advance Directive's** existence.
- Human error. For example, your **AD** requests no tube feeding but the staff on duty forgets to tell the incoming shift, who then re-attach your naso-gastric tube and recommence feeding.
- Unlawful instructions in your **Advance Directive**. For example, you request active assistance to die. This is unlawful and medical staff cannot comply.
- Unclear instructions in your **AD**. For example, your **Advance Directive** says: "Do not make heroic efforts to save me". This is too vague and too subjective for medical staff to take into account.
- Conflicting advice from your family members when you cannot speak for yourself. For example, your children argue about whether or not you should undergo surgery designed to gain you another few months life; one agrees with your **Advance Directive** and the other pleads against it.

## What can you lawfully request either verbally or in your *Advance Directive*?

- You can refuse further treatment (for example, decline a further operation or a new course of medication) even knowing that earlier death is likely to result.
- You can refuse treatment for a new disease or condition that arises after the reason for hospitalisation (for example refuse treatment for pneumonia that arises after the stroke that caused you to become hospitalised).
- You can refuse spoon feeding of food and water, and also if these have to be given artificially, for example, via intravenous feeding or a tube.
- You can request maximum symptom control, including sedation if your symptoms are otherwise uncontrolled.
- You can request maximum pain relief, even if this is likely to hasten your death.

## What can you not lawfully request in your *Advance Directive*?

Although a request for an assisted death (voluntary euthanasia) will become lawful in New Zealand from 7 November 2021, the person must still retain the power to communicate directly to their doctor right up to the last minute before their assisted death. Therefore, assisted dying cannot be requested via an ***Advance Directive*** and, if requested in error, will be unlawful under any circumstances. Even so, a clear, witnessed ***AD*** could better inform your Agent/Enduring Power of Attorney for Health (see later) who will have to make decisions about your treatment in the event you can no longer speak for yourself. The clarification provided by an ***AD*** could therefore save you some unwanted medical interventions.

## What will happen if medical staff ignore your abovementioned lawful requests?

They could be legally liable on charges ranging from assault (forcing you to accept treatment against your will) to malpractice (withholding adequate pain relief if your condition is acknowledged to be one likely to cause extreme pain).

You or your ***Agent*** (see about *Agents* later) would need to press charges if medical staff ignores lawful ***Advance Directive*** requests. Charges will not happen automatically.

## The role of medical discretion

Medical staff will diagnose your condition (decide what is wrong with you), clarify a prognosis (what is likely to happen to you in the future) and decide a treatment plan based on these. Be aware that your idea of "hopeless condition" or "irreversible condition" may not be the same as theirs. They may tend to err on the conservative and optimistic side. Their knowledge and experience may cause them to diagnose a situation that appears hopeless to you as merely a situation to be observed for possible future improvement.

For example, a stroke could cause you paralysis and loss of speech. Medical staff know that often there is a full or partial correction of these losses over time. Even if your **Advance Directive** rejects further treatment if such conditions are found in the immediate aftermath of a stroke, your medical team may suggest waiting to see how you recover after a few days or weeks. During this time, they will want to nourish, hydrate and treat you in hopes of your full or partial recovery. This may on the surface seem to be a rejection of your **Advance Directive** but it is one you should expect.

## Your Agent

Your **Agent** is a person you trust to ensure medical staff carry out your wishes when you cannot speak for yourself. If you do not nominate an **Agent**, medical staff may turn to your next-of-kin when choices are to be made. This may or may not be what you want.

***NOTE: Your Agent and your Advance Directive document together are far more powerful than either is alone. In other words, your wishes stand a better chance of being respected if you have both. Needless to say, they both need to be consistent.***

Your **Agent** does not need to be legally-appointed. That is, a lawyer does not have to draw up a document that you sign to confirm who your **Agent** is. You can hand-write the name of your **Agent** in your **Advance Directive** and this is sufficient. However, many people have an “Enduring Power of Attorney for Personal Care and Welfare”. When you are not competent they will make decisions for you regarding your welfare e.g. consent for operation, or admission to a rest home. This person is entitled to present your Advance Directive to medical professionals. However they cannot refuse specific life- saving treatments on your behalf. They can merely present the Advance Directive as a legal document outlining your wishes. In summary, if you have one, use the person who has your ‘Enduring Power of Attorney for Personal Care and Welfare’ as your **Agent** on your **Advance Directive**.

