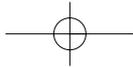


*Consent – what
you have a right to
expect*

A guide for parents

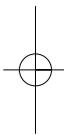
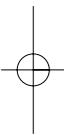


Giving consent for medical examination or treatment of your child

Before a doctor, nurse or therapist can examine or treat your child, they need **consent** or agreement. Sometimes children can give consent for themselves, depending on their age and how well they understand. Sometimes you will be asked to give consent for them as their parent.

This leaflet will help make it clear to you who can give consent and when and how.

How will your child or you be asked?



The way people providing health care (doctors, nurses or therapists) ask for consent partly depends on what they plan to do. It may be simple. For example, your GP might ask to have a look at your child's throat. You would then encourage a young child to open his or her mouth for the doctor. Older children will do so of their own accord. That shows you and they have given consent. For something more complicated, like an operation, you or they will be asked to sign a form agreeing to the treatment.

Who is responsible for giving consent?

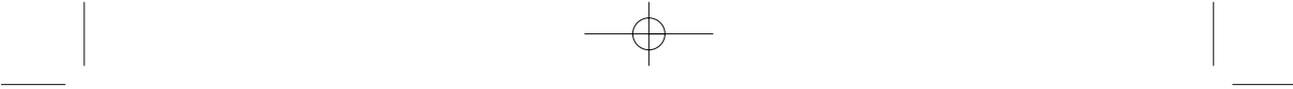
You are entitled to agree to treatment on behalf of a child up to age 18 for whom you have what is called “parental responsibility”.

However, **children** also gain rights to agree for themselves as they get older – as you’ll see over the page.

Who has parental responsibility?

- **Mothers** automatically have parental responsibility for their children.
- **Fathers** also have parental responsibility if they were married to the mother when the child was conceived or born, or if they got married to her later.
- **Unmarried fathers** do not automatically have parental responsibility for their child, but a court order or a “parental responsibility agreement” can give it to them.*
- **People looking after your child** like childminders or grandparents do not have parental responsibility, but you can authorise them to take medical decisions for your child, if you wish.

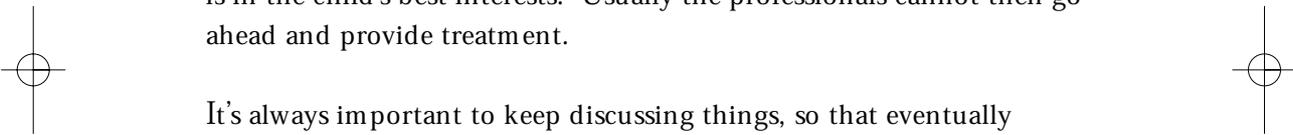
*The National Family and Parenting Institute produce a leaflet *Is it legal? a parents’ guide to the law* which gives more information about parental responsibility and how to acquire it (www.e-parents.org or telephone 020 7424 3460)



How do you decide what's best?

Parents are expected to make health care decisions for their children, based on what they feel is in a child's "welfare" or "best interests". But it's still a good idea to involve children as much as possible. Even when they're not old enough to make decisions completely on their own, children can still play a part in decisions about their health care. The more they're involved, the more likely they are to feel positive about treatment.

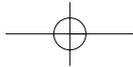
What if you and people providing health care don't agree?



Sometimes health care professionals and parents may not agree on what is in the child's best interests. Usually the professionals cannot then go ahead and provide treatment.

It's always important to keep discussing things, so that eventually agreement can be reached. For example, it may help to ask for a second medical opinion, or talk to other people involved in caring for your child. But sometimes health care professionals may believe a particular treatment is crucial for the child, perhaps life saving. Then they can ask a court to decide. Equally, after seeking legal advice, it may be possible for you to go to court to request or prevent treatment, if you think it's in your child's best interests.

On the rare occasion things go this far without agreement, the court has the power to grant or refuse the request of you or the practitioner if it thinks this is the right thing to do.



When can children give consent for themselves?

16-18 year olds

Once children reach the age of 16, they can agree to examination or treatment just like adults. People providing health care do not then have to ask you for consent as well.

Under 16s

The rules say that children under 16 may still be able to give consent for themselves, provided they are mature enough to understand fully what is involved.

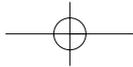


So who gives consent – your child or you?



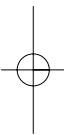
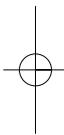
There is no hard and fast rule. A lot depends on the seriousness or difficulty of the proposed treatment. Although your child might be grown-up enough to consent to a meningitis vaccination, for instance, it might be too much to expect him or her to grasp all they need to know for consenting to a heart operation.

Even if your child is grown-up enough to give consent independently, people providing treatment will still encourage them to involve you in their decision. However, if children refuse to share information with parents, health care professionals must normally respect their wishes.



What do you and your child need to know?

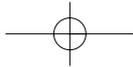
In order to make a decision, you and your child need to be provided with information about the treatment being offered. **If you feel you haven't understood or don't have enough information, you should always ask questions.** For example:

- What sort of things will the treatment involve?
 - What benefits do 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 your child doesn't have treatment?
- 
- 

If the person who is asking you to agree 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.

How much time can we take to decide?

If your child or you want more time to think about the decision, say so. In emergencies, decisions may have to be taken quickly, but at other times it will usually be possible for you and your child to take as much time as you need. It is up to the two of you to decide whether or not to go ahead.

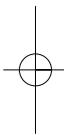
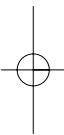


What if my child refuses treatment?

Sometimes children who are able to take their own decisions refuse treatment which their parents wish them to accept. In spite of that, health care professionals *can* legally overrule them and go ahead with the treatment if a parent has given consent.

But young people may resent treatment given to them against their will. So it's better for everyone to avoid this happening.

If your child is refusing treatment, try to find out what's worrying them before considering going against their wishes. So long as the child's condition is not life-threatening, it may be possible to delay treatment until the child is willing for it to go ahead.



Suppose I don't want my child to have treatment?

You may not want your child to have a particular treatment or intervention – contraception, for example. But if your child has the maturity to understand what's involved and asks for it, the law **does** allow health care professionals to provide treatment or care they believe is appropriate. Although they will always try to persuade children to keep parents informed, they must respect the wishes of a child who refuses to share information with you.

What if children are asked to take part in research?

This may be as part of their treatment, for example to compare two different kinds of treatment; 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 your child is asked to take part in it.

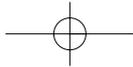
You and your child should usually be given an information sheet about the research project, and you should both ask as many questions as you want before coming to a decision, for instance about:

(for all kinds of research)

- the purpose of the research;
- any possible risks;
- how great or small the risks might be;
- any possible benefits;

(and if the research is a new or different treatment)

- what the standard treatment would be;
- any possible alternatives.

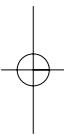


Only you and your child can decide whether any risks are worth taking for possible benefits to them or future patients.

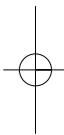
The older children are, the more you should involve them in decisions about whether to take part. If children are mature enough (see page 5), they can decide for themselves.

If you or your child decide they do not wish to take part, this ought not to affect the rest of their care. Having agreed to take part, if either of you change your mind, your child is free to withdraw at any time.

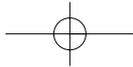
Is there any advantage or disadvantage to taking part in research?



Sometimes your child may only be able to get a certain treatment as part of a research trial. This is because it is new or experimental and cannot be made generally available until properly tested.



There is a type of research in which neither you, your child or doctor knows whether the proposed treatment is new, standard or even no treatment. (You and your child will always be told what options are being used in the research project, even though you will not know which option your child will receive.) If you or your child is not happy about being involved in this kind of trial, either of you should feel free to say no. Your child 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.



Suppose we're 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.

Would you like more help with giving 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.

Action for Sick Children

300 Kingston Road, London, SW20 8LX
Telephone: Helpline 0800 0744519; Office 020 8542 4848
Fax: 020 8542 2424
Email:
enquiries@actionforsickchildren.org
Website:
www.actionforsickchildren.org
Provides written information and a freephone advice service for parents.

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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