

**contact** a family  
for families with disabled children



# The NHS and caring for a disabled child

Information for families

England

Incorporating **The Lady Hoare Trust**

## Introduction

All families will come into contact with the NHS at some point, but if your child has a disability or health condition then you may use different parts of the NHS or have more frequent contact with health professionals. This guide is designed to 'walk you through' the different parts of the health service and explains your rights, your child's rights and what options you might have if, for whatever reason, you are unhappy with any aspect of the NHS.

The information in this guide is for families using the NHS in England only. Families in Wales, Scotland and Northern Ireland should ring the helpline for further information.

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## Introduction to the NHS

The NHS is very complex, you may find yourself in contact with a number of parts of the service. This section gives a brief description of the main parts of the NHS and agencies working alongside the NHS. You can find more information at this link to NHS Choices: [www.nhs.uk](http://www.nhs.uk)

NHS Choices is now the umbrella organisation for the NHS on the internet, including NHS Direct. You can look up NHS Choices for all the information for the NHS online.

In July 2010, the government set out its plans for the NHS in a White Paper, *Equity and Excellence: Liberating the NHS*. Under the new plans, they say patients will be given more choice and control over their healthcare, GPs will be responsible for commissioning services and Strategic Health Authorities and Primary Care Trusts will be phased out. The proposed changes are scheduled to come in no later than 2013/14 for the majority of NHS services. They depend on the outcome of the consultation and on Parliamentary approval for any new laws that are needed. We will update this guide as and when changes are announced.

### Department of Health (DH)

The Department of Health (DH) is responsible for the NHS. It controls England's 10 Strategic Health Authorities (SHAs), and they oversee all NHS activities in England which includes NHS services in local areas.



**Primary Care Trusts (PCTs)** are responsible for managing the health services in a local area such as GPs, dentists, opticians and walk in centres – the people you normally see first when you or your child have a health problem.

PCTs are now at the centre of the NHS and control 80% of the NHS budget. PCTs must make sure there are enough services for people within their area and that these services are accessible.

They must also make sure that all other health services are provided, including hospitals, dentists, opticians, mental health services, NHS walk-in centres, NHS Choices, patient transport (including accident and emergency), screening and pharmacies.

**NHS Trusts** (also known as Acute Trusts) manage hospitals. They make sure that hospitals provide high-quality healthcare and that they spend their money efficiently.

Freephone helpline: **0808 808 3555**  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

**NHS Foundation Trusts** are a fairly new type of NHS hospital run by local managers, staff and members of the public. They are tailored to the needs of the local population. Foundation trusts have much more financial and operational freedom in running their services, but they remain within the NHS and its performance inspection system.

**Care Trusts** combine NHS and social care. They deliver a range of services and are designed to provide more joined up care for people whose needs are more complex. At the moment there are only a small number of care trusts, but more will be set up in the future.

**Mental Health Trusts** provide health and social care services for people with mental health problems.

**National Institute for Health and Clinical Excellence (NICE)** provides national guidance on the promotion of good health and the prevention and treatment of ill health in England and Wales. It produces guidance on the use of new and existing medicines and treatments and on the appropriate care and treatment of people with specific conditions. You can find more information at [www.nice.org.uk](http://www.nice.org.uk)

**Special Health Authorities** provide a health service to the whole of England, not just to a local community, such as The National Blood Authority.

**Children's Trusts** bring together health, education and social services for children, young people and families. A reform of Children's Trusts has been announced.

## Getting information about your child's condition or treatment

You may want further information about your child's condition or disability. Contact a Family produces a wide range of family friendly information on specific conditions and syndromes, available online at [www.cafamily.org.uk](http://www.cafamily.org.uk) or by calling the Contact a Family freephone helpline on 0808 808 3555.