Your **Agent** should be a person who knows how you feel about your future medical treatment and who is willing to support your wishes, even if he/she disagrees with them personally. Your **Agent** needs to accept your appointment of him/her as the person who will speak on your behalf when you cannot. That means directly asking the person you want to appoint as **Agent** if he/she is willing to play that role.

Your **Agent** may have to make demands on medical staff or insist they follow your wishes, so your **Agent** should be the kind of person who is willing to speak out and speak up as soon as he/she detects a breach of your wishes. So that he/she knows exactly what you want, communicate regularly and make sure your **Agent** gets every update and renewal of your **Advance Directive**. Your **Agent** needs to be very clear about your wishes; hesitation on his/her part may cause medical staff to doubt his/her capacity to know what you want. In this case, they may default to standard practice for your condition. Your medical team may suggest waiting to see how you recover after a few days or weeks, if the **Advance Directive** is not absolutely clear on the issue.

Finally, avoid appointing someone who lives far away from you as your **Agent**. You want someone who can visit you in hospital/hospice/nursing home every day as necessary to ensure everything possible is being done to follow your wishes.

## Communicating with your doctor

Your doctor can be an ally in ensuring the correct implementation of your **Advance Directive**. To help your doctor to help you later on, follow these suggestions:

- Communicate regularly and early with your doctor about your **Advance Directive** wishes. Do not wait until you are close to hospitalisation and then surprise your doctor with information about you that he/she would never have anticipated.
- Few doctors are resistant to discussing end of life matters these days. Many welcome it. If you detect resistance when you try to raise the topic, consider changing doctors.
- If you detect resistance when you try to raise the topic or you simply feel awkward about raising the subject, but you do not want to change doctors, take a trusted friend or family member (ideally your **Agent**) with you to your next medical appointment. Together, you may be more persuasive and more insistent on being heard.
- Best of all, get your doctor to witness your signing of the **Advance Directive** and, at the same time, to attest to your mental competency. This is especially important if an early diagnosis of Alzheimer's disease or other dementia has been made while competence is still present.

Studies show that **Advance Directives** written with the assistance or oversight of a doctor or healthcare professional are more effective because they result in an **AD** that is more explicit and realistic, therefore more likely to be acted upon. Of course, this is easier if you have been diagnosed with a specific disease. If you are creating an **AD** while still in full health, you may prefer to use the pro-forma at the end of this document and simply add a few statements explaining your personal values such as: "I would rather be dead than ". . . e.g. be permanently immobilised, be unable to communicate in any meaningful way, be unable to attend to my own personal care such as toileting and hygiene. Either way, when requesting your doctor to witness your signature, ask your doctor for his/her assessment of the appropriateness of your AD and be willing to accept feedback that seems realistic to you.

## Disease progression

Most diseases progress in stages, each of which has its own symptoms.

- Ask your doctor about the likely progress of your disease (if you have been diagnosed).
- Take time after your consultation to read /discuss available information about your diagnosis and prognosis, and think about which of the likely symptoms will be a "trigger point" for you to opt out of further treatment. This requires you to use your imagination and project yourself into that situation.
- At each subsequent consultation with your doctor, tell him/her how you feel about each symptom he/she described (for example if you fear pain, you fear immobility, you fear being unable to recognise your family when they visit, you fear permanent incontinence of the bladder and bowel, or you fear the panic of being breathless).
- Make sure he/she understands your anxieties.

## Disease-specific *Advance Directives*

The form included in this guide is just a suggestion. You can amend the **AD** by adding or deleting options. Some of the options are general and a few relate to the symptoms likely to be experienced with specific diseases like Alzheimer's disease and other dementias.

Consider showing your doctor the **Advance Directive** form at the end of this guide and asking his/her advice on what options are best for you. Ask if there is anything else your **AD** should contain so as to protect you against unwanted treatments that may prolong your dying beyond your wishes or hasten your death against your wishes.

### Alzheimer's disease and other dementias

The **Advance Directive** of a dementia patient causes medical staff a significant moral and ethical problem. On one hand, they want to do what you have requested, on the other hand, they are not sure if you are still of the same mind about these requests as you were when you signed up to them and when you were still mentally competent. Furthermore, they may be in doubt as to your mental competency to sign an **Advance Directive** at the time you did (this is why your doctor is the best person to witness you sign your **AD**).

