

Caring and consent

Your right to be involved in decisions about the health care of the adult you care for



This leaflet is for you if you are the carer of an adult (someone aged 16 or over) who is unable to make decisions about their health care and treatment without help.

The information is for adult carers, young carers under 16, paid and unpaid carers.

What is this leaflet about?

This leaflet explains:

- the rights of people who are unable to consent (agree) to medical treatment
- the rights of their carers to be involved in decisions about their health care, and
- the rights of a legal proxy (someone allowed by law to act on someone else's behalf).

The information is based on the Adults with Incapacity (Scotland) Act 2000.

What is the Adults with Incapacity (Scotland) Act 2000?

It is a law that:

- gives several rights to adults who cannot make decisions for themselves to help them manage their lives
- allows another adult to be given powers to make decisions on behalf of someone who cannot make their own decisions.

An 'adult with incapacity' is someone aged 16 or over who has a mental disorder that makes them unable to:

- come to a decision
- communicate a decision
- understand a decision
- act on a decision, or
- remember a decision they have made.

When a decision is needed about the health care of the person you care for, then the health professional (for example, the doctor, optician, dentist or registered nurse) must decide if that person has the capacity to do this.

How will a health professional decide if the person I care for has the capacity to make decisions?

- The health professional should first talk to the person you care for about their health care and treatment.
- If the health professional is unsure whether the person can give consent, they should talk to you and anyone else who is closely involved in the person's care. You may know how much the person can understand and if this changes from day to day.

The health professional must make sure that the person you care for:

- understands what the treatment is and why it is needed
- understands the benefits and risks of the treatment
- understands that there are other options and can decide between these options
- understands what happens if no treatment is given
- remembers information long enough to make a decision, and
- can tell the health professional what they have decided.

If the person can't do this, the health professional will issue a certificate of incapacity for the specific treatment needed (called a section 47 certificate).

The certificate is kept with the person's health record and it should not normally last for longer than a year. However, in certain cases where the person's condition is unlikely to improve it can last up to three years.

- People who have a learning disability or have difficulty communicating may still be able to make decisions.
- You and others must always assume that people can make decisions unless there is evidence suggesting they can't.
- Each decision about health care and treatment is different. Some people can make decisions about some things but not others. For example, understanding and agreeing to have your temperature checked is easier than understanding and being able to agree to an operation.
- The person you care for should always be given information in a clear and simple way and be given help to communicate.

What rights do I have as a carer?

If the person you care for can't make a decision about their health care without help, you have the right to be involved. This is true whether you are an adult carer, a young carer under 16, a paid or an unpaid carer.

This means that:

- you can say what you think about any planned health care or treatment
- your views should be taken into account when a final decision is made about the care and treatment
- you have the right to disagree with a decision
- you have the right to ask for a second opinion from another doctor if you are unhappy with the decision that the health professional or the legal proxy has made (see page 5 for more about legal proxies)
- you have the right to go to court about a decision.
- if you would like written information about the care and treatment to take away, you should say so.
- **As the person's carer, you should be involved in decisions about their health care. But you do not have the right to make any final decisions unless you are the person's legal proxy (see page 5 for more about legal proxies).**
- **If you know what the person you care for wants, you should tell the health professional looking after them. Any information you give health professionals should be kept in the person's health record.**

What rights does a legal proxy have?

A legal proxy can make medical, welfare or financial decisions for an adult with incapacity. In this leaflet we talk only about legal proxies with the power to make medical decisions.

There are different types of legal proxy.

- Someone can appoint a **welfare attorney** to make decisions about their health care and treatment if they later become unable to do this on their own.
- The court can appoint a **welfare guardian** to make decisions about a person's health care and treatment on their behalf.
- An **intervention order** is when a person is appointed by the court to make a one-off decision within a certain period about another person's health care or treatment.

How do I become a legal proxy for the person I care for?

- This depends on the type of decisions that the person you care for needs help to make.
- Applying to become a legal proxy can be complicated and you may need to seek advice from a solicitor or legal advisor.
- There are various organisations that can give you more general advice, for example, the Office of the Public Guardian (OPG) and some carers' organisations. Their contact details are on pages 11 to 13.

I am a legal proxy. What rights do I have?

