

A briefing paper on

# ADVANCE HEALTHCARE DIRECTIVES

Prepared by the Forum on End of Life in Ireland and the Irish Hospice Foundation.

The Assisted Decision-Making (Capacity) Act 2015 was passed by the Oireachtas on December 17th 2015. Within this Act is a new provision to legislate for Advance Healthcare Directives.

Under the provision, an adult with capacity can make a legally binding statement – an Advance Healthcare Directive – and refuse any form of treatment, including life-sustaining treatment. This Directive comes into effect if an adult loses capacity at some time in the future and is unable to make treatment decisions for themselves.

A section providing for a valid Advance Healthcare Directive is contained in the Think Ahead Form – see [www.thinkahead.ie](http://www.thinkahead.ie)

## 12 key things you should know:

1. Advance Healthcare Directives have been recognised in common law for some time but the new Act provides for a legislative framework
2. Under the new provision, a person aged 18 and over who has capacity can prepare an Advance Healthcare Directive
3. They must put their decisions on future medical treatment in writing and their Advance Healthcare Directive must be witnessed
4. A person can revoke an Advance Healthcare Directive **at any time** – in writing providing the person still has capacity to do so.
5. No-one can be forced to create an Advance Healthcare Directive
6. Having witnesses to the Advance Healthcare Directive is designed to prevent people being forced to make certain decisions
7. You can nominate people who will be legally recognised as acting on your behalf at a time when you lose capacity and can ensure your Advance Healthcare Directive is enforced
8. An Advance Healthcare Directive only comes into force when you have lost capacity and cannot make a decision
9. Having an Advance Healthcare Directive helps healthcare professionals in caring for you the way you want
10. Having an Advance Healthcare Directive helps families as it removes doubt about what care their loved one wanted
11. If there is any doubt about an Advance Healthcare Directive, a person can go to the courts
12. This is not euthanasia or assisted suicide. These acts are illegal in Ireland.

# QUESTIONS AND ANSWERS

## on Advance Healthcare Directives

---

### What does it all mean?

Until now, Advance Healthcare Directives were recognised under common law. So if a person made one, it was recognised as legal by the courts, but there was no legislation in this area. That has now changed. The Government has enacted a new law to govern Advance Healthcare Directives. It is included in the Assisted Decision-Making (Capacity) Act 2015 which was passed by the Oireachtas in December 2015.

### So what is an Advance Healthcare Directive?

An Advance Healthcare Directive is a statement made by a person with capacity (the ability to make and understand information and make decisions) setting out his/her will and preferences about medical treatments that may arise in the future at a time when they no longer have capacity and so cannot make decisions.

### And they were legal in Ireland even before this Act passed?

Yes, they were legally binding in Ireland according to Irish case law and international law to which Ireland is bound although there was no Irish legislation on Advance Healthcare Directives before now. The decision of the Irish Supreme Court in *Re a Ward of Court (No 2)* [1996] 2 IR 79 says that Advance Healthcare Directives are recognised by Irish law, provided that the author was competent and that the directive was specific to the patient's current situation.

### What's the point of this new provision?

It's an important law because it promotes the autonomy of a person to make decisions about their treatment in line with their will and preferences. It also helps healthcare professionals as it provides them with important information about a person and their preferences in relation to treatment.

### What does the new provision actually do?

It does a few things:

- It outlines what needs to happen to make a Directive legally binding
- It gives a structure when there is a dispute about the validity of an Advance Healthcare Directive
- It provides a structure to help people in having their wishes fulfilled
- It provides for people to be able to appoint another person called a **Designated Healthcare Representative** to make treatment decisions for them or to interpret the terms of their Advance Healthcare Directive. The legislation also sets out who cannot act as a Designated Healthcare Representative
- It recognises that a person can also nominate another person by way of an **enduring power of attorney** to make certain specified healthcare decisions and act on his/her behalf at a time in the future when they lack capacity.