When in doubt, they will err on the side of caution and will default to standard treatments which may or may not be what you want. One way you can affirm your wishes is to review and renew your **AD** regularly, perhaps every year. While you are still mentally competent, your last signed **Advance Directive** takes precedence over previous ones.

Dementia covers a range of degenerative diseases that affect the mind. Most forms can be considered in three broad stages. In the first, recognition of onset stage, you may be only too well aware that unacceptable changes are occurring, yet you still have the ability to complete an **Advance Directive** as you will still be deemed to be mentally competent. In the second, significant deterioration stage, you will be unable to engage in intelligent and meaningful conversation and you may find it difficult to express frustration, anger, terror, pain or suffering. The third stage exhibits increasing vegetative features. Food and fluids have no significance for you and you are likely to waste from lack of nutrition.

Your carers will spoon feed you unless your **Advance Directive** requests the contrary. You may appear to be enjoying food still because when the spoon is touched to your lips you will tend to open your mouth and allow yourself to be fed; understand that this is similar to a reflex action and not necessarily indicative of genuine enjoyment or of a desire to be fed. Unless some fatal, unrelated disease occurs, you are then likely to die of either wasting or exhaustion or of an infective complication of the dementia such as pneumonia, urinary sepsis or bedsores. Treatment of such complications, if successful, will have the effect of prolonging your life in this condition.

If you wish to avoid this situation, you can refuse spoon feeding in your **Advance Directive**. The process of dying of lack of nutrition and hydration can take as long as three weeks and may be distressing, especially at the beginning. For this reason, it is important to request maximum palliation, good comfort care and sedation for the relief of physical or mental suffering associated with the process. Make it clear that you wish such palliation and care to commence as soon as the spoon feeding is discontinued, as any delay is likely to cause distress and pain. Good comfort care should involve mouth care, bladder and bowel care, attention to skin and pressure areas, pain relief and sedation. You should request all of these in your **Advance Directive**; this also makes it easier for your **Agent** to insist upon their early provision.

### Cancer and painful diseases

It is appropriate to request alleviation of symptoms even if a necessary medication may have, as an unintended consequence, the possibility of hastening of your death.

The "principle of double effect" allows a doctor to give symptom control medication to the fullest extent that you need it, as long as their intention is to relieve symptoms and not to hasten death. An **Advance Directive** that explicitly makes a request for maximum symptom control and, in the event of symptoms of extreme pain or suffering, even when the patient knows that death could result, allows the doctor to follow your wishes.

It is up to you or your **Agent** to advocate for you and your need for better symptom control. Do not assume that the medical staff will "know what you want" or act as you wish, unless you voice your need strongly and consistently. If you cannot speak for yourself, your **Agent** will need to do this. Be persistent without being abusive.

There is no legal limit to the use of medications for pain and symptom control: the dose used should be the dose required. Sedation may be needed.

### Refusal of foods and fluids

If your incapacity reaches the point where you cannot ingest by mouth in the normal way, you are legally entitled to refuse nutrition and hydration intravenously or by naso-gastric tube (tube inserted through your nostrils and down your throat directly into your stomach), or via PEG (a tube through the abdominal wall directly into one's stomach). You can nevertheless request comfort care, sedation and symptom control so that the process of voluntarily stopping eating and drinking is not distressing or painful to you. As for dementia above, requesting the cessation of artificial feeding together with the immediate commencement of comfort care, sedation, pain-relief and symptom control is best made explicit in your **Advance Directive**, even if this may hasten your death.

## Hospice care

Is hospice care a better option for you than hospitalisation or care in another facility such as a rest home or your own home? You should consider this even if you do not anticipate a difficult death, as hospice staff are specifically trained to make dying easier for you and your family; indeed, it is their whole focus. You may not need a doctor to refer you to hospice; you can refer yourself or your **Agent** can refer you. You will only be accepted if your condition is considered sufficiently serious.

In a hospice situation, there is continuous monitoring of your situation and discussion about what you need. If you reach a situation where you no longer want to eat or drink or can no longer swallow, necessary medications can be given via a small needle under the skin and special care will be taken with your pressure areas, bladder and bowel and, most importantly, your mouth.

