

# Advance Care Planning and Advance Healthcare Directives

## Assisted Decision-Making (Capacity) Act 2015

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The Assisted Decision-Making (Capacity) Act 2015 was passed by the Oireachtas on December 17, 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. This Act applies to everyone and has relevance for all health and social care services.

[Read the act in its entirety here.](#)

### 12 key things you should know:

1. Advance Healthcare Directives have been recognised in common law for some time, but the 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 providing the person still has capacity to do so. This must be done in writing.
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 decide.
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.

## What is an Advance Healthcare Directive?

It informs family, friends and doctors of your wishes for your treatment in the event you can no longer communicate them yourself.

It's a legally binding document where you write down what healthcare treatments you wouldn't like in the future.

You can write what treatments you would like to receive too but that is not legally binding. Health professionals are obliged to explain why they did not follow your preferences though

It relates specifically to your health care and your wishes regarding your personal health.

For example, if a person did not want to be resuscitated in the event their heart stopped beating, or they did not want to be kept alive by a ventilator they could state that in the document. It is important to be specific about the circumstances in which you wish to refuse treatment and to make sure that you update your directive if you change your mind. You can also verbally revoke a directive at any time

Is that not euthanasia or assisted suicide?

Absolutely not. Euthanasia and assisted suicide are both illegal in Ireland. A patient has the legal right to consent or refuse treatment even if their doctors strongly disagree with their decision

Is there an official Advanced Healthcare Directive form?

The Irish Hospice Foundation's Think Ahead form allows you to specifically document an Advance Healthcare Directive. If you would like to order your own copy click here.

But you can write your Advance Healthcare Directive on any piece of paper and as long as it is signed, dated and witnessed by two people it is valid. Both witnesses need to be over 18 and at least one of them must not be a member of your family and preferably should not be your attorney or your designated healthcare representative. If you don't want to write it down, you can make a voice or video recording of your Advanced Healthcare Directive.

## Does it cost any money to get one?

The Irish Hospice Foundation's Think Ahead form is available for free on-line at <http://www.thinkahead.ie/> Hard copies are also available to order your copy please click here. Some people may like to discuss their options with their GP but that this is not necessary. There is also no need to consult a solicitor. But if you would like to you will incur solicitor fees.

## When should I make an Advance Healthcare Directive?

An Advance Healthcare Directive is recommended no matter what your age. However, you don't have to fill one out. It is not mandatory.

## What's the benefit?

It means there is no decision-making burden placed on family members if your healthcare wishes and preferences are known to them. In the absence of your directive end-of-life decisions will be made by your healthcare team. However, a directive makes it easier for healthcare professionals too because they know what a person's wishes and preferences are in different healthcare situations that might arise.

If you have been diagnosed with an illness having an advance healthcare directive will give you peace of mind and help you to focus on living well. Planning for end-of-life care in advance gives people and their families' peace of mind during their final days, according to research.

## Where do I keep it?

There will eventually be an Office of Decision Support Services and a record of valid Advanced Healthcare Directives will be kept there. Until that office is set up it is recommended that you tell the people that are likely to be there at the time of an emergency. Your GP is one option. But if you are keeping the document at home you should tell family members or friends where it is.

How would my GP or hospital staff know it exists? Who would be responsible for bringing it to their attention?

You are ultimately relying on family and friends to tell healthcare professionals about the directive if they are unaware of it until a registry is established in the Office of Decision Support Services. Some people sometimes carry their directive with them

Can't you already tell healthcare professionals how you want to be treated?

Yes, you can, and you will. The Advance Healthcare Directive only comes into play if you lose decision making capacity and issues you have outlined in the document arise. Up until that point your healthcare professional will presume you have decision making capacity.

## **What is the legislation behind this called?**

The Assisted Decision-Making (Capacity) Act 2015. It has been enacted and is on the Statute Books but hasn't been commenced.

## **What does the legislation mean?**

It's a really important step for Ireland in promoting human rights. It was a necessary step for Ireland to take in ratifying the United Nations Convention of the Rights of Persons with Disabilities in 2006. It supports the autonomy of all people regardless of any disability. So, it enables people with disability to be treated the same as a person who doesn't have any disability.

The Constitution of Ireland also indicates the rights of bodily integrity and promotes the autonomy of people.

## **Are Advance Healthcare Directives legal if the Act hasn't been commenced?**

Yes. Court rulings have 'upheld' a person's right to decide what they wouldn't want in their end-of-life (health)care.

What this legislation brings is a framework to underpin that. It provides the structures to support the operation of Advance Healthcare Directives which are already legally binding.

Resources on Advance Healthcare Directives

## **RESOURCES FOR THE PUBLIC**

### **Where can I find more information?**

The Think Ahead programme offers a Think Ahead form which includes an advance health directive that is compliant with the legislation. (Order your form here)

Citizen Information Board: [Click here](#) for an article on the Act and its provisions.