Great Ormond Street Hospital also produces jargon-free factsheets for families on a wide range of conditions, treatments and tests. These factsheets are available online at [www.gosh.nhs.uk/gosh\\_families](http://www.gosh.nhs.uk/gosh_families)

### Finding information on the internet

Many people use the internet as a source of medical information but information found there is not always reliable. Contact a Family produces a short guide, *Sources of medical information on the internet*, which aims to help families judge if a website provides relevant, quality information. You can get a free copy of this leaflet from the helpline or see [www.cafamily.org.uk/about\\_diagnosis\\_parta.pdf](http://www.cafamily.org.uk/about_diagnosis_parta.pdf)

### Unsure about treatment?

You may come into contact with many different professionals within the NHS – GPs, health visitors, audiologists, consultants, paediatricians, nutritionists, physiotherapists, and speech and language therapists to name but a few.

If you're unsure about the role of any health professional, or the purpose of

any treatment or test, ask the person who referred you. Contact a Family's leaflet 'Concerned about your child?' includes descriptions of specialist terms and roles within the NHS. Ring the helpline if you would like a copy.

## Patients' rights

The main purpose of the NHS is to provide universal healthcare services for all, based on a clinical need and not an individual's ability to pay. The rest of this guide sets out what your family's rights are when using the most common services in the NHS.

## General Practitioners (GPs)

Your GP is likely to be the first person that you will get in contact with if you have any concerns about your child. Your GP surgery can provide a wide range of services including: advice on health problems, examinations and treatment, prescriptions for medicine, referrals to other health services and vaccinations.

### How do I register my child with a GP?

Every individual living lawfully and on a settled basis in the UK has a right to be registered with a local GP surgery.

You can get a list of local GPs from your local Primary Care Trust (PCT), or the local Patient Advice Liaison Service (PALS) or NHS Direct.

You can find details of your local PCT by contacting NHS Direct on 0845 46 47, 24 hours a day or by visiting the NHS Choices website at [www.nhs.uk](http://www.nhs.uk)

If the surgery of your choice is able to add you to their patient list you will be asked to complete the registration forms. The local PCT will write to you to confirm that you are registered with the GP practice. Your medical records will be transferred to the new practice. It is useful to take your NHS number or your medical card when registering with a new GP.

Most parents prefer to register their child with their own GP or at the same practice. Each child has to be registered separately regardless of their age.

NHS numbers help staff across the NHS get up-to-date information from each other on a patient's health. Not having an NHS number does not prevent you from having NHS treatment. A baby is given an NHS number shortly after birth, usually by the hospital where they are born. Children who were born abroad and who do not have an NHS number can get one by registering with a GP.

### What if my local surgery refuses to register my child?

A surgery can refuse an application if you don't live in the surgery area or if it is not accepting new patients. If a surgery refuses to accept you or your child, it must have reasonable grounds. If you are refused registration, you must be given reasons in writing.

### Can I change my GP?

You can change your GP at any time without having to give a reason to the new surgery or to your old GP. If you are

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[www.cafamily.org.uk](http://www.cafamily.org.uk)

in a practice you may be able to see another GP at that surgery. The process of finding a new GP is similar to registering with a GP practice.

If you have a problem with your GP or surgery it is worth discussing it with your GP or the practice manager before deciding to change GPs. If you do have problems changing GP you should contact your PCT.

### Consulting your GP

If your child is ill then you should see the GP at the surgery. But if your child is too ill to visit the surgery, you can ask the GP to visit you at home. You should contact your surgery as early as possible if you want to arrange a home visit.

### What if I need to consult the GP when the surgery is closed ?

If your child needs to see a GP out of normal surgery hours, you will still need to contact the surgery. Each surgery should have an answering machine message telling you about out of hours services. You can also ring NHS Direct 0845 46 47 if you need advice about a health problem.

For minor injuries or illness you can visit an NHS walk-in centre or minor injuries unit. For more serious injuries or illnesses go to your nearest hospital with an Accident and Emergency department (A&E).

## Dentists

Dental practices can take private and NHS patients and most take both.



### How to find a dentist for your child

To find information about dentists in your area you can contact your local Primary Care Trust (PCT) which will have a dental access helpline, or call NHS Direct on 0845 46 47. You can also search online at [www.nhs.uk/dentists](http://www.nhs.uk/dentists) or text 'dentist' to 64746 from your mobile phone from the area where you need a dentist.