If your disease means that you cannot be kept comfortable and awake, then you can be given medications so that you sleep through the last few hours or days. This process is called terminal sedation. The term "terminal sedation" or "deep continuous sedation" refers to a practice that combines the withdrawal of nutrition and hydration with the ending of all unnecessary medication with the provision of whatever you need to keep you comfortable, often administered by continuous subcutaneous (under the skin) infusion. The goal is to keep you comfortable and peaceful during the dying process, to neither hasten nor prolong your dying.

During terminal sedation all non-essential medications are stopped and you are given whatever you need to keep you comfortable, peaceful and asleep until you die. Pain medications and sleep enhancers are usually given using a syringe driver attached to a very small needle inserted under your skin. Attention is needed for your pressure areas so you don't develop bed sores. Mouth care and bladder care also contribute to your comfort. If terminal sedation is recommended by your hospice/palliative care medical team, you can reject or accept their recommendation in your **Advance Directive**. Understand that the process of dying under terminal sedation can take up to three weeks.

## Getting your *Advance Directive* witnessed

Your **AD** must be witnessed or "executed". This means that you must sign the document in the presence of another person, i.e. your witness. The witness then also signs to affirm that:

- They personally witnessed you sign (to prevent deception by another person) and
- They consider you to be mentally competent (you understand what you are requesting and refusing).

**The best person to witness the *Advance Directive* is your doctor**, especially if there is doubt with regard to mental competency. In New Zealand, the signing of your **AD** does not have to be witnessed by a lawyer, although a lawyer is a good second option.

## Distributing copies of your *Advance Directive*

It is helpful to distribute copies of your **Advance Directive**. Photocopies are acceptable.

Keep a few copies yourself and put them in a place where others will know to look, such as any personal records file you might have or attached to your personal medication chart. Stuck on the fridge is a good place. This makes it easy for others to pass a copy to medical staff if you are taken to hospital in an emergency. If your medical centre uses specific software for patient records such as Manage My Health, Indici or other, ask your GP to upload your **Advance Directive** to your patient record. Send a copy of your **AD** together with your NHI Number and a covering letter to your DHB, requesting them to keep it on file.

In addition, please give a copy to some or all of the following people:

- Your **Agent**
- Your General Practitioner, hospital and specialist
- Your spouse or next of kin
- All of your adult children
- Your lawyer
- A spare copy to take with you to hospital.

## Renewing your *Advance Directive*

For your medical team to take your **AD** instructions seriously, it should have been recently signed or recently renewed. If it is more than five years out of date, medical staff will wonder whether you are still of the same mind as you were when you signed the original. Therefore, renew regularly - at least once every five years.

You can renew your **Advance Directive** without any change (see attached suggested form) or you can make changes and then re-sign. Ensure that any changes are clear.

Every time you renew your **AD**, photocopy and re-distribute a copy of the renewed document to the appropriate people. This is also a good time to re-engage these people in a conversation about your wishes.

## Updating your *Advance Directive*

An **AD** can be revoked or destroyed at any time by you yourself or by someone else at your direction and in your presence. Your latest **Advance Directive** is a permanent record of your wishes. You may change it whenever you wish.

## Keep it simple

It appears complicated, but it doesn't need to be. Take the following steps for your own peace of mind:

1. Fill in the attached **Advance Directive**, ignoring the parts that don't apply.
2. Ask someone to be your **Agent** and explain his or her role. Tell this person what you want and don't want by way of medical treatment.
3. Sign the document in the presence of your doctor or your lawyer, and have them sign it, too.
4. Make some copies and give them to the people who need them.
5. Renew at least once every five years, or more frequently if there is any suggestion that mental competency might be in question within the next five years.