### Can anyone make one?

Yes. But to be legally binding, you must fulfil five requirements:

1. It must be made by an adult – someone who is 18 years or older
2. The person must have capacity at the time when the directive is being made
3. It must be in writing
4. You must clearly state the specific treatments that you are refusing and also the situation in which the treatment refusal applies. You can also set out treatment requests and while not legally binding they shall be taken in to consideration if they are relevant to your medical situation
5. It must be witnessed

### How do you know someone has capacity?

Having capacity is the ability to make a decision. Capacity can be defined as the ability to understand the nature and consequences of a decision to be made by a person, in the context of available choices, at the time the decision has to be made.

An adult is presumed to have capacity unless, **having been given all appropriate help and support**, it is clear that he/she cannot understand, retain, use or weigh up the information needed to make a particular decision or to communicate his/her wishes.

### What if a person changes their mind?

They can do that at any time provided they have capacity. A person can revoke or amend their Advance Healthcare Directive in writing. Any verbal revocation to their Advance Healthcare Directive must be recorded in their healthcare record.

### So what can a person decide exactly?

- You can indicate what treatments you would not want in the future – this **IS** legally binding
- You can indicate what treatments you would like in the future – this is **NOT** legally binding.

An Advance Healthcare Directive made by a person with capacity only comes into effect when that person has lost capacity.

### Why is a treatment request not legally binding?

A person's views will be taken into account but no-one can force a doctor to give a treatment that - for a number of reasons - they don't believe is appropriate.

### Can a person make a decision that could lead to their death?

Yes. A person can refuse treatment up to and including life-sustaining treatments. This is happening every day with patients deciding against further treatment knowing they will not survive.

### How do we know that a person was not forced to make a Directive?

The provision has safeguards such as the fact that the directive must be witnessed and the legislation specifies who may not act as a witness.

---

### **Is this not euthanasia or assisted suicide?**

No. Euthanasia and assisted suicide are illegal in Ireland. A patient **has always had** the legal right to consent to and refuse treatment even if refusal means they will die and their doctors strongly disagree with their decision. If a person has capacity, they can make that decision for themselves.

### **Does this Provision not undermine the relationship between the doctor and patient?**

This provision will enhance the relationship between the doctor and patient by supporting the concept of a partnership in healthcare which is promoted in Irish health policy and help give clarity and certainty about the patient's wishes to healthcare professionals.

### **Does it not undermine public trust in the medical profession to do the right thing?**

Making an Advance Healthcare Directive will actually help doctors. It will guide any doctor who is treating a patient to care for them in a way that the patient would have wanted.

### **Does this undermine the role of families?**

The doctor's duty of care is to the patient. Therefore, the patient's views on treatment are paramount. Of course, these views may be at odds with the views of a patient's loved ones or even the opinion of the doctor. But once that patient has capacity when making their decision, their wishes must be respected. Advance Healthcare Directives can be helpful in preventing family disputes at already difficult times by removing uncertainty about a person's wishes.

### **Can legislators be accused of wanting to save money through this provision by not wanting to treat older people?**

No. This law brings Ireland into line with international conventions fulfils government policy to take the patient's views into account when treatment decisions are being made. It enhances the engagement of older people in their healthcare.

### **When will an Advance Healthcare Directive come into effect?**

The Advance Healthcare Directive comes into effect only when a patient loses capacity, becomes ill and the circumstances in their Directive arise.

The Directive is valid under the following circumstances:

- If the person had capacity at the time they made the directive
- It was made voluntarily
- It was not altered or revoked
- The person who made the Directive did not do anything inconsistent with the terms of the Advance Healthcare Directive while they had capacity

### **Does a Healthcare Professional have to comply with an Advance Healthcare Directive?**

Once all of the legal requirements are in place, a Healthcare Professional must comply with the Advance Healthcare Directive. They don't have to agree with the patient's decision.

### **What if they have a doubt?**

If there is any doubt, the Healthcare Professional must consult the Designated Healthcare Representative and seek the opinion of a second healthcare professional. In cases of doubt, they must act in favour of the preservation of life. If there is a dispute, they can apply to have the matter decided in the courts.

### **What if the Healthcare Professional fails to fulfil the terms of an Advance Care Directive?**

If a Healthcare Professional, acting in good faith, fails to comply with the terms of a valid Advance Healthcare Directive – they didn't know it existed or its contents – they will not incur any civil or criminal liability.

