



**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 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 incapacity.



How will a health professional decide if the person I care for has incapacity?

- 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 that suggests 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.

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 a paid carer, an unpaid carer, or a young carer under the age of 16.

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 be present at any health care appointment, unless the person you care for doesn't want this,
- you have the right to ask for written information about the care and treatment to take away,
- 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 8 for more about legal proxies).
- You have the right to go to court about a decision.
- 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 8 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.

You can become a person's legal proxy if:

- you are aged 16 or over, and
- it is in the person's best interests.

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.

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.
- 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 19.
- 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.

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).



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 Act, 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.

Information about the rights of people with a mental illness, learning disability, dementia or other mental disorder

The Mental Welfare Commission for Scotland (MWC)

Thistle House, 91 Haymarket Terrace, Edinburgh EH12 5HE

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

Telephone: 0131 313 8777

Freephone: 0800 389 6809 (for service users and carers)

Email: enquiries@mwscot.org.uk

Website: www.mwscot.org.uk

The Scottish Government Health Directorates have produced a series of guides for people with a mental disorder and their carers. These include a guide on giving consent to treatment. If you would like a copy of any of these guides, contact:

Mental Health Division (Policy & Legislation Team)

Scottish Government Health Directorates

St. Andrew's House, Regent Road, Edinburgh EH1 3DG

Telephone: 0131 244 5668

Email: mentalhealthlaw@scotland.gsi.gov.uk

Website: www.scotland.gov.uk

(follow links to mental health, law reform and guidance)

Advocacy

For information about advocacy and to find a local advocacy group.

Scottish Independent Advocacy Alliance

69a George Street, Edinburgh EH2 2JG

Telephone: 0131 260 5380

Website: www.siaa.org.uk

People First (Scotland)

Is 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

Alzheimer Scotland

22 Drumsheugh Gardens, Edinburgh EH3 7RN

Telephone: 0131 243 1453

Dementia helpline: 0808 808 3000 (24 hour)

Email: alzheimerscot.org

Website: www.alzscot.org

Legal proxy

For information about becoming a legal proxy.

The Office of the Public Guardian (Scotland)

Hadrian House, Callendar Business Park

Callendar Road, Falkirk FK1 1XR

(open 9am–5pm, Monday to Friday)

Telephone: 0845 603 1185

Email: opg@scotcourts.gov.uk

Website: www.publicguardian-scotland.gov.uk

Support for carers

Carers Scotland

The Cottage, The Pearce Institute
840–860 Govan Road, Govan, Glasgow G51 3UU

Helpline: 0808 808 7777

(Wednesday and Thursday 10am–12pm and 2pm–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@carerscotland.org

Website: www.carers.org

PAMIS

Work 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.dundee.ac.uk/pamis

Young carers

Carers Scotland

The Cottage, The Pearce Institute
840–860 Govan Road, Govan, Glasgow G51 3UU

Helpline: 0808 808 7777

(Wednesday and Thursday 10am–12pm and 2pm–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: youngcarers@carers.org

Website: www.youngcarers.net

Health rights

- **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 Helpline on: 0800 22 44 88
or 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).

To ask for this information in another language or format email: ask@hris.org.uk

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.



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