## Tips for relief of pain and suffering

1. Develop a good relationship with your treating doctor while you are well, but particularly if you develop a serious disease. Remember that your treating doctor may change from doctor to doctor to oncologist to palliative care physician. Do not assume that the information you have given to your doctor will be passed on to the others. You may need to ask your doctor to discuss your previously expressed wishes with the others.
2. Develop a dialogue with your doctor while you are well by discussing your **Advance Directive** when lodging a copy with the practice. Ask your doctor to witness your **AD** and attest to your soundness of mind.
3. Communication about your end-of-life wishes will develop over time. Do not assume that one conversation is all that is necessary. The more you discuss this, the more your views will be accepted as sound and persistent. The unexpected expression of your wish for a hastened death may be difficult for those around you, and especially for a doctor who will be required to assess your state of mind in order to fulfil your request.
4. Do not minimize your symptoms. Your doctor is there to alleviate pain and suffering but cannot treat symptoms of which he or she is unaware. It may be helpful to firmly restate them. If your doctor can record symptoms, then these can be treated. If the treatment is ineffective, then the doctor can increase dosages.
5. If you are dying, your doctor can provide maximum relief of pain and suffering. You can refuse treatment through your **Advance Directive**. You can specifically ask for maximum relief of pain and suffering, even if such treatment has the secondary but foreseeable consequence of shortening your life.
6. If possible, acquire the help of a relative(s) and/or friend to assist you in advocating for maximum relief of pain and suffering. Indicate to the nurses that you have unrelieved pain and/or suffering—be specific. You need to be persistent (which does not mean abusive). Do not assume that your pleas are passed on to your doctor. Complain to your doctor. Do not wait for a scheduled visit.

7. You may request sedation for unrelieved anxiety or psychological distress. Do not say you feel depressed unless you have good reason to believe you are.

8. If your doctor suggests you are depressed, do not agree unless you are firmly of the same opinion. You may agree to a trial course of anti-depressants, but this will involve three or more weeks of treatment. If you are in an early stage of distress, this may help to disprove the idea of depression when the treatment fails.

9. If you meet the eligibility criteria of “unbearable suffering that cannot be relieved in a manner that the person considers tolerable” and if you believe you meet all the other criteria and wish to access an assisted death, ask your doctor if he/she would be willing to help you achieve it. Your doctor is not allowed by law to raise the issue with you: therefore, this discussion must be raised by you. For criteria, see: <https://www.health.govt.nz/our-work/regulation-health-and-disability-system/end-life-choice-act>

## Frequently asked questions

### What is the difference between a Living Will and an *Advance Directive*? Or between an *Advance Care Plan* and an *Advance Directive*?

“Living Will” is an informal term for *Advance Directive*. “Advance Care Plan” is a term currently being promoted by most DHBs. They are both the same thing as an *Advance Directive*. According to the Health and Disability Commissioner, they are a written or oral directive, a) by which a consumer makes a choice about a possible future healthcare decision and b) that is intended to be effective only when he or she is not competent.

### Is there a specific form or signature that I need to validate my *Advance Directive*?

There is no specific form or signature required. An *AD* can be verbalised, can be outlined in a letter, and can even be tattooed on the body! This document contains recommended forms for use as *ADs*, and for our purposes we will consider the *Advance Directive* as a written legal document that falls under “common law” enforcement.

### What should my *Advance Directive* contain to comply with “Common law?”

To comply with common law requirements, the document must meet four conditions:

- 1) It must be given or signed by a person who is mentally competent.
- 2) It must be intended to cover circumstances which have arisen.
- 3) It must be given when a person is not unduly influenced by someone else.
- 4) It must be given when the person understands the purpose of the document.

### What constitutes mental competency?

Generally speaking a person is mentally competent if he or she understands the nature and purpose and consequences of his or her decisions. Competency can come and go. For instance, a patient under general anaesthetic during surgery would lose his or her ability to communicate their wishes. However, upon waking, they regain competency. The *Advance Directive* would be in effect for the duration of the surgery.

## What if my healthcare *Agent* or family members don't agree with what I've outlined in my *Advance Directive*?

As long as you understood the implications and consequences of your actions when you created your ***Advance Directive***, your family members and healthcare agents cannot disregard your wishes, no matter how inappropriate they may seem.

## What is undue influence?

Undue influence is when a person in a vulnerable position is influenced by someone to adjust their ***Advance Directive*** to reflect that person's opinion rather than their own.

## What is the difference between being properly informed and being mentally competent?

Being mentally competent reflects an understanding of one's actions. Being properly informed reflects an understanding of the purpose of the document in the current situation.

## Who decides if my *Advance Directive* meets the four criteria of common law? Can my *AD* be discounted or ignored?

Medical practitioners are encouraged within the medical community to scrutinise ***ADs***. They are often particularly interested in whether or not their patients are properly informed. For instance, if a medical provider thinks the patient doesn't know enough about the disease or illness to outline their own wishes for care, they may declare the patient didn't understand the current situation, and therefore the ***Advance Directive*** is not valid.