- If you are a legal proxy for someone who cannot consent to their health care or treatment, the health professional should ask you to consent on the person's behalf. The health professional may ask to see a copy of the power of attorney document to show that you are allowed to give consent.
- If it is an emergency there may not be time to do this – in this situation the doctor can go ahead with treatment, but only if it is needed to save the person's life or stop them suffering more serious harm.
- If you are a legal proxy for someone, you may have the right to see their health records.

A person's health record should include the names and contact details of their carers, particularly anyone who is a legal proxy.

I am a legal proxy. Can I disagree with a decision about health care and treatment?

- Yes. If you disagree with the health care or treatment the doctor suggests for the person you care for, you should discuss this with them.
- You cannot demand that a particular treatment is given. But you can object to a treatment that you think should not be given.
- If you can't agree, the doctor should ask the Mental Welfare Commission for Scotland to find an independent doctor who will give a second opinion. Contact details for the Mental Welfare Commission for Scotland are on page 10.
- If the second doctor agrees with the first doctor's decision, the health care or treatment can be given.

- If the second doctor does not agree with the first doctor's decision, the health care or treatment cannot be given.
- If you disagree with the second doctor's opinion, you can go to the Court of Session to ask for the treatment to be stopped. You may need to get help from a solicitor if you want to do this.

I am not a legal proxy. Can I disagree with a decision about health care and treatment?

- The doctor should take account of your views if possible. If you disagree with the decision, you can ask for a second opinion. But the doctor can still give the treatment unless you go to court and get an order to stop it. You may need to get help from a solicitor if you want to do this.

If you are unhappy about a medical decision, you can make a complaint using the NHS complaints procedure (see pages 14 and 15 for where to get our leaflet on making a complaint).

What rights does the person I care for have?

The person you care for has the right to:

- make decisions about their health care and treatment, unless there is evidence that they can't do this
- be properly consulted about their health care and treatment
- have someone with them at their medical appointment if that's what they want, and
- have help with making any decisions and saying what they want to happen (for example, help from you as the carer, from an advocacy service or through communication support).

An advocacy service can help someone express their views or make their own decisions, or can speak on their behalf. The contact details of some advocacy organisations are on page 11.

Any decisions about a person's health care or treatment must always:

- benefit them
- be necessary
- restrict their freedom as little as possible, and
- take into account their past and present wishes, if possible.

Can a health professional treat the person I care for without consent?

Yes. In special cases, the person you care for can be treated without consent in the following situations:

- If the person you care for cannot make a decision on their own and no one is available to make the decision, treatment can be given without consent. But the treatment must benefit the person, and the health professional must complete a certificate of incapacity.
- In an emergency, when there is no time for anyone else to make a decision, doctors can give treatment without consent but only if it is needed to save the person's life or stop them suffering more serious harm.
- If the person you care for is being looked after under the Mental Health (Care and Treatment) (Scotland) Act 2003, there may be times when they can be treated for their mental illness or disorder without consent.

Are there special rules for some kinds of treatment?

Only a doctor appointed by the Mental Welfare Commission for Scotland can allow the following treatments to be given to people with incapacity:

- abortion
- electroconvulsive therapy (ECT) for mental disorder
- drugs to reduce sex drive
- any treatment that may lead to sterilisation (for example, some treatments for cancer).

Only the Court of Session can allow the following treatments to be given to people with incapacity:

- sterilisation
- surgical treatment to reduce sex drive.

What happens if the person I care for is asked to take part in research?

Research on adults with incapacity can only be done if:

- it will increase knowledge of the condition causing the person's incapacity
- it will benefit the person or others with a similar condition, and will cause little or no risk or discomfort (if the research is to test a medicine, the benefit to the person must be greater than any risk, or there should be no risk)
- the person does not object
- consent has been obtained from a legal proxy, or the person's nearest relative if they don't have a legal proxy, and

- the research has been approved by a Research Ethics Committee.

How to find out more

For more information about anything in this leaflet, contact:

- a member of NHS staff involved in the health care of the person you care for
- the NHS inform Helpline on 0800 22 44 88 (textphone 18001 0800 22 44 88; the NHS inform Helpline also provides an interpreting service)
- your local citizens advice bureau (find your nearest bureau online at www.cas.org.uk or in your local phone book).

