



INCLUSION IRELAND

Your right to make medical decisions

Easy to Read information





Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



Your right to health

The United Nations says that health is a human right and that States must support people to have the best health possible.

This is written in the International Covenant on Economic, Social and Cultural Rights, the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities.

The Health Act 1970 says you have the right to access health services.

Privacy

You have a right to privacy, based on the Constitution of Ireland.

Giving and refusing consent

You have the right to autonomy. Having autonomy means having and making choices and decisions.

If you are a 16-year-old or older, you can give consent for medical treatment. This means you can say yes or no to medical treatment.

You should be given information to help you make decisions.

You should not be rushed into making a decision but you should be aware of any risks if there is a delay in getting treatment.

You have the right to look at your medical records.

Complaints

You have the right to make a complaint about your medical treatment. You can find how to make a complaint on page 6 of this document.

Being Supported to Make Decisions



Some people may need support when making a decision.

Just because you may need support does not mean you cannot make your own decision.

Having a disability does not mean you cannot make a decision.



There are different types of people who can support a person.

These could be:

- Advocates
- Social Workers
- Support workers
- Family
- Lawyers
- Doctors



All of these people should support a person to understand the choices they have.

Lawyers can support people to make a legal document about future decisions.



This would say, in writing, who the person wants to make certain decisions for them when they can no longer make those decisions in the future.



Doctors should support people by explaining medical information to a patient in a way that the person can understand.



This means using clear and easy to understand language.

Who can decide if I cannot?



A parent can decide on medical treatment for their son or daughter until they turn 16 years of age.

Once a person is over 16, they can make their own medical decisions.

If you have decision-making capacity, you can pick a person to make "personal care decisions" in the future if you lose your capacity.

That person is called an Enduring Power of Attorney.

Personal care decisions include:

- Where you live
- Who you can see
- What you should eat
- Social welfare



Every adult should be presumed to be able to make their own medical decisions.

If a person has decision-making difficulty, a number of steps can be taken to support them to make their own decision.

Nobody can make a medical decision for another adult. This includes family members or next of kin.

Family do have a role in helping the medical team understand the person's wishes and views.

Sometimes family are asked to sign a consent form for their family member.

This consent form is not the same as your consent and is only a record that the family were asked for their views.



Ward of Court



A Ward of Court is the name for someone whose decisions are made by the courts.



If a doctor thinks that you might not be able to give consent or say yes or no to medical treatment, they can apply to make you a Ward of Court.



When you become a Ward of Court you cannot make any of your own decisions including medical decisions.



We know that people with intellectual disabilities are often made Ward of Court when they need to make medical decisions.



The number of people who are becoming Wards of Court is going up. This is a bad thing.



It is really important to know that if you are a Ward of Court, the court makes all of your decisions, not just some of them.



This means the person has no choice and control over their own life.

It is difficult to come out of being a Ward of Court once you are one.



Under the new Assisted Decision Making Capacity Act the Ward of Court system will change. This is a good thing but it has not started yet.

Getting Support and Making a Complaint



If you are unhappy with the service that you have received from the Health Service Executive (HSE) or a service provider, you can make a complaint.

You can make a complaint about the HSE or a service provider if you have been treated unfairly or if you are unhappy with the decisions made by staff about your health.



Reasons to complain include:

- You are unhappy with the treatment you get,
- Staff have got your treatment wrong,
- Staff have got your information wrong,
- You feel you have been treated unfairly by staff because of a disability
- Staff are behaving in an unsafe way.



You can make a complaint for yourself or you can complain for someone else. You can get support to make a complaint from someone you trust



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You can find out how to make a complaint to the HSE by calling the LoCall number on 1890 424 555 or by sending an email to yoursay@hse.ie.

If you are not happy after making a complaint



If you live in residential services and you need to make a complaint, each service should have a complaints policy to help you make complaints.

If this doesn't work, you can contact the Confidential Recipient, Leigh Gath.

LoCall 1890 100 014 or 087 6657269

Email leigh.gath@crhealth.ie



If you make a complaint to the HSE or another public body and you are not happy with what happened, you can complain to the Office of the Ombudsman

LoCall 1890 22 30 30

Email info@ombudsman.ie



If you have made complaints and contacted the Ombudsman and you are still unhappy you might think about taking a case to court.

You will need a solicitor to help you take a court case in Ireland.



You can also take cases about human rights, like making medical decisions, to the European Court of Human Rights.

There is an online form to contact the European Court of Human Rights. It is a big decision to decide to take a case to a European Court.

Case Studies



Andy is a 25-year-old man and goes into hospital to have his appendix removed. Andy does not communicate by speaking.

The doctor is concerned that Andy lacks capacity and asks Andy's mother to sign a consent form for the operation.

Andy's mother contacts Inclusion Ireland for support.

Inclusion Ireland tells Andy's mother that it is only Andy who can give consent to the operation.

Inclusion Ireland tells Andy's mother that having a disability or not being able to speak does not mean that Andy does not have capacity.

Andy's mother tells the doctor that Andy can decide for himself but that she can help the doctor to understand Andy.



Jackie is 82, and has dementia and cancer.

Jackie's doctor wants to treat her but her son can't decide on what Jackie would want.

Jackie's doctor tells them that the hospital will have to make Jackie a ward of court.

Jackie's son contacts Inclusion Ireland and we tell her to make sure that Jackie has an advocate.

Inclusion Ireland tells Jackie's son that Jackie should be supported to say what her own wishes and views are.

Being a ward of court means that Jackie's decisions about money and medical care are taken away from her.



More information

There is more information at the links below. This information may be harder to read.



1. Connect Family Network information leaflets on supporting decision-making.

http://bit.ly/CFN_ADM



2. Information from the Citizen's Information Board about making an Advance Healthcare Directive

http://bit.ly/CIB_AHD



3. The Decision Support Service

http://bit.ly/DSS_MHC



4. HSE Information about decision-making

http://bit.ly/HSE_ADM



For further information or support with anything you read in this booklet, you can contact Inclusion Ireland at:



Phone 01 8559891



Email info@inclusionireland.ie



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