This is why it is important to be very clear when completing the ***Advance Directive***. Some wishes are based on religious values or quality of life issues that have nothing to do with the particular disease or circumstance. Be clear in your ***Advance Directive*** about why you wish to have or refuse the treatments you indicate.

## Am I required to accept medical treatment?

No. You can refuse medical treatment including nutrition and hydration. There are several pieces of legislation that support this.

The **New Zealand Bill of Rights Act 1990, Part 2, section 11**, states: "Everyone has the right to refuse to undergo any medical treatment." You may seek legal advice to understand your rights in preventing unwanted medical treatment.

In addition, the **Code of Health and Disability Services Consumers' Rights Act 1996, Right 7(5)**, states that: "Every consumer may use an advance directive in accordance with the common law".

**Right 7(7)** of this Code states: "Every consumer has the right to refuse services and to withdraw consent to services."

## What if medical staff ignore my wishes in my *Advance Directive*?

Your **Agent** may lodge a complaint with the Health and Disability Commissioner who will investigate the case. To do this, go to [www.hdc.org.nz/complaints](http://www.hdc.org.nz/complaints) or you can phone the office on 0800 11 22 33.

If the Commissioner finds there has been a breach, he or she may report an opinion to the Human Rights Review Tribunal (or other disciplinary body) for possible disciplinary action for the medical staff involved.

The Tribunal may then:

- Make a declaration that the healthcare provider made a breach of the Code.
- Grant an order restraining the offender from repeating the action that was a breach of the Code.
- Award damages.

If the Commissioner finds a breach, but does not report the action to a Tribunal, your **Agent** can do so personally.

## Who should receive a copy of my *Advance Directive*?

You should discuss your **AD** and your wishes with your doctor and ensure that he or she has a copy for your medical records.

- Attach a copy of your **Advance Directive** to any consent form you complete for a medical procedure. Indicate on the bottom of the consent form that consent for treatment is subject to the attached **AD**.
- Provide a copy to managers and providers of a retirement village or care facility in which you reside. This includes your GP, specialist and hospital.
- Discuss your *Advance Directive* and give a copy to any family members and others who may be involved in your healthcare should you become incapacitated.
- Attach a copy of the **Advance Directive** to any care and welfare documents held by your lawyer. You may add an additional message: "I request my lawyer ensure my attached **AD** is delivered to medical personnel involved in my care and to take all reasonable steps to ensure it is adhered to including, if necessary laying a complaint with the Health and Disability Commissioner."

## Does my *Advance Directive* expire?

No, it doesn't expire. However, it is wise to review and update your **AD** every year or so. This keeps clear your intentions and ensures that those who will act as **Agent** for you are aware of your wishes. You may update the document by re-signing it at the bottom, with a new date. **ADs** more than 5 years old may leave doubt in the minds of medical staff.

## Can I revoke or change my *Advance Directive*?

Yes. Simply tell your **Agent** that you have decided to revoke or change your **Advance Directive**, and destroy all outdated copies.

# What we've learned from other cases

## *Headaches*

Paula was only 50 when she died. Her family are struggling to remember the real Paula, instead of the speechless person, unable to recognise anybody, which she became. Her breast cancer had been treated eight years before, she had been declared "disease free," and discharged from any regular radio/oncology follow-up.

She went to her doctor complaining of a severe headache. Her doctor examined her, noted some things that were of concern, discussed her case with oncology, and an urgent scan of her head was organised.

This confirmed what the doctor had suspected: she had secondary deposits in her brain. An urgent radio/oncology appointment was made for the following Monday, for her to come in with her adult daughters to discuss options. In the meantime, high dose steroids were started and her headache improved.

On Monday morning, Paula failed to answer her phone. One of her daughters rushed round to check and found her unconscious on the floor. She was immediately admitted to hospital. Paula did not have an **Advance Directive** and her two daughters had very different ideas about what she would want. She 'woke up' over the next few days but never regained her ability to speak or use her right side.

Her condition deteriorated: she no longer recognised her family. A transfer to a hospice was made where considerable time and effort went into helping the daughters understand the situation. When Paula could no longer swallow, she was given sedation as well as pain relief, and later died peacefully.

Her family still struggles to come to terms with what happened and wish that their strong-willed mother had written down what she would have wanted so that things could have been easier for everybody, and that the two daughters had not wasted precious time fighting about it.