To get NHS dental treatment, just contact a practice providing NHS dentistry and ask for an NHS appointment. When you have been accepted for treatment by an NHS dentist you will then be a patient of that provider (a practice of one or more dentists working under contract with the PCT) for the duration of your course of

treatment. You can then choose either to use the same dentist, or to use another dentist under the same provider, or even another provider on future occasions, if you prefer.

### Urgent and out-of-hours dental treatment

If you think your child might need urgent treatment and you have a dentist, you should contact your dentist on the usual number. They will usually have an answerphone message with information about local dentist services. If you do not have a dentist your local PCT has the responsibility for out-of-hours care. You can call your Primary Care Trust's dental access helpline or call NHS Direct on Tel: 0845 46 47.

### Who is entitled to free NHS dental treatment?

NHS dental treatment is free to pregnant women and for the first year after your baby is born. You need to take your MatB1 certificate or NHS prescription maternity exemption certificate to your dentist as proof. You can request these from your GP or midwife using the FW8 (this is the form that entitles you to free prescriptions).

In England children and young people under 18 years of age and young people under 19 and in full time education do not need to pay for NHS dental treatment.

If your family is on a low income you may be entitled to help with health costs.

For further information see the section on 'NHS Charges'.

### Community Dental Services (CDS)

The CDS provides treatment for people who may not otherwise seek or receive dental care, such as disabled children, people with learning disabilities, mental health needs or other conditions which may prevent them from visiting a local dental practice.

Some CDS will accept a self referral, others will only accept a referral from your GP or a General Dental Practitioner. To find out how to access your nearest CDS contact your local PCT.

More information about NHS dentists services can be in this online leaflet *Guide to NHS dental services in England*: <http://bit.ly/bCVJV2>

### What help can I get if my child has complex needs?

New guidance has been introduced to provide a care package for children and young people under the age of 18 who require a high level of support due to their complex health needs. The health service arranges a holistic assessment which may include other services such as education and social services. If it's decided that the child or young person requires 'continuing care', then provision can be made by health, education and social services.

If you would like more information, you can download the guidance *National Framework for Children and*

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**



*Young People's Continuing Care, produced by the Department of Health at <http://tinyurl.com/yafsvbn>*

## NHS Charges

Most NHS treatment is free to the majority of people who live in the UK. But there are charges for things like prescriptions, dental treatment and eye tests. The following section explains who is exempt from paying NHS charges:

### Children and young people

Children under 16 years of age and young people in full time education age 16, 17 and 18 years of age are entitled to:

- free prescriptions
- NHS dental treatment for any course of treatment that starts before their 19th birthday
- NHS sight tests
- NHS wigs and fabric support

- vouchers towards the cost of glasses or contact lenses.

### Families on low incomes

If your family is on a low income, you may be entitled to help with health costs. Families receiving Income Support, income-related Employment and Support Allowance, income-based Jobseeker's Allowance, Pension Credit (guarantee credit) are entitled to:

- free NHS prescriptions
- NHS dental treatment
- NHS sight tests
- NHS wigs and fabric support
- vouchers towards the cost of glasses or contact lenses
- help with travel costs.

Some families in receipt of Child Tax Credit and/or Working Tax Credit can also receive the above help. For advice about

your family please contact our freephone helpline on 0808 808 3555.

### How do I claim help with travel costs for NHS treatment?

You can claim help with travel costs to and from hospital for NHS treatment when escorting your child. Usually you can get a refund of your fares directly from the hospital on the day of your visit if you show proof that you are in receipt of one of the benefits mentioned above. If you are not able to afford to pay for the travel in advance you can ask for a payment in advance.

If you want to claim a refund for travel costs or other health costs you will need to complete a HC5 claim form. Forms are available from hospitals, benefit offices, GP surgeries or from the Department of Health publications orderline, on Tel: 0300 123 1002.