Information on the law and adults with incapacity or mental disorder

For more information about the rights of people with a mental illness, learning disability, dementia or other mental disorder, contact:

- **The Mental Welfare Commission for Scotland (MWC)**
Thistle House
91 Haymarket Terrace
Edinburgh EH12 5HE
Telephone **0131 313 8777**
Freephone **0800 389 6809** (for service users and carers)
Email **enquiries@mwscot.org.uk**
Website **www.mwscot.org.uk**

The Mental Welfare Commission for Scotland can also give you information and advice on people's rights under the Adults with Incapacity Act.

Advocacy

For information about advocacy and to find a local advocacy group, contact:

- **Scottish Independent Advocacy Alliance**

69a George Street
Edinburgh EH2 2JG
Telephone **0131 260 5380**
Website **www.siaa.org.uk**

- **People First (Scotland)**

(an independent self-advocacy organisation for people with learning disabilities)

77–79 Easter Road
Edinburgh EH7 5PW
Telephone **0131 478 7707**
Email **peoplefirst1@btconnect.com**
Website **www.peoplefirstscotland.org**

Dementia

For information about dementia, contact:

- **Alzheimer Scotland**

22 Drumsheugh Gardens
Edinburgh EH3 7RN
Telephone **0131 243 1453**
Dementia helpline **0808 808 3000** (24 hour)
Email **alzheimer@alzscot.org**
Website **www.alzscot.org**

Legal proxy

For legal advice, contact a solicitor or legal advisor.

For general information about becoming a legal proxy, contact:

- **The Office of the Public Guardian (Scotland)**

Hadrian House

Callendar Business Park

Callendar Road

Falkirk FK1 1XR

(open 9am to 5pm, Monday to Friday)

Telephone **01324 678 300**

Email **opg@scotcourts.gov.uk**

Website **www.publicguardian-scotland.gov.uk**

Support for carers

For support for carers, contact:

- **Carers Scotland**

The Cottage

21 Pearce Street

Glasgow G51 3UT

Telephone **0141 445 3070**

Helpline **0808 808 7777**

(Wednesday and Thursday 10am to 12pm and 2pm to 4pm)

Email **info@carerscotland.org**

Website **www.carerscotland.org**

- **The Princess Royal Trust for Carers**

Charles Oakley House
125 West Regent Street
Glasgow G2 2SD
Telephone **0141 221 5066**
Email **info@carers.org**
Website **www.carers.org**

- **PAMIS**

(works with families caring for a child or adult with profound and multiple learning disabilities and complex health needs)

Springfield House
15/16 Springfield
University of Dundee
Dundee DD1 4JE
Telephone **01382 385 154**
Email **pamis@dundee.ac.uk**
Website **www.pamis.org.uk**

Young carers

For information for young carers, contact:

- **The Princess Royal Trust for Carers**

Charles Oakley House
125 West Regent Street
Glasgow G2 2SD
Telephone 0141 221 5066
Email **youngcarers@carers.org**
Website **www.youngcarers.net**

Information about health rights

Health Rights Information Scotland produces information on your rights within the NHS.

- **Confidentiality – it's your right** explains how the NHS protects your personal health information.
- **How to see your Health Records** explains your right to see or have a copy of your health record.
- **Making a complaint about the NHS** tells you how to complain using the NHS complaints procedure.
- **Consent – it's your decision** explains how you should be involved in decisions about your health care and treatment.
- **The NHS and You** explains what you can expect from the NHS in Scotland and what the NHS expects from you.
- **Health care for overseas visitors** is a set of factsheets explaining what NHS services overseas visitors can expect to receive while they are in Scotland.

Information for young people

- **Confidentiality – your rights** tells you how the NHS keeps information about you private.
- **Have your say! Your right to be heard** tells you how to give feedback or make a complaint about the NHS.
- **Consent – your rights** explains how you should be involved in decisions about your health care and treatment.

You can get this information from:

- GP and dental surgeries, hospitals and anywhere you get NHS care
- the NHS inform Helpline on 0800 22 44 88 (textphone 18001 0800 22 44 88)

- www.hris.org.uk, and
- your local citizens advice bureau (find your nearest bureau on the internet at www.cas.org.uk or in your local phone book).

Email ask@hris.org.uk to ask for this information in another language or format.

We have tried our best to make sure the information in this leaflet is correct. However, the leaflet is for guidance only so you should not rely on it as a full statement of the law. If you are thinking about taking legal action, you should contact a solicitor, a citizens advice bureau or other advice agency.



Produced by Health Rights Information Scotland, a project of Consumer Focus Scotland, for the Scottish Government Health Directorates.