

Your Guide to

an Advance Healthcare Directive



**seirbhís tacaíochta
cinnteoireachta**

decision support service

IMPORTANT: This guide does not constitute a statement of the law or the provisions under the Assisted Decision-Making (Capacity) Act 2015 (as amended) or any ancillary or related legislation. Please do not rely on it for legal advice.

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1 About this guide

What is this guide about?

At different times in our lives, we all need to make decisions. We make important decisions about our finances, property, employment, accommodation, healthcare and social supports.

Decision support arrangements are legally recognised arrangements made under the Assisted Decision-Making (Capacity) Act 2015 (as amended) (the Act) for people who need support to make certain decisions.

This guide tells you about what you need to know if you are thinking of making a particular type of future planning arrangement called an advance healthcare directive. This is a legally recognised arrangement setting out your wishes in relation to one or more healthcare treatment decisions.

It will come into effect if you are unable to make certain healthcare treatment decisions for yourself. You may also appoint a person as your designated healthcare representative in your advance healthcare directive. Their role will be to ensure that people are aware of the advance healthcare directive and know how to follow it in specific situations.

Who is this guide for?

This guide is for people who want to make an advance healthcare

directive or to find out more about this type of advance planning.

It may also be helpful for the designated healthcare representative, family, friends and carers of a person who is planning to make or has an advance healthcare directive.

Guidance for professionals or organisations interacting with a person who has an advance healthcare directive is also available on our website decisionsupportservice.ie.

What is treatment?

In the Act, **treatment** has a specific definition in relation to a person. It includes any act:

“for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person, and includes life sustaining treatment.”

When should you read this guide?

We recommend that you read this guide before you make an advance healthcare directive. This is because it contains important information that you should know about:

- the things you need to consider before you make an advance healthcare directive

1. About this guide

- the types of treatment decisions you can include in your advance healthcare directive
- what your designated healthcare representative can and cannot do and what their responsibilities are
- the steps for completing the advance healthcare directive
- what happens after you make an advance healthcare directive

You do not have to read this guide all at once, but we do recommend that you look at all of the information in it before you make an advance healthcare directive.

If you need some help understanding the information in this guide, it might be a good idea to ask someone you trust to read through it with you.

You may find it helpful to read some sections again when you are making your advance healthcare directive. This will help you to avoid common mistakes people make when they are making an advance healthcare directive.

2 About the Decision Support Service

2. About the Decision Support Service

The Decision Support Service was established under a law called the Assisted Decision-Making (Capacity) Act 2015 (as amended). We are part of the Mental Health Commission but have a separate role.

We provide an essential service for people who may need support to make certain decisions about their personal welfare, property and affairs.

This may include, for example, people with an intellectual disability, acquired brain injury, mental health difficulty or dementia.

The Decision Support Service also provides services for all people who want to plan for a time when they might not have decision-making capacity.

Some of our key functions include:

- promoting awareness and providing information
- registering decision support arrangements
- supervising the actions of decision supporters
- investigating complaints
- maintaining a panel of experts who assist us in our functions

You can find out more about the Decision Support Service and the new law on our [website](#).

What is capacity?

Capacity, or 'decision-making capacity' means your ability to make decisions. When we talk about capacity, we mean your ability to make a specific decision at a specific time.

Some people have capacity to make some decisions (for example, relating to their healthcare) but not others (for example, about their finances or selling a property). Some people need someone to help them to exercise their capacity, this may be by providing them with information, or helping them to communicate.

What are decision support arrangements?

Decision support arrangements are legally recognised arrangements for people who need support to make certain decisions. This can include, for example, decisions about finances, property, employment, accommodation, healthcare and social supports.

There are five different decision support arrangements available. These arrangements are based on the different levels of support that a person requires to make a specific decision at a specific time.

Under these arrangements, people can be appointed as **decision supporters**. A decision supporter has the legal authority to help with certain decisions about a person's personal welfare, property and money matters. The type of support they can provide depends on the decision support arrangement in place.

A person's needs may change over time. The different levels of decision support arrangements available means they can be changed, cancelled or replaced by another type of arrangement, depending on the person's capacity and needs.

What types of decision support arrangements are available?