### **What if a pregnant woman has an Advance Healthcare Directive, loses capacity and becomes ill?**

If her Advance Healthcare Directive did not specifically state whether or not she intended the treatment refusal to apply if she was pregnant and the refusal would harm her pregnancy, there should be a presumption that treatment be provided or continued.

If her Advance Healthcare Directive states that she would want her treatment refusal to apply even if she was pregnant and the treatment refusal would harm the pregnancy, an application can be made to the High Court to determine if the Advance Healthcare Directive is valid and applicable.

### **Are there any other circumstances in which an otherwise valid and applicable Advance Healthcare Directive will not apply?**

A valid and applicable Advance Healthcare Directive must be followed unless, at the time when it is proposed to treat the person, his/her treatment is regulated by Part 4 of the Mental Health Act (2001) and/or by the Criminal Law (Insanity) Act (2006).

### **So if a person does not want any treatment under their Advance Care Directive, will they be left to die with no care at all?**

An Advance Healthcare Directive does not apply to basic care. You cannot refuse basic care through an Advance Healthcare Directive. Basic care is provided in order to keep an individual comfortable. So if you are at the end of your life, you will receive basic care which includes (for example):

- warmth,
- shelter,
- oral nutrition
- oral hydration
- hygiene measures.

Advance Healthcare Directives enable a person to refuse intrusive futile treatment at the end of life when they simply wish to die in comfort, and to receive appropriate end of life care.

### **Why is this a good thing?**

It is now recognised that planning options for care with patients leads to:

- More appropriate management of care
- Higher quality end of life care that is better tailored to the needs and preferences of patients
- Supported decision-making
- Improved family satisfaction and supported bereavement experience
- Reduction of the effects of complicated grief, stress, anxiety and depression in surviving family members.

### **What should happen now?**

The Act provides that Codes of Practice to support Healthcare Professionals to understand the new law and to enforce it should be drawn up immediately. The Forum on End of Life in Ireland and the Irish Hospice Foundation urge the Government to support, enable and encourage people of all ages to discuss and plan for end of life needs – to Think Ahead.

# International and national policy

## Remember...

- Advance Healthcare Directives are not compulsory
- Preparing an Advance Healthcare Directive is a voluntary act
- A person can change their mind at any time

## International Policy Context – International rights instruments

- The European Convention on Human Rights has enshrined the right to self-determination.
- The 2006 UN Convention on the Rights of Persons with Disabilities also calls for states to facilitate people with disabilities to exercise their right to make choices and express preferences in relation to their care.
- In December 2009, the Council of Europe issued a recommendation which noted that where legal systems provide for advance care directives, increasing numbers of people avail of them. The statement recommended that Member States promote self-determination for adults in the event of their future incapacity by means of powers of attorney and advance directives.
- In February 2014, a Council of Europe recommendation on the promotion of human rights of older people stated that older people are entitled to lead their lives in an autonomous manner, which encompasses the taking of independent decision with regard to all issues which concern them. This includes those regarding property, income, finances, place of residence, health, medical treatment or care, as well as funeral arrangements. The statement recommended that Member States should provide for legislation which allows older persons to regulate their affairs in the event that they are unable to express their instructions at a later stage.

### Where are Advance Healthcare Directives being used?

As well as Ireland, advance care directives enjoy legal status in countries such as the USA, England and Wales (in certain circumstances), Germany, the Netherlands, New Zealand, Canada and Australia.

#### The Irish Medical Council

The Irish Medical Council's Guide to Professional Conduct and Ethics (7th ed, 2009) advises doctors that a patient's advance treatment plan should be respected if it represents an informed choice by the patient at a time when they had capacity, it covers the relevant situation which has now arisen and there is no evidence that the patient has changed their mind.

#### Health Services Executive

The HSE National Consent Policy (2013) also provides that a person's advance refusal of treatment should be respected if the decision was the informed choice of the person, the decision specifically covers the situation that has arisen and that there is no evidence of change of mind.