Department of Health

Consent – what you have a right to expect

A guide for adults

Consent – it's up to you

When a doctor, nurse or therapist asks you to agree to any form of examination, treatment or care, remember you have a choice. You are always free to say no, or to ask for more information before you make up your mind.

This leaflet aims to answer your questions about what you have a right to expect and what to do. It is for adults; there are separate leaflets for relatives and carers, for children and young people and for their parents.

What we say mainly concerns physical conditions. The rules may be different if you are being treated for a mental disorder. You'll find more information on page 10.

What does consent really mean?

Before any doctor, nurse or therapist examines or treats you, they must seek your *consent* or permission. This could simply mean following their suggestions, such as your GP asking to have a look at your throat and you showing your consent by opening your mouth. Sometimes they will ask you to sign a form, depending on the seriousness of what they're proposing or whether it carries risks as well as benefits.

It does not matter so much *how* you show your consent: whether you sign or say you agree. What is important is that your consent is genuine or *valid*. That means:

- you must be able to give your consent
- you must be given enough information to enable you to make a decision
- you must be acting under your own free will and not, say, under the strong influence of another person.

English law assumes that if you're an adult you are able to make your own decisions, unless it's proved otherwise. As long as you can understand and weigh up the information you need to make the decision, you should be able to make it.

What if I’m not able to take a particular decision?

Suppose, for example, you are unconscious after a road accident or cannot communicate after a severe stroke, in general people providing health care can still give you treatment that they believe is in your best interests. The only exception is if you have clearly refused a particular treatment in advance (see page 7).

Although no-one (not even husbands, wives, partners or close relatives) can give consent to treatment on behalf of another adult, friends and relatives may have useful advice to give. They may be able to tell health care professionals about the person’s beliefs and values - for example whether they have accepted or refused certain kinds of treatment in the past or have strong views on some health questions. So it is important to discuss your views with your friends and relatives in case anything happens.

What if I’m asked about students being present?

Sometimes you may be asked if you mind students being present while you are treated. If you are undecided, ask what they intend doing - just observing, taking notes or examining you. If you prefer, you can specify students of one sex only.

If you are not comfortable about students being present, you can always say no. It shouldn’t make any difference to the quality of the care you receive.

What sort of information do I need?

In order to make a decision, you need to have information from health professionals about the treatment or investigation which is being offered to you. **You should always ask them more questions if you don't understand or if you want more information.** For example:

- What sort of things will the treatment involve?
- What are the benefits they hope will result?
- How good are the chances of getting such benefits?
- Are there any alternatives?
- What are the risks, if any?
- If there are risks, are they minor or serious?
- What may happen if you don't have treatment?

If the person asking for your consent to the treatment isn't able to answer your questions, ask them to find out or arrange for someone else to talk to you about your concerns. If you would find it easier to ask questions with someone supporting you, take a friend with you, or ask about local advocacy services. You can also ask for some-one of the same sex as yourself to be with you while you are being examined or treated.

How much do I need to know?

Some people want to know as much as possible about their condition and possible treatments; others prefer to leave decisions to the experts. No one providing health care will force information on you, for example, about the risks of treatment if you don't want to know. But remember, the person in the best position to know what matters most to you is **you** yourself.

Perhaps you're the kind of person who is prepared to take some risks if there is also a chance of a very good outcome. On the other hand, you might rather put up with some discomfort than have treatment which carries a small risk of making things worse – even though it ought to improve your condition. Only you can know what is most important to you.

How much time can I take to decide?

Your doctor, nurse or therapist may certainly encourage you to accept a particular treatment if they believe it will be helpful for you, but it is **your** decision whether or not to go ahead.

If you want more time to think about your decision, say so. In emergencies, decisions may have to be taken quickly, but at other times it is often possible to take as much time as you need.

Can I refuse treatment in advance?

You may be quite certain that you would **not** want a particular treatment in the future. In that case you may like to make a written record of your wishes (a document sometimes called a Living Will), and make sure people close to you know. Then if this situation arises at some point in the future and you are not in a position to tell your wishes to people providing health care, they will be bound by your earlier decision.

It is important to be very precise about any treatment you are refusing in advance, otherwise you could exclude treatments which you would want to accept. It is also important to let people close to you know if you have changed your mind so they can pass on this information if necessary.

Can I say in advance which treatment I'd prefer?

You may want to write down the sorts of treatment you would rather have, and the concerns that you have about other kinds. These wishes would not be binding in the same way as an advance refusal. You cannot, for example, insist on a particular kind of treatment if a health care professional does not believe it is right for you. But if the time ever comes when you can no longer make decisions or tell people about them, it would help people providing health care to have your wishes as a guide when deciding what is in your best interests.

You **cannot** request something that is against the law, such as euthanasia.

What if I’m asked to take part in research?

This may be as part of your treatment, for example to compare two different treatments; or it may be quite separate, for example being asked to provide extra blood samples for a research project. In any case, a research project will always be approved by a Research Ethics Committee before you are asked to take part in it.

It is for **you** to decide whether or not to take part. You should usually be given an information sheet about the research project, and you should ask as many additional questions as you want before coming to a decision. If you choose not to take part, this ought not to affect the rest of your care. If you agree to take part in a research project, and then change your mind, you are free to withdraw at any time.

Is there any advantage or disadvantage to taking part in research?

Sometimes you may only be able to get particular treatments as part of a research trial. This is because they are new and cannot be made generally available until they have been properly tested. If the person responsible for your care suggests that you might benefit from being in the trial, ask as many questions as you want:

- about the new treatment
- about any risks
- and about the alternatives to being involved

There is a type of research in which neither you nor your doctor will know whether you are being given the new treatment, the standard treatment or possibly any treatment at all. (You will always be told what options are being used in the research project, even though you will not know which option you will receive.) If you are not happy about being involved in this or indeed in any kind of trial, you should feel free to say so. You will always be able to have the available standard treatment. All treatments, even established ones, have risks and these have to be weighed up when making your decision.

What if I have a mental illness?

If you are suffering from a serious mental illness, it may be necessary for you to stay in hospital under the *Mental Health Act 1983*. If so, you may be given treatment for your mental disorder, even if you do not consent. There are safeguards for patients in this situation.

However, the terms of that Act only apply to treatment for *mental* disorder. You may also have a *physical* disorder (concerned with your body) that has nothing to do with your mental condition. If treatment is suggested for that, you are entitled to choose whether or not to accept it, as long as you are able to understand enough about the choices to make a decision.

Suppose I'm not happy about how I'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 scheme 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 and support about giving consent to treatment and taking part in research.

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.

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.

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.

CERES

(Consumers for Ethics in Research)
Address: P.O. Box 1365, London N16 0BW
Email: info@ceres.org.uk
Website: www.ceres.org.uk
Produces leaflets, *Medical research and you* and *Genetic research and you* for people considering taking part in medical research.

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