There are three types of support arrangements for people who currently, or may shortly, face challenges when making certain decisions:

- decision-making assistance agreement
- co-decision-making agreement
- decision-making representation order

Each of these arrangements provide a different level of support, with a decision-making assistance agreement being the lowest and decision-making representation order being the highest.

There are also arrangements available for people who do not currently face difficulties when making decisions but wish to plan for a time when they might:

- advance healthcare directive
- enduring power of attorney

An advance healthcare directive sets out a person's wishes in relation to treatment decisions.

An enduring power of attorney can include decisions about the person's personal welfare, not including treatment, and their property and money matters.

This guide tells you what you need to know about an advance healthcare directive and how to make one. You can find out more about the other types of decision support arrangements on our website decisionsupportservice.ie.

3 Before you make an advance healthcare directive

What is an advance healthcare directive?

An advance healthcare directive is a legally recognised document that sets out your wishes in relation to healthcare treatment decisions in case you are unable to make these decisions for yourself in the future.

By creating an advance healthcare directive, you are preparing in advance for any expected or unexpected circumstances that may lead to you no longer being able to make healthcare treatment decisions yourself.

Who can make an advance healthcare directive?

You can make an advance healthcare directive if you:

- Are 18 years old or more
- Have decision-making capacity at the time you are making your advance healthcare directive

What can you do in your advance healthcare directive?

In your advance healthcare directive you can refuse and request healthcare treatment. You can also appoint someone you trust, such as a family member or friend, to act as your designated healthcare representative.

Why should you make an advance healthcare directive?

There are lots of reasons why you might want to make an advance healthcare directive:

- having an advance healthcare directive allows you to make plans for your future healthcare treatment if you lack decision-making capacity in the future
- an advance healthcare directive provides healthcare professionals with important information about your choices and ensures that the care you receive is the most appropriate for you taking into account your will and preferences
- an advance healthcare directive reduces the burden on those close to you, and on healthcare professionals, in trying to decide what your will and preferences might be

In an advance healthcare directive, you can appoint someone that you trust to be your designated healthcare representative to act on your behalf if you lack capacity to make these decisions for yourself.

They have the legal authority to interpret your will and preferences regarding treatment and to consent to or refuse treatment, including life-sustaining treatment on your behalf.

3. Before you make an advance healthcare directive

What are the benefits of making an advance healthcare directive?

The biggest benefit of making an advance healthcare directive is peace of mind. It gives comfort that your will and preferences and treatment decisions will be acted on and respected.

It may be particularly beneficial where:

- for religious or other personal reasons, you have strong views about the kinds of healthcare treatment you wish to receive or refuse
- you have a life-limiting or terminal illness (for example, some forms of cancer) and want to make plans for your end of life
- you have fluctuating capacity (sometimes you are able to make decisions and sometimes you are not) and you want to continue to control your healthcare treatment during periods when you lack capacity to make decisions about your healthcare
- you have received a diagnosis of a progressive illness that may impact on your memory and ability to communicate

Do you have to make an advance healthcare directive?

No, there is no obligation for you to make an advance healthcare directive. No one should force or pressure you into making one.

When should you make an advance healthcare directive?

You should make an advance healthcare directive when you have considered and fully understand all that is involved in making one and what happens when it comes into effect.

You should also think about whether you have someone you trust who you want to be your designated healthcare representative. You should talk to those close to you about what is involved and decide in your own time.

Do you need to get legal or medical advice before making an advance healthcare directive?

It is not required that you seek legal or medical advice before making an advance healthcare directive.

However, it is a good idea for you to talk to those close to you and that you trust about your plans to make an advance healthcare directive.

It is also recommended that you talk to your healthcare professional to ensure that you are fully informed about

treatment and care options for future care needs. It will be helpful to know about the potential implications of refusing certain treatments.

Can you make an advance healthcare directive if you have another type of decision support arrangement?

Yes, you can make an advance healthcare directive if you have another type of decision support arrangement, like a decision-making assistance agreement, or co-decision-making agreement, so long as you have the capacity to do so.

You can contact us at the Decision Support Service if you are unsure and need more information.

Can you make more than one advance healthcare directive?

Yes, you can have more than one advance healthcare directive. For example, you may have one advance healthcare directive for a mental health condition and one for a physical condition.