If you are in receipt of Income Support, income-related Employment and Support Allowance, income-based Jobseeker's Allowance or Pension Credit (guarantee credit) you can apply for a Community Care Grant to visit someone in hospital. This is a discretionary payment from the Social Fund. You can get an application form from your local Jobcentre Plus office or online at <http://tinyurl.com/cvnfoj>

### Help with NHS costs for others on a low income

If you are on a low income but are not exempt from NHS charges, the NHS Low Income Scheme may be able to help you with some health costs. To apply you would need to complete a HC1 form and return it to your local benefit

*"When we were in the hospital we kept watching the bleeps on the monitor. The nurse came in and said don't worry about looking at the monitor so much, the child is here on the bed."*

**David**

office. You can get an HC1 form from benefit offices, hospitals, GP, dentists, opticians and other health providers. It can be ordered from the NHS Business Services Authority website [www.nhsbsa.nhs.uk](http://www.nhsbsa.nhs.uk) or by calling 0845 850 1166.

### Overseas visitors

If you don't normally live in the UK or have been living outside of the UK for more than three months you may be required to pay for any treatment you have. This is regardless of whether you are a British citizen or if you've lived or worked here in the past.

The hospital providing the treatment is responsible for deciding who is entitled to receive free hospital treatment. For further information about overseas visitors and people who have recently moved to the UK and access to healthcare ring the helpline.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**



## Consent to treatment

Before a medical practitioner can examine or treat your child, they need consent. The way consent is asked for partly depends on what the medical practitioner plans to do.

If a GP wishes to look in our child's throat they will ask your child to open their mouth. You may then need to encourage your child to do so. This is usually enough to demonstrate that they and you have given consent. For more complex health care and treatment there are some differences in the rules about consent for children, young people and adults.

### Adults

The Mental Capacity Act 2005 governs decisions you can make on behalf of adults when they lose mental capacity to make their own decisions, either at some point in their lives, or where an incapacitating condition has been present since birth.

The Act says that a person must be presumed to have mental capacity unless it is established that they lack mental capacity. This means that every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise.

The Act also outlines that a person must be given all practicable help to allow them to make their own decisions before anyone treats them as not being able to make their own decisions.

Once a person has reached the age of 18, no-one can give consent on their behalf. If they are not competent, clinicians can provide treatment and care providing this is in their best interests.

An application to the Court of Protection may be necessary for particularly difficult decisions, or situations where ongoing personal welfare decisions must be made about someone who lacks capacity. For more information about decision making for adults see this information on Directgov's website: <http://bit.ly/csxQ03>

### Young people aged 16 and 17 years

These young people are presumed to have the competence to give consent to treatment for themselves. The Department of Health recommends that it is good practice to encourage young people of this age to involve their families in decisions about their care, unless it would not be in their interests to do so.

If a young person is incapable of giving their consent, for example a young person who is severely disabled, the person with

parental responsibility will usually be able to give consent for them.

If a young person between 16 and 18 who has sufficient understanding refuses treatment, the treatment may still be given if it has been agreed by a person with parental responsibility, or the Court, and it is in the young person's best interests. It's in this way they do not have the same legal status as adults.

There is helpful information about consent to treatment on Patient UK's website: [www.patient.co.uk/doctor/Consent-to-Treatment-in-Children.htm](http://www.patient.co.uk/doctor/Consent-to-Treatment-in-Children.htm)

### Children under 16 years of age

Children under 16 years of age can give consent to medical treatment, providing they have demonstrated they have sufficient capacity to decide. This depends on their ability to understand what is involved in making the decision. There isn't a general test to assess a child's capability and each case should be assessed based on the individual circumstances.

When a child is not able to give informed consent, a person with parental responsibility can give consent for them.

### Refusing consent for a child under 16 years of age

If a parent, guardian or child refuses to give consent for treatment which a doctor thinks is necessary, the course of action a doctor will take depends on how urgently the treatment is required. The doctor may obtain a court order if a child's life is in danger.

If the child's life is not in danger, the doctor will ask the local authority for a care and protection order so the doctor can give

consent instead of the parent or guardian. The PCT can also obtain a court order. If a parent fails to provide medical help for a child, or unreasonably refuses to allow treatment, they could be prosecuted for neglect.