Support and Advocacy Service for Older People (SAGE) [Guide to the Act](#)

Support and Advocacy Service for Older People (SAGE) [FAQ on enduring power of attorney](#)

Support and Advocacy Service for Older People (SAGE) [briefing paper on empowerment](#)

For information from Inclusion Ireland on capacity, click [here](#).

Law Reform Commission Report: Vulnerable Adults and the Law (2006)

Law Reform Commission Report on Bioethics Advance Care Directives (2009)

## RESOURCES FOR PROFESSIONALS

### Additional resources for health and social care professionals

- Irish Hospice Foundation Perspectives Series 4: A perspective on advance planning for end of life an exploration of contemporary developments concerning the concept and practice of Advance Planning, Advance Care Planning and Advance Healthcare Directives (2016).
- Guidance Document 'Advance care planning and advance healthcare directives with a person with dementia'
- Irish Hospice Foundation Dementia video clips outline Kathy Ryan's journey with dementia (2016)
- The Guide to Professional Conduct and Ethics for Registered Practitioners 8th Edition 2016
- The Nursing and Midwifery Board of Ireland Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (2014)
- National Standards for Residential Care Settings for Older People in Ireland (2016)
- Supporting people's autonomy: a guidance document (2016)
- All Ireland Institute of Hospice and Palliative Care Learning Platform has programmes for professionals on palliative care, formal family meetings, palliative dementia care and advance care planning among others (2016)

### What is Assisted Decision-Making?

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### What is the Assisted Decision Making (Capacity) Act 2015 and why is it important?

The Assisted Decision Making (Capacity) Act 2015 (ADMA) provides the statutory framework that will support all adults to make their own decisions in relation to all aspects of their lives. Throughout our life, our capacity to make decisions about health, finance, and property may be compromised for a range of reasons. This Act places a legal requirement on service providers to enable a person to decide through the provision of a range of supports and information appropriate to their individual needs. All adults are presumed to have decision-making capacity under the Act. It takes a 'rights-based approach' to decision making, and a person cannot be regarded as being unable to decide unless all practicable steps to support them have been taken without success. This legislation represents a major shift away from a 'paternalistic' or 'best interests' approach where decisions are made on a person's behalf if their capacity is called into question (e.g. decisions such as consent to treatment, financial decisions, property related decisions, etc.).

### 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 that 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 making of independent decisions with regard to all issues that concern them. This includes decisions 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 that allows older people to regulate their affairs if they are unable to express their instructions at a later stage.

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.

## **IMPLICATIONS FOR HEALTHCARE & END-OF-LIFE DECISIONS**

### **Relevance to healthcare and end-of-life decisions**

The Assisted Decision-Making (Capacity) Act 2015 applies to all health and social care settings and will have a significant impact on the delivery of good quality end-of-life care.

The Act provides for the individual's right to autonomy and self-determination to be respected when they may have an issue with decision-making capacity through provisions relating to an Enduring Power of Attorney and Advance Healthcare Directives. Both documents can be made by a person when they have capacity and state what they would like/not like to happen in relation to different aspects of their healthcare, should the need arise.

The legislation supports advance care planning, a process of discussion and reflection about goals, values, and preferences for future and end-of-life care. This process usually takes place with a doctor or nurse.

The legislation includes a provision for creating an Advance Healthcare Directive, a document where a person can write down what they would not like to happen in relation to certain medical care treatments. An advance healthcare directive only comes into force when that person loses decision-making capacity, becomes ill, and the circumstances in their advance healthcare directive arise. Within an advance healthcare directive, a person can refuse treatment up to and including life-sustaining treatments but cannot refuse "basic care". See IHF Briefing Paper on advance healthcare directives, the Think Ahead programme and this guidance document for more information. When commenced, the legislation will enable healthcare professionals to be provided with important information about a person and their preferences in relation to treatment up to and including the end of life in order to ensure that the care they provide is in keeping with the person's expressed wishes. It will offer clarity on the roles and responsibilities of healthcare professionals regarding advance care planning and advance healthcare directives.

## **STATUS OF THE LEGISLATION**

### **What is the current status with the legislation?**

Although the legislation was enacted on December 17, 2015 and is registered in the Statute Book (the Laws of Ireland), it has not yet been commenced. This means that the Lunacy Regulations (Ireland) Act (1871) is still applicable and in use in Ireland. However, it is recommended that the guiding principles as set out in the legislation

are used along with existing case law and other national guidelines/policies (such as the HSE National Consent Policy, 2013) to guide practice in the interim to ensure that people's rights are upheld and their wishes are acted upon.

## **What needs to happen for the Act to be commenced and made into law?**

A Director of Decision Support Services needs to be appointed.

A code of practice needs to be developed. This will outline how the Act will be implemented.

The Minister for Justice has responsibility for commencing most of the Act. However, the Minister for Health is responsible for the commencement of the provision relating to advance healthcare directives.

The HSE has established an Assisted Decision-Making Steering Group with four working groups (guidance and documentation, information and communication, training and education and advance healthcare directives). These working groups are tasked with addressing implementation of the Assisted Decision-Making (Capacity) Act 2015 for health and social care providers.