You can also appoint a different designated healthcare representative in each advance healthcare directive.

If you make more than one advance healthcare directive, it is important that you make sure you do not put anything in one that contradicts the other. This may affect the validity of the advance healthcare directive.

It is also important that you clearly state the circumstances for which each advance healthcare directive applies.

When does an advance healthcare directive apply?

An advance healthcare directive will apply only if you lack capacity to make certain healthcare treatment decisions for yourself.

It will be presumed that you have capacity to make the treatment decision until it is proven or shown otherwise.

It will only be applicable if you are required to decide about a certain treatment and the present circumstances have been covered in your advance healthcare directive.

When does an advance healthcare directive end?

An advance healthcare directive may end if you decide to revoke it, meaning that you cancel it.

You can cancel your advance healthcare directive at any time as long as you have the capacity to do so.

3. Before you make an advance healthcare directive

If you have an enduring power of attorney, will that affect your advance healthcare directive?

An enduring power of attorney may not include decisions relating to the consent to or refusal of treatment.

If you have an advance healthcare directive which outlines certain healthcare decisions, your advance healthcare directive will cancel any specific decisions in your existing enduring power of attorney.

However, if you include healthcare decisions in your enduring power of attorney that are contradictory to your advance healthcare directive, this may create ambiguity and affect the validity of your advance healthcare directive.

Can you still make decisions for yourself after you make an advance healthcare directive?

Yes, you can still make decisions for yourself after you make an advance healthcare directive.

Your advance healthcare directive will only apply, or come into effect, when you no longer have the capacity to make the decisions you have outlined in your advance healthcare directive.

It will be presumed that you have capacity until it is proven or shown otherwise.

4 About your designated healthcare representative

4. About your designated healthcare representative

What is a designated healthcare representative?

A designated healthcare representative is a person chosen by you who makes sure that the terms of your advance healthcare directive are followed.

They will act on your behalf regarding the decisions in your advance healthcare directive. They do this by letting people know about the advance healthcare directive and by providing direction to healthcare professionals and taking steps to ensure that your will and preferences are respected.

They can agree to, or refuse treatment on your behalf, based on your advance healthcare directive.

What is the difference between my 'next of kin' and a designated healthcare representative?

A designated healthcare representative has legal authority to act on your behalf to make healthcare decisions based on your advance healthcare directive if you lack capacity.

The term 'next of kin' is often misunderstood. Your 'next of kin' or close family member does not have legal authority to make treatment decisions on your behalf if you are unable to do so.

Who can be your designated healthcare representative?

You can appoint someone you know and trust as your designated healthcare representative. For example, it could be a family member, a friend, or somebody else that you trust.

Your designated healthcare representative must be 18 years old or older.

They must be willing and able to perform the role and responsibilities of a designated healthcare representative.

Is there anyone who cannot be your designated healthcare representative?

Under the law a person is not allowed to be your designated healthcare representative if they:

- have been convicted of an offence against you or your child
- have been the subject of a safety or barring order against you or your child
- are the owner or a registered provider of a designated centre or mental health facility where you live

- live with, or are the employee or agent of, the owner or a registered provider of a designated care or mental health facility where you live
- provide you with paid personal care or healthcare services, unless they are your spouse, civil partner, cohabitant, parent, child, sibling or primary carer

Can you have more than one designated healthcare representative?

You can have one main designated healthcare representative and one alternate designated healthcare representative.

The alternate designated healthcare representative will act for you should your main designated healthcare representative die or be unable to carry out their functions.

Your designated healthcare representative cannot appoint an alternate on your behalf. You must do this yourself in your advance healthcare directive.

Do you have to appoint a designated healthcare representative?

You do not have to appoint a designated healthcare representative.

Your advance healthcare directive is still effective even if you do not have a designated healthcare representative and will still be respected by healthcare professionals.

What if you do not have a trusted person to appoint as your designated healthcare representative?

If you do not have a designated healthcare directive, it is a good idea to make sure you give a copy of your advance healthcare directive to your healthcare professionals, like your GP, so that they are aware of it.

What powers will your designated healthcare representative have?

Your designated healthcare representative has the authority to ensure that the terms of your advance healthcare directive are respected and acted on by healthcare professionals.