### Who has parental responsibility

Parental responsibility is a legal concept that consists of the rights, duties, powers, responsibilities and authority that most parents have in respect of their children.

Mothers automatically have parental responsibility for their children.

Fathers have parental responsibility if they are married to the mother when the child was born, or if they were married later.

Unmarried fathers, since 1 December 2003, have automatic parental responsibility for their children if they have jointly registered the birth of their child with the mother.

Unmarried fathers can also acquire parental responsibility by marrying the child's mother, by entering into a parental responsibility agreement with the mother, or through a parental responsibility order made by a court.

Mothers and fathers who are married but have separated or divorced will not lose their parental responsibility.

Other people with an interest in the child's upbringing such as grandparents and step parents can be granted parental responsibility by the courts.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

### Gay and lesbian couples who have children

From December 2005, the Civil Partnership Act enabled gay and lesbian couples to gain rights and responsibilities in respect of children they have. Information is available online at [www.stonewall.org.uk](http://www.stonewall.org.uk)

## Looking at your child's health records

Generally, it's presumed that a child or young person of 12 years of age or over has sufficient age and maturity to exercise their rights under the Data Protection Act 1998, the law governing how personal records about individuals should be managed.

Parents don't have an automatic right to see their child's records (except educational records). If a child or young person is capable of understanding the nature of any application to see their records, their consent must be sought before giving you access – or the request must be deemed to be in the interest of the child or young person.

As a child gets older, it's likely that evidence of the child's agreement will be required before a parent can see the records. It may be suggested that the child makes a request for the record themselves.

### When a request to see records may be refused

If the health practitioner feels a child is not capable of understanding the nature of the application and feels it is not in the patient's best interest to let the parent

access the record, the record holder is entitled to deny a parent's request to see it.

### What can I do if I am refused access to my child's health records?

If you have been refused access to your child's records, you can make a complaint to the record holder. Similarly, you can make a complaint if you have seen the records but are unhappy with the content, for example if you believe it is inaccurate or out of date. The record holder will try to resolve the complaint.

If you are still dissatisfied after making a complaint to the record holder, you can make a complaint to the Information Commissioner (see *Useful Organisations*).

### NHS Care Records Service

The NHS in England is introducing the NHS Care Records Service. This means that over time, NHS organisations will store health care records electronically. This will take place over several years.

The electronic records will be subject to the same confidentiality as paper records



are now. The amount of information health professionals will be able to see will depend on their job. Also, a patient will be able to request that certain details on their health record are not generally available to other health professionals seeing them.

Your local PCT or GP surgery will write to you when they are planning to start using the NHS Care Records Service. You will then receive an information pack and have the opportunity to decide what information you want to share.

Further information is available at the NHS Care Records Service: [www.nhsocarerecords.nhs.uk](http://www.nhsocarerecords.nhs.uk) or ring our helpline.

## Getting a referral

If you, or your child, need to see a specialist for further treatment you can now choose where and when you receive the treatment. When you and your GP agree that your child or you need to see a specialist, you will be able to choose from at least four hospitals or clinics.

From April 2009 you can choose to go to any hospital which offers suitable treatment that meets NHS standards and costs. You can choose a hospital according to what matters most to you, whether it's location, waiting times, reputation, clinical performance, visiting policies, parking facilities or patients' comments. You will also be able to choose the date and time of your appointment.

If you prefer, your GP can still make the choice for you and recommend a hospital for your treatment.

You can use 'Choose and Book' to book your first outpatient appointment. Choose and Book is an electronic booking service which allows you to choose the date and time of your appointment. It's being introduced across England. For further information, visit: [www.chooseandbook.nhs.uk](http://www.chooseandbook.nhs.uk)

NHS Choices is an online information service, which aims to increase patient choice and encourage patients to engage more with their health care. Visit NHS Choices website at [www.nhs.uk](http://www.nhs.uk)

Further information about choices following a referral can be found at the Patient UK website [www.patient.co.uk](http://www.patient.co.uk)

### Waiting times

The NHS Constitution gives you the right to access services within maximum waiting times, or for the NHS to take all reasonable steps to offer you a range of suitable alternative providers if this is not possible.