## *"Dad, you can't die – we love you"*

Henk was a busy active man of 70, planning his retirement. When he was 65, he had learned that he had mild chronic kidney failure. He and his wife managed this with careful attention to diet and regular check-ups. Henk had a couple of friends with kidney failure who were on dialysis, something that he did not want for himself.

He became aware that he was uncharacteristically very tired and a check-up with his doctor showed that his kidney failure had become acute and total. Henk's doctor explained that he needed an urgent urological review, hospital admission, immediate dialysis and regular maintenance dialysis for life. Henk declined this offer and, with some difficulty, persuaded his urologist to refer him to a hospice instead. He was adamant that he was happy with the rich and happy life he had lived; he loved his family and had no desire to prolong what he called a "halflife".

Henk remained adamant. He trusted the medical staff to care for him and his family while he was dying and later, to support his wife. His family disagreed with his decision. Henk's children were distraught, but they loved him enough to respect his decision and let him go. He died with a smile on his face and his family with him.

Before he died, Henk commented that he wished he had written down his wishes and appointed a particular friend to advocate for him. He felt it would have made his decision easier for his family to cope with and understand.

### *A prolonged and unhappy death*

This is the story of Jock, a very busy energetic farmer who loved sports, fast cars and his wife, Ann.

He was 55 when he was told he had motor neuron disease. Jock and his wife explored what this meant and talked a lot about what he did and did not want. Things were okay for a while but, when walking became difficult, he acquired a mobility scooter which he hated using.

One day he drove it as fast as he could over the steepest bank he could find. Jock survived this, adding fractured ribs to his problems. His disease progressed rapidly with speaking and then swallowing becoming impossible. Jock and Ann had discussed these eventualities and Jock did not want his life prolonged.

After a session with the neurologist, a PEG (a tube through the abdominal wall directly into one's stomach) was inserted. Ann expressed Jock's wishes but there was no **Advance Directive** in place.

The response was, "If you don't feed him he will die of starvation." Ann had to feed Jock through this tube for nearly 12 weeks until he finally died. She still has nightmares about Jock's suffering and her inability to help him get what he wanted, which was to not prolong a poor quality of life.

### *I don't want my family to go through this*

This is a heartfelt plea from Sandra, who is now 40. She watched both her grandmother and mother die in their 40s from early-onset hereditary dementia.

She has recently been diagnosed with this, too. Sandra is married with two teenage children. If her illness follows the same pattern as her mother's and grandmother's, things will change very quickly over the next two to three years. She has been offered no treatment, and no amount of reassurance or offers of palliative care can change how she sees her future.

Sandra has written her **Advance Directive** and appointed her advocate, now, while she can. She does not want to be spoon fed while she starves slowly, incontinent and unable to recognise those she loves so much. If she gets pneumonia, she would prefer not to be given antibiotics. Because she has appointed an **Agent**, she knows her wishes will be followed.

## *Ten green bottles*

This is the story of Amelia who is 90. She has no children, no husband and no family. All her close friends have died, one by one, “like the bottles falling off the wall,” she says.

She’s a retired English teacher, intelligent, well read and very definite about what she does and does not want.

Amelia still lives in her house, with a lot of help. She finds organising things difficult when they go wrong. It can be frightening and exhausting. She is nearly blind and her mobility is limited. She had her cat, Fred, put to sleep because she was terrified that she would fail to see him, trip over him, break a bone and get put into the rest home next door.

Having used this facility for respite a few times, she knows this is the next step. It’s one she would prefer to avoid. Last winter Amelia was admitted to hospital with a serious chest infection and nearly died. In spite of her clear, repeated requests for comfort care only, she was given intravenous antibiotics and, to her despair, survived. At that time she had no **Advance Directive** and no **Agent**; now she has organised both and feels considerably, as she puts it, “safer”.

***We are grateful to Dr Rodney Syme for his assistance in compiling this document. Dr Syme is a distinguished retired urologist, the Vice President of Dying With Dignity, Victoria, Australia, and the author of “A Good Death”.***

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## **Advance Directive for health care**

Full name: .....

Address: .....

DOB: .....

