

ADVANCE HEALTHCARE DIRECTIVES

What can i do now?

► Learn more

- Read the draft legislation
www.dohc.ie/consultations/open/AHDs/Draft_General_Scheme_AHDs.pdf?direct=1
www.dohc.ie/consultations/open/AHDs/Discussion_Paper_AHDs.pdf?direct=1
- Consider taking part in the consultation process if you have an opinion or concern
www.dohc.ie/consultations

► Take political action

- Telephone or visit the office of your local TD or Senator – tell them you support Advance Healthcare Directives
- Tell the candidates in the local and European elections who are on your doorstep that you support the introduction of legislation for Advance Healthcare Directives

Tell them:

1. I support Advance Healthcare Directives
2. I want your party to support this provision in the Oireachtas
3. Advance Healthcare Directives is one provision to be included in the Assisted Decision-Making (Capacity) Act. I want the Minister for Health to sign a “commencement order” to bring the Advance Healthcare Directives provision into operation as soon as the law is enacted

► Take personal action

- Talk to your family or trusted friend about any views you have on end-of-life issues
- Fill out all or part of the Think Ahead form
- Put a date in your diary and review the decisions in the Think Ahead form

ADVANCE HEALTHCARE DIRECTIVES

What you need to know

The Department of Health has published a draft general scheme for Advance Healthcare Directives which will be included in the Assisted Decision-Making (Capacity) Bill 2013. A national public consultation is underway until 7th March.

This means that the government proposes to introduce legislation to enable an adult with capacity to make a legally binding Advance Healthcare Directive and refuse any form of treatment up to and including life-sustaining treatment.

In this short document, the details in the draft general scheme are outlined in the questions and answers. There is also information on what you can do in vital area.

Here are the 12 key things you should know about new legislation as it is currently proposed:

1. Advance Healthcare Directives are recognised in common law but until now there was no legislative framework
2. Under the new provisions, 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 will be able to revoke an Advance Healthcare Directive at any time – verbally or in writing
5. No-one will be under any obligation to create an Advance Healthcare Directive – people are free to make them but are not required to do so
6. Having witnesses to the Advance Healthcare Directive is geared 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 serious doubt about an Advance Healthcare Directive, a person can go to the courts
12. This is not euthanasia or assisted suicide. These acts are and continue to be illegal in Ireland. An Advance Healthcare Directive is a method of obtaining consent for treatment in advance.

QUESTIONS AND ANSWERS

on Advance Healthcare Directives

What is happening?

The Department of Health has published a draft general scheme for Advance Healthcare Directives which will be included in the Assisted Decision-Making (Capacity) Bill 2013. A public consultation is underway until 7th March.

What does it all mean?

Advance Healthcare Directives are currently recognised under common law. So if you prepare one, they are recognised by the courts. But there was no legislation governing them. Until now! That is about to change. The Government proposes to bring in a law to govern Advance Healthcare Directives. It will be included in the Assisted Decision-Making (Capacity) Bill 2013.

So what is an Advance Healthcare Directive?

An Advance Healthcare Directive is a statement made by a person with capacity (the ability to make an 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.

What's the point of this provision?

It's an important law because it promotes the autonomy of a person to make decisions about 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 this law actually do?

It does a few things:

- It outlines what needs to happen to make a Directive made in advance legally binding
- It gives clarity 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 **Patient Designated Healthcare representative** to make treatment decisions for them or to interpret the terms of their Advance Healthcare Directive
- It recognises that a person can also nominate another person to hold an **enduring power of attorney** to make certain specified decisions and act on his/her behalf at a time in the future when they lack capacity to include not only decisions about property and financial matters but will also include decisions about healthcare matters.

Can anyone prepare one?

Yes. But to be legally binding, five requirements are necessary:

1. It must be made by an adult – someone who is 18 years or older
2. The person must have capacity (able to make decisions freely and to understand them)
3. It must be in writing
4. It must clearly state the specific treatments that a person wishes to refuse and also the situation which the treatment refusal applies
5. It must be witnessed

What if I change my mind?

You can do that at any time provided you have capacity to do it. You can revoke your Advance Healthcare Directive verbally or in writing. Any verbal change to your Advance Healthcare Directive should be recorded in your healthcare record.

So what can I 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.

Why is a treatment request not legally binding?

Your views will be taken into account but you can't force a doctor to give you a treatment that - for a number of reasons - they don't believe is appropriate.

Can I make a decision that could lead to my death?

Yes. You can refuse treatment up to and including life-sustaining treatments but you cannot refuse what is called 'basic care.'

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

The provision has safeguards such as the fact that the directive must be in writing and witnessed by two people.

Is this not euthanasia or assisted suicide?

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

Why is this a good thing?

This legislation promotes individual autonomy and respect for a person's will and preference.

My doctor is very good to me. I trust him/her?

That is a good thing. But your GP or treating doctor must always get your consent for any treatment and may not be the medical person who cares for you when you are not in a position to make decision for yourself. Preparing an Advance Healthcare Directive will actually help any doctor who is treating you to care for you in a way that you would have wanted. It is helpful to doctors.

My family know what I want?

Do they? Have you spoken to them or if you prefer a trusted friend about what your will and preference for treatment are should you lose capacity? Advance Healthcare Directives can be helpful in preventing family disputes at already difficult times by taking out the uncertainty about your wishes.

Is this not all about saving money. They won't want to treat older people?

No. This law will bring Ireland into line with international commitments and will also fulfil government policy to take the patient's views into account when treatment decisions are being made.

When will a doctor enforce an Advance Healthcare Directive?

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

Doctors will enforce it under the following circumstances:

if the person had capacity at the time they made the directive – there is a presumption of capacity at the time of making the Advance Healthcare 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 doctor have to enforce an Advance Healthcare Directive?

Once all of the legal requirements are in place, they have to fulfil 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 doctor must consult the Patient Designated Representative and/or the family 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 a doctor fails to fulfil the terms of an Advance Care Directive?

If a doctor, 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 doctor deliberately decides not to fulfil the terms of an Advance Healthcare Directive?

The existing common law rule remains in that a healthcare professional can be liable under either criminal or civil law if a healthcare professional fails to comply with a valid and applicable Advance Healthcare Directive. This position is in line with a decision of the European Court of Human Rights.

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 have harm the pregnancy, the doctor can apply to the High Court to determine if the Advance Healthcare Directive is valid and applicable.

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.

What can I do now?

Why not consider one or all of the following steps:

- ▶ Read the draft legislation (including the explanatory notes which are very helpful)
- ▶ Consider taking part in the consultation process if you have an opinion or concern
- ▶ **Telephone or visit the office of your local TD or Senator – tell them you want the provision on Advance Healthcare Directives to be brought into operation as soon as possible**
- ▶ Talk to your family/trusted friend about any views you have on end-of-life issues
- ▶ Fill out the Think Ahead form
- ▶ Put a date in your diary and review the decisions in the Think Ahead form