With a small number of exceptions you, or your child, have the right to start your consultant-led treatment within a maximum of 18 weeks from referral for non-urgent conditions. If this is not possible, you will be offered the choice to move to another hospital for faster treatment. More information about waiting times for consultant led services can be found at NHS Choices at [www.nhs.uk](http://www.nhs.uk)

Freephone helpline: **0808 808 3555**  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

## What do I do if I would like a second opinion?

You can ask for a second opinion (also known as a further opinion) if you're not satisfied with the advice you've received or the treatment that's been offered to you by your GP, consultant or other medical practitioner. A medical practitioner may also ask for a further opinion from colleagues when a case is unusually complex or difficult.

You have no legal right to a second opinion. But a request for a second opinion is rarely refused unless there is sufficient reason or the request is not considered necessary. You can't insist on seeing a particular expert but you shouldn't be referred to someone you don't wish to see.

The responsibility for finding a suitable medical practitioner to give a second opinion rests with the referring GP, but you can also make a request for a second opinion to the medical practitioner who provided initial advice.

You should try to discuss your reasons for wanting a second opinion with the first medical practitioner in case it's an issue that can be resolved without a second opinion.

### Waiting for a second opinion

A second opinion isn't usually considered a priority case and you may find that you have to wait some time for an appointment. It could also mean having to travel to a different hospital.

### Disagreement over treatment options

In some cases medical practitioners may

feel so strongly that a certain treatment is in the best interests of a child that they ask a court to decide.

If a young person under 18 years of age refuses treatment, a person with parental responsibility or medical staff may seek a court order to override them. In both of these situations seek specialist legal advice.

## What to do if you're unhappy about any aspect of the NHS

Unfortunately, sometimes things go wrong. If you're unhappy with any service or treatment your child has received from the NHS you can make a complaint.

Since April 2009, there is no longer an 'NHS Complaints Procedure'. Individual NHS organisations should have their own two stage complaint process. It is always useful to ask the hospital or trust that you wish to complain about for a copy of its complaints procedure which will explain how to take things forward.

### Stage 1

You can complain orally, in writing or electronically. If you make the complaint orally, then a written record of the complaint will be made and a copy will be sent to you unless it is resolved by the next working day that the complaint was made.

If you decide to complain in writing or electronically, then you should include full details of the complaint, who you are complaining about, giving details of any

people involved. You should also say what outcome you would like for example, an explanation or apology.

Your complaint must be acknowledged within three working days of you making it. You can receive this either orally or in writing.

You should make the complaint as soon as possible. Complaints should normally be made within 12 months of the date of the event that you're complaining about, or as soon as the matter first came to your attention.

The time limit can sometimes be extended (so long as it's still possible to investigate the complaint). An extension might be possible, in some situations where it would have been difficult for you to complain earlier, for example, when you were grieving or undergoing trauma.

### How your complaint should be resolved

Once your complaint has been made, your complaint should then be resolved speedily and efficiently and you should also be kept informed as far as reasonable about the progress.

You may be asked to a meeting to discuss the complaint to see if the matter can be resolved by conciliation or mediation. If you are invited to a meeting you can have someone to represent you, for example the Independent Complaints Advocacy Service (ICAS), (see Useful Organisations).

The response to your complaint must be sent to you within six months of the day on which the complaint was



received. If there is a delay beyond this time limit you should be given a written explanation and you should then receive a written response as soon as reasonably practicable.

### Stage 2 – If the complaint is not resolved

If you're not happy with the outcome of the complaint and you would like to take the matter further, then you can take the complaint to The Parliamentary and Health Service Ombudsmen. Their role is to investigate 'maladministration'. Examples of maladministration include prejudice, unreasonable delays and failure to follow procedures and rules.