Depending on the terms of the advance healthcare directive, this may include:

- advising on and interpreting what your will and preferences are regarding treatment decisions outlined in your advance healthcare directive
- consenting to or refusing a particular healthcare treatment

4. About your designated healthcare representative

- consenting to or refusing life-sustaining treatment, based on your known will and preferences outlined in your advance healthcare directive

What can your designated healthcare representative not do?

Your designated healthcare representative does not have any other powers except those which you have specified in your advance healthcare directive.

Your designated healthcare representative cannot pass on their powers to another person.

What information should you give your designated healthcare representative?

You should talk openly and honestly with your designated healthcare representative. They will be the person who makes the decisions on your behalf in line with your advance healthcare directive so it is important that you provide them with as much information about your will, preferences, beliefs and values so that they can make the best possible decisions for you.

It might be helpful to discuss different possible scenarios with your designated healthcare representative and how you would like them to

approach certain situations if you lack capacity.

Here is a list of things you might provide them with:

- any medications you are taking
- any supports that you are receiving. For example, you might attend a day centre or respite. They may need details of when and for how long you attend for, who your key healthcare professionals are, and how to contact the service
- who your doctors and healthcare professionals are and how to contact them
- who you would like them to contact if they need some input on a particular decision. For example, you might like a close friend or family member that knows you well to help understand your will and preferences around a certain decision

Can anyone help your designated healthcare representative to make decisions?

In gathering information to make a decision, your designated healthcare representative may consider whether there are any people they could consult that might provide them with useful information on your will and preferences in relation to a specific

decision at hand. They may consider talking to:

- people who are caring for you
- a person who has a genuine interest in your welfare
- healthcare professionals
- subject matter experts, for example, a specialist medical consultant

Who supervises your designated healthcare representative's activities and how?

Your designated healthcare representative must make a record of any decision that they make that relates to your advance healthcare directive. They must do this as soon as possible and no later than seven days after the decision has been made.

If you regain capacity, your designated healthcare representative must provide a copy of this record to you.

The Decision Support Service can also request a copy of this record if we receive a complaint about your designated healthcare representative.

We can send someone to talk to you or your designated healthcare representative. For example, we can send a [general visitor](#) or [special visitor](#).

Can your designated healthcare representative access your personal information?

Your designated healthcare representative will only have access to information about you that is relevant to the powers you have given them in your advance healthcare directive.

They must store this information securely while acting as your designated healthcare representative. If they stop being your designated healthcare representative, they must either return the information to you or dispose of it securely.

Does your designated healthcare representative get paid?

No, this is a voluntary role. Your designated healthcare representative does not get paid for their role. They are also not allowed to claim for any of their expenses.

5 Planning your advance healthcare directive

What should you consider when making an advance healthcare directive?

Making an advance healthcare directive is a serious decision. It is important to take care in creating it to avoid any unintended consequences. It is important that you think about what you really want to happen if you no longer have the capacity to make treatment decisions for yourself.

How much does it cost to make an advance healthcare directive?

It will not cost anything to make, change or cancel an advance healthcare directive.

Can you request treatments in your advance healthcare directive?

Yes, you can include requests for specific treatments, but these requests are not legally binding.

For example, you cannot insist that a healthcare treatment that is not available or appropriate is provided to you.

Even though the requests for treatment are not legally binding, they can help your designated healthcare representative and healthcare professionals to consider them if they have to make a decision about your healthcare.

If your healthcare professional decides not to respect a request for treatment in your advance healthcare directive, they have to record their reasons in writing and give a copy of this record to your designated healthcare representative, if you have one, within seven working days.

Can you refuse treatments in an advance healthcare directive?

Yes, you can refuse treatment in your advance healthcare directive. You must record the specific treatment and the specific circumstances when you want to refuse it in your advance healthcare directive.

Your refusal of treatment in your advance healthcare treatment will be legally binding if the following three conditions are met:

- 1) you lack the capacity to make a decision about the treatment
- 2) the treatment you want to refuse is clearly expressed in your advance healthcare directive
- 3) the circumstances when you want to refuse treatment are clearly written in your advance healthcare directive and these are the present circumstances

A refusal of treatment must be respected by all healthcare professionals who are treating you, if it meets these requirements.