**It is my express wish that should I develop any of the following conditions**

- a) senility, or severe degenerative brain disease (due to Alzheimer’s disease, arterial disease, AIDS, or other agency); or
- b) serious brain damage resulting from accidental or other injury or illness; or
- c) advanced or terminal malignant disease; or
- d) severely incapacitating and progressive degenerative disease of the nerves or muscles;

**AND as a result, become mentally incompetent to express my wishes about accepting or declining life sustaining treatment, then I request that:**

(NOTE: Tick as applicable)

**In the event of a cardiac arrest, regardless of the cause**

- I want cardiopulmonary resuscitation
- I do not want cardiopulmonary resuscitation

**In the event that I cannot breathe for myself, regardless of the cause**

- I wish to be placed on a respirator or other means of life support
- I do not wish to be placed on a respirator or other means of life support

**In the event of any separate illness that may threaten my life**

- I want appropriate treatment
- I do not want treatment for any separate illness – for example, pneumonia, a heart or kidney condition

### **If I become unable to swallow food, fluid, or medication**

- I wish to receive these by artificial means
- I do not wish to receive these by artificial means. However, in this situation, I request immediate and maximum care for the relief of physical or mental suffering associated with refusal of food, fluid or medication, such as good comfort care, mouth care, attention to skin and pressure areas, bladder and bowel care, analgesia and sedation.

### **If my behavior becomes violent, noisy, or in other ways degrading, or if I appear to be suffering pain, those symptoms**

- Should be controlled with suitable drugs, regardless of the consequences to my physical health or my survival.

### **If I have severe dementia and am totally physically dependent e.g. consistently unable to recognise family and friends and needing assistance with toileting and dressing, unable to feed myself, then (tick only one)**

- I wish to receive nutrition by assisted spoon feeding
- I accept spoon feeding, but only if my acceptance appears to my treating doctor to be voluntary and only if it appears that I am enjoying my food
- I do not wish to receive nutrition by assisted spoon feeding even if it appears that I do so voluntarily and with enjoyment. However, in this situation, I request immediate and maximum care for the physical or mental suffering associated with refusal of spoon feeding, such as good comfort care, mouth care, attention to skin and pressure areas, bladder and bowel care, analgesia and sedation.

### **I understand that terminal sedation is different from assisted dying. Under terminal sedation, the goal is to keep me comfortable and peaceful during the dying process, to neither hasten nor prolong my dying. If I am offered terminal sedation by my attending medical practitioner, then**

- I wish to accept this
- I wish to reject this but nevertheless I wish to receive maximum relief for pain, distress or suffering, even if that may have the consequence of shortening my life.

### **Relief of pain, distress or suffering**

- I wish to receive maximum relief for pain, distress or suffering, even if that may have the consequence of shortening my life.

### **Other Wishes:**

*(If you wish, you can write your own additional instructions here or attach them separately).*

**Important Notes for my treating doctor:**

*(Here you can document anything your hospital doctor should know about your medical history. This could be an underlying condition such as epilepsy, or any allergic reactions you may have to certain medications that you know about at the time of writing this **Advance Directive**. Or attach your notes separately.)*

**The objective of this *Advance Directive* is to minimise distress or indignity which I may suffer during an incurable illness, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.**

Signed by me, ..... Date .....

My full name .....

## **Witness**

*(It is preferable that the witness be your doctor or lawyer. This is necessary where there may be some doubt as to competency.)*

Statement by witness: I, ....., hereby declare that in

my opinion the above person ..... is of sound mind and understands the meaning and implications of this **Advance Directive**.

Signed .....Date .....

Full name .....

## **Agent**

*(It is necessary that the **Agent** be a person who knows you well and understands you. You need to be able to trust your **Agent** to make decisions on your behalf.)*

I have asked the following person to ensure that my wishes expressed in this **Advance Directive** are complied with to the fullest extent possible.

Full name of **Agent**: .....

**Agent's** contact details e.g. phone, email : .....

**Agent's** home address: .....

**Agent's** Signature: .....

# Review

**Reviewed and confirmed by me (full name) .....**

Date: ..... Signature: .....

**Witness name: .....**

Date: ..... Signature: .....

**Reviewed and confirmed by me (full name) .....**

Date: ..... Signature: .....

**Witness name: .....**

Date: ..... Signature: .....

**Reviewed and confirmed by me (full name) .....**

Date: ..... Signature: .....

**Witness name: .....**

Date: ..... Signature: .....

**Reviewed and confirmed by me (full name) .....**

Date: ..... Signature: .....

**Witness name: .....**

Date: ..... Signature: .....