

*Consent – what
you have a right to
expect*

A guide for relatives and carers

Consent – what you have a right to expect

Before a doctor, nurse or therapist can examine or treat a patient, they usually need his or her *consent* or agreement. As long as the person you care for can understand what's involved in the treatment, like anyone else over 18 he or she is the only person who can give consent. (For advice see our leaflet *Consent: A guide for adults*.)

But what happens about consent if they have problems in understanding?

Big problems Suppose someone is unconscious after an accident, cannot communicate at all after a severe stroke, or is too bewildered to make decisions because of advanced dementia – then they're not usually in a position to give consent. Then who is?

Some problems Sometimes people can understand enough to make everyday decisions about health care, such as pain relief. But when it comes to a major operation, perhaps because of a learning disability, they have too much of a problem in understanding to give consent. Or do they?

Where do you stand as a relative or carer in situations like these? This guide is designed to help you.

How far is the person you care for able to decide for themselves?

A patient might *seem* unable to understand enough to consent to, or refuse, proposed medical treatment. Or they might seem unable to communicate their wishes.

But no one should assume – neither carers nor health care professionals – that a patient with for example a learning disability or dementia is not capable of consenting. No one knows better than you that if time is spent explaining the options simply, they may be able to reach a decision.

Making the most of people's abilities

If individuals have some ability to understand and think things over, they should always be encouraged to decide for themselves.

It may not be a decision you agree with, but that's not the key test. What you and the people providing the health care need to ask yourselves is: *can the patient understand and weigh up the information provided?*

What if a person is totally unable to decide for themselves?

Under English law, no-one (not even husbands or wives, partners, close relatives or carers) can give consent to treatment on behalf of another adult. This obviously causes a problem if patients are not in a condition to give consent for themselves.

How can they be treated?

Doctors, nurses and therapists are generally allowed to provide treatment which they believe is in their patient's "best interests". This doesn't just mean what might be best for the patient's physical health. It takes into account their general well-being and what they're known to believe in.

You can help

It's true that friends and relatives cannot make decisions on behalf of patients who can't decide for themselves. Even so, they may be able to tell health care professionals about the person's opinions and beliefs – for example whether they've ever accepted or refused certain kinds of treatment, or if they have strong views about particular health conditions or treatments.

This will help health care professionals make a better decision about what will be in the patient's best interests. People close to the patient should be involved in this way, unless the patient has made clear in the past that he or she would not want a particular person involved.

So – who does decide?

Whose opinion counts on whether or not the person you care for understands enough to decide about consent? And if they cannot decide, who is to judge what's in their best interests?

On the one hand, health care professionals may feel the need to take urgent action; but this should not lead them to assume a patient isn't capable of deciding. On the other, no one is in a better position than you to stand up for the patient, but you need to take on board medical opinion.

It's a difficult area and requires give and take all round. In the end, everyone usually agrees what's best. Occasionally they don't. If this is about a serious matter, either you or the person providing health care can ask a Court to intervene and decide what is in the patient's best interests.

You should never be asked to sign a consent form on behalf of the person you are looking after. However you may be asked to sign a form to say that you have been consulted.

Refusing treatment in advance

Sometimes people may decide that they would not want a particular treatment if something happened to them in the future and they were no longer capable of refusing consent. This is sometimes called a Living Will. What if this situation actually comes about?

- If you know that the person you care for has taken such a decision in the past, you should tell the health care professionals caring for them.
- If the patient has signed a document in which they refuse treatment, you should, if possible, give a copy to the health care professionals.
- Health care professionals are bound by that earlier decision, even if you disagree with it.

Suppose I or the person I care for is not happy about how we've been approached about consent?

You can tell the health care professionals concerned that you're worried. But if you're still not satisfied, you are entitled to complain. You can find out how to go about it from *Your Guide to the NHS* or from NHS Direct on 0845 4647. NHS Direct can also give you details of a new service called PALS (Patient Advocacy and Liaison Service) designed to help sort out problems simply and quickly.

Want more help with consent?

Here's a list of useful organisations you can ask for more help or support about giving consent to treatment.

The Patients Association

Address: P.O. Box 935, Harrow, Middlesex, HA1 3YJ
Telephone: Helpline 0845 6084455 Office 020 8423 9111
Fax: 020 8423 9119
Website:
www.patients-association.com
Provides a helpline, information and advisory service and publications; campaigns for a better health care service for patients.

Patient Concern

PO Box 23732, London SW5 9FY
Phone/fax: 020 7373 0794
Email:
patientconcern@hotmail.com
Website:
www.patientconcern.org.uk
Provides patient leaflets and a patient advisory service specialising in consent-related issues; campaigns for patient choice and empowerment.

Mencap

123 Golden Lane, London EC1Y 0RT
Telephone: 020 7454 0454
Fax: 020 7696 6930
Website: www.mencap.org.uk
Provides advice and support to people with learning disabilities and their families on a local basis through community support teams and family advisers.

Alzheimer's Society

Gordon House, 10 Greencoat Place, London, SW1P 1PH
Telephone: Helpline: 0845 300 0336 Office: 020 7306 0606
Fax: 020 7306 0808
Email info@alzheimers.org.uk
Website: www.alzheimers.org.uk
Provides advice on coping with dementia; has network of regional groups which can put people with dementia and their carers in touch with local support.

Carers National Association

20/25 Glasshouse Yard, London
EC1A 4JT

Telephone: Carers Line: 0808
808 7777 Office: 020 7490
8818

Fax: 020 7490 8824

Email: info@ukcarers.org

Offers advice through a national
telephone Carers Line; has a
network of groups for local
support.

UKAN: UK Advocacy Network

Address: 14-18 West Bar Green,
Sheffield, S1 2DA

Telephone: 01142 728171

Fax: 01142 727786

E-mail: ukan@can-online.org.uk

A national network of
organisations involved in mental
health advocacy who may be able
to put you in touch with a local
project.



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