5. Planning your advance healthcare directive

You cannot refuse **basic care** in an advance healthcare directive. This includes hygiene measures, food and liquids by mouth.

Can you refuse life-sustaining treatment in your advance healthcare directive?

Yes, you can refuse life-sustaining treatment in your advance healthcare directive.

Life-sustaining treatment is any medical treatment, technology, procedure or medication that is administered to preserve life. This may include mechanical ventilation, artificial hydration and nutrition, and chemotherapy.

Treatment is considered life-sustaining where failure to provide that treatment at that time would result in a significant risk of death.

If you wish to refuse life-sustaining treatment, you must make a clear statement in your advance healthcare directive that you wish to refuse the particular treatment even if it leads to your death.

What are some examples of treatment that can be requested or refused in your advance healthcare directive?

Some examples of healthcare treatments that can be refused or requested in your advance healthcare directive include:

- cardiopulmonary resuscitation (CPR)
- mechanical ventilation
- tube feeding
- dialysis
- antibiotics or antiviral medications
- electro-convulsive therapy (ECT)
- chemotherapy for treatment of cancer

6

Making an advance healthcare directive

6. Making an advance healthcare directive

How do you make an advance healthcare directive?

To make an advance healthcare directive you must:

- be 18 years or older
- have capacity at the time you are making it

Your advance healthcare directive must be in writing and meet certain legal requirements.

What must you include in an advance healthcare directive?

There is no specified form to fill out when making an advance healthcare directive. The law states that there is some information that needs to be contained in your advance healthcare directive, including:

- your name, date of birth and contact details
- your signature and the date that you signed it on
- the name, date of birth and contact details of your designated healthcare representative, if you appoint one
- the signature of your designated healthcare representative if you have appointed one and the date that they signed it on

- the signature of your alternate designated healthcare representative if you have appointed one and the date that they signed it on

Does an advance healthcare directive need to be made in writing?

Your advance healthcare directive can be made in writing or by recording it in a non-written format. For example, by using voice and video recording or speech recognition technologies.

However, if it is not made in writing, it should then be transcribed into writing, so that it can be signed and witnessed.

How many witnesses do you need when making an advance healthcare directive?

Your advance healthcare directive must be signed by you, in the presence of two witnesses. The witnesses:

- must be 18 years or older
- at least one witness must not be a member of your immediate family

Each witness must observe you and your designated healthcare representative (if you are appointing one) and your alternate designated healthcare representative (if you are appointing one) signing the advance

healthcare directive. They must sign to acknowledge they have observed this.

What happens if you are unable to sign your advance healthcare directive?

If you are physically unable to sign your advance healthcare directive, you can instruct someone else to sign it on your behalf.

This person must be 18 years or older and must sign your advance healthcare directive in front of you. Their signature must be witnessed in the same way as your signature would have been.

Do you have to set up an account with the Decision Support Service to make an advance healthcare directive?

No, you do not need to set up an account with the Decision Support Service to make an advance healthcare directive. An advance healthcare directive does not have to be registered with the Decision Support Service to be valid.

The Decision Support Service does not have a register of advance healthcare directives at present.

Can someone help you to make an advance healthcare directive?

Yes, you can have help when making an advance healthcare directive. Your designated healthcare representative or another trusted person can help you with this.

However, it is important that you make the decisions of your own free will and that the person helping you does not coerce or force you into making any decisions.

7 After you make an advance healthcare directive

Can you change your advance healthcare directive?

Yes, you can change your advance healthcare directive at any time so long as you have the capacity to do so. This is called a **variation**.

Varying your advance healthcare directive can include:

- changing the treatment decisions in your advance healthcare directive
- adding decisions to your advance healthcare directive
- removing decisions from your advance healthcare directive

Any change to your advance healthcare directive must be:

- made in writing, or recorded in a non-written format and then be transcribed into writing as soon as possible
- signed by you
- signed by your designated healthcare representative if you have one
- signed by two witnesses

You should make sure that all people who have a copy of your previous advance healthcare directive are made aware that you have changed it and you should provide them with a new copy.

Can you cancel your advance healthcare directive?

Yes, you can cancel your advance healthcare directive at any time as long as you have the capacity to do so. This is called a **revocation**.