For further information, visit [www.ombudsman.org.uk](http://www.ombudsman.org.uk) or contact them on their complaints helpline on 0345 015 4033, or write to them at the following address: The Parliamentary and Health Service Ombudsman Millbank Tower, Millbank, London SW1P 4QP

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

## Help with making a complaint

There are organisations that can help you with the complaints procedure:

Patient Advice and Liaison Service (PALS) provides information and advice on local NHS services for patients their families and carers. They are able to provide independent confidential assistance to resolve problems, questions and concerns.

They can support and help you use the complaints procedure and help you to resolve a complaint informally. To find your local PALS office visit their website [www.pals.nhs.uk](http://www.pals.nhs.uk). You can also contact NHS Direct on 0845 46 47 for their details.

The Independent Complaints Advocacy Service (ICAS) supports patients, their families and carers wishing to make a complaint about the NHS. It is a confidential service and is independent of the NHS. You can find contact details of your local ICAS office from PALS, from NHS Direct on 0845 46 47 or online at: [www.nhs.uk](http://www.nhs.uk)

## Judicial review

You would be able to make a claim for judicial review if you believe you have been affected by an unlawful act or decision of an NHS body. This may be appropriate, for example, if you urgently need to challenge a decision. An example of this could be where an NHS body makes a decision not to provide certain treatment. You would need specialist legal advice, and if you are on a low income you may qualify for legal aid. Please call our helpline for information about legal advice services in your area.

In many places parents are setting up forums to enable ongoing communication with service providers.

## Clinical negligence

Clinical negligence is the legal term used to describe a medical accident where a patient has been harmed because a doctor or other healthcare professional hasn't given the proper standard of care.

If your child has been a victim of a medical accident, you may want to consider possible courses of action as soon as possible. It is important to remember that taking legal action is only about getting compensation, and other things like an apology may be more important to you. Once you start a legal claim you may not be able to take another course of action.

If you are considering taking legal action, you will need specialist advice. Action against Medical Accidents (AvMA) can provide further information on possible courses of action, advise you of your rights and put you in touch with a specialist solicitor.

For more information, see their website: [www.avma.org.uk](http://www.avma.org.uk) You can contact them on their helpline 0845 123 2352 (Mon-Fri 10.00am-5.00pm) or write to them at the following address: Action against Medical Accidents (AvMA) 44 High Street, Croydon CR0 1YB.

## Getting involved in health services

It is important that families with disabled children have a voice in improving and developing local services. There is a wealth of government policy and legislation placing a requirement on health services to engage with people and involve them in decisions about how they develop and deliver services. In response, in many places parents are setting up forums to enable ongoing communication with service providers.

Contact a Family has been supporting the development of parent forums across England working with local authorities and health services to improve services. For information about this in your area please call our helpline on 0808 808 3555.

Another forum to help people influence the way that health services and social care are delivered is known as Local Involvement Networks (LINks). Individuals and community groups work together in LINks to improve local health and social care services. Any member of the local community can join a LINK.

The networks undertake a range of activities, including consulting people about what they think of local health and social care services, and suggesting improvements to the people who deliver those services. They also make suggestions about specific concerns, such as the need for more community services, and can carry out visits to see for themselves how local health and social care services are performing.

To find out what is happening in your area you can visit:



[www.nhs.uk/NHSEngland/links/yourrights/Pages/getinvolved.aspx](http://www.nhs.uk/NHSEngland/links/yourrights/Pages/getinvolved.aspx) or call our helpline.

## Useful Organisations

### Benefits Enquiry Line for people with disabilities

Tel: 0800 88 22 00 (Mon-Fri 8.30am-8.30pm & Sat 8.30am-1.30pm)  
Benefits helpline for people with disabilities, carers and representatives.

### Citizens Advice Bureau (CAB)

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)  
Free, confidential, independent advice on your rights.

### Department of Health Customer Service Centre

Tel: 020 7210 4850 (Mon-Fri 9am-5pm)  
Textphone: 020 7210 5025  
[www.dh.gov.uk](http://www.dh.gov.uk)  
Deals with enquiries on Department of Health policies.