An advance healthcare directive must be cancelled in writing. This does not need to be signed or witnessed.

If you have more than one advance healthcare directive, you must clearly identify which advance healthcare directive you are cancelling.

You should make sure that all people who have a copy of your previous advance healthcare directive are made aware that you have cancelled it.

Who should you tell about your advance healthcare directive?

It is up to you who you tell about your advance healthcare directive. However, it is important and useful for several people to know about your advance healthcare directive. These people include:

- your designated healthcare representative (if you have one)
- your alternate designated healthcare representative (if you have one)
- your GP
- any healthcare professionals that you are dealing with

7. After you make an advance healthcare directive

- the emergency department and hospital admission team if you are admitted to hospital
- the person in charge of any healthcare or residential facility where you live
- family members, people you live with and any other people you trust who can inform healthcare professionals of your advance healthcare directive in an emergency

What happens if a healthcare professional doesn't have access to your advance healthcare directive?

If a circumstance arises where immediate or urgent action is needed to avoid causing you significant harm, injury or death, a healthcare professional may not be aware of, or have access to, your advance healthcare directive.

Where possible, and where time permits, the healthcare professional should try to find out if you have a valid and applicable advance healthcare directive.

In emergency circumstances where this is not possible, the healthcare professional may provide you with the treatment required.

If the healthcare professional finds out about your advance healthcare directive after they have provided you

with treatment, they must consider it as part of any ongoing treatment.

What happens if a healthcare professional is not sure about whether your advance healthcare directive is valid or applicable?

A healthcare professional will only follow your advance healthcare directive if it is valid and applicable to the specific treatment that is being considered.

If it is not clear whether or not the advance healthcare directive should apply, the healthcare professionals considering the directive may take the following steps:

- consult with your designated healthcare representative if you have one
- consult with other people you trust
- seek the opinion of another healthcare professional
- consider any other evidence of your will and preference

If it is still not clear whether the advance healthcare directive applies, the healthcare professional will take action to preserve your life, where relevant.

If there is a disagreement about the correct course of action to be taken, an application may be made to

court to make a determination on the matter.

Any applications relating to life-sustaining treatment will be made to the High Court.

What happens if you are detained under the Mental Health Act 2001?

If you are involuntarily detained in a mental health facility under the Mental Health Act 2001, this may affect whether your advance healthcare directive will apply.

If you are detained on 'risk grounds', which means you are suffering from a mental disorder and there is a serious risk of harm to you or other people, then your advance healthcare directive:

- will apply to treatment for a physical illness in the same way as any other advance healthcare directive
- will not apply to treatment for a mental disorder, but may still be taken into consideration

Should you review your advance healthcare directive?

You should review your advance healthcare directive, and your designated healthcare representative if you have appointed one, from time to time to make sure that you are still

happy with the decisions you have planned for.

As time goes on you may think of more things that you wish to include in your advance healthcare directive. You should make a note of anything important that you might think of and consider whether you would want to or need to include it in your advance healthcare directive.

You can add or remove any decisions in your advance healthcare directive at any time through the variation process, so long as you have capacity to do so.

What happens if your designated healthcare representative is unwilling or unable to do their job?

If your designated healthcare representative cannot or no longer wishes to perform their role, they can resign from the role.

If you have appointed an alternate healthcare representative, they can take over the responsibilities of the main designated healthcare representative.

Your advance healthcare directive remains valid even if your designated healthcare representative is unable or unwilling to continue in their role.

7. After you make an advance healthcare directive

Can you change your designated healthcare representative?

You cannot change your designated healthcare representative in your existing advance healthcare directive.

To appoint a new designated healthcare representative, you will have to cancel your advance healthcare directive and create a new one with a new designated healthcare representative.

Can you make a complaint about your designated healthcare representative?

Yes. Any person, including you, can make a complaint about how your designated healthcare is exercising their powers.

The Decision Support Service will review the complaint and see if we need to investigate it further.

You can find out more about making a complaint on our website and in the Decision Support Service Complaints Policy.

Where can you find more information?

You can contact our Information Services Team on **(01) 211 9750**.

You can also ask a question on our website, or by email to queries@decisionsupportservice.ie





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