Freephone helpline: **0808 808 3555**  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

### **Parliamentary and Health Service Ombudsman**

Tel: 0845 015 4033.

[www.ombudsman.org.uk](http://www.ombudsman.org.uk)

The Ombudsman can investigate if you're unhappy with the outcome of a complaint.

### **Independent Complaints Advocacy Service**

ICAS is the independent complaints authority and has contracted these three organisations to carry out its work:

#### **The Carers Federation**

covers the North East, North West, Yorkshire and Humberside and East Midlands

[www.carersfederation.co.uk](http://www.carersfederation.co.uk)

Information and advice for patients on any aspect of the NHS, including how to make a complaint.

**POhWER** covers the East of England, London and West Midlands  
[www.pohwer.net/](http://www.pohwer.net/)

**SEAP** covers the South East and South West of England  
[www.seap.org.uk](http://www.seap.org.uk)

#### **Patients Association**

Tel: 0845 608 4455

[www.patients-association.com](http://www.patients-association.com)

Charity that advocates for patients' rights.

#### **Information Commissioner's Office**

Helpline: 0303 123 1113.

(Mon-Fri 9am - 5pm)

[www.ico.gov.uk](http://www.ico.gov.uk)

For information, advice and complaints about data protection, privacy and freedom of information.

### **NHS Direct**

Tel: 0845 46 47 (24 hours a day)

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

24 hour helpline for medical advice staffed by NHS nurses.

### **NHS Choices**

[www.nhs.uk](http://www.nhs.uk)

Medical and health information from the NHS, including Carers Direct, the NHS service for carers.

### **Patient Advice and Liaison Service (PALS)**

[www.pals.nhs.uk](http://www.pals.nhs.uk)

Information and advice for patients plus help with complaints.

### **National Institute for Health and Clinical Excellence (NICE)**

Tel: 0845 003 7780

[www.nice.org.uk](http://www.nice.org.uk)

Responsible for guidance on medicines and treatments for the NHS.

Written by Seán Meaney

#### **Social networking**

Contact a Family is on Facebook and Twitter. Join us at:

#### **Facebook**

[www.facebook.com/contactafamily](http://www.facebook.com/contactafamily)

#### **Twitter**

[www.twitter.com/contactafamily](http://www.twitter.com/contactafamily)

#### **Podcasts**

You can download podcasts from our website at:  
[www.cafamily.org.uk/news/podcasts.html](http://www.cafamily.org.uk/news/podcasts.html)

iTunes users can listen to our podcasts at:  
[www.cafamily.org.uk/itunes](http://www.cafamily.org.uk/itunes)

#### **Videos**

You can watch videos on our YouTube channel at:  
[www.youtube.com/cafamily](http://www.youtube.com/cafamily)

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

## Getting in contact with us

Free helpline for parents and families

**0808 808 3555**

Textphone

**0808 808 3556**

Open Monday-Friday

Access to over 170 languages

**[www.cafamily.org.uk](http://www.cafamily.org.uk)**  
**[www.makingcontact.org](http://www.makingcontact.org)**

Contact a Family Head Office:

**209-211 City Road, London EC1V 1JN**

Tel **020 7608 8700**

Fax **020 7608 8701**

Email **[info@cafamily.org.uk](mailto:info@cafamily.org.uk)**

Web **[www.cafamily.org.uk](http://www.cafamily.org.uk)**



Language Line  
services

Registered Office: 209-211 City Road,  
London EC1V 1JN

Registered Charity Number: 284912

Company limited by guarantee

Registered in England and Wales No. 1633333

VAT Registration No. GB 749 3846 82

## Other information booklets available

This factsheet is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website [www.cafamily.org.uk](http://www.cafamily.org.uk)

- About Families with Disabled Children (UK)
- Transition (England and Wales)
- Fathers (UK)
- Understanding your child's Behaviour (UK)
- Living without a Diagnosis (UK)
- Grandparents (UK)
- Siblings
- Special Educational Needs (England)

Although great care has been taken in the compilation and preparation of this guide to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions.