



The NHS and caring for a disabled child - England

Information for families

England

Incorporating **The Lady Hoare Trust**

About this guide

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 find you use lots of different services provided by the NHS and 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 the NHS services you receive.

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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More information on any word in **blue** can be found in the 'How the NHS is run' section on page 21. Any word in **brown** has contact details in 'Useful organisations' on page 25.

Introduction to the NHS

Finding your way around the NHS can seem bewildering at times for families of disabled children as there can be so many different health professionals to see, and different hospitals, clinics and health centres to find your way around.

This guide gives a brief description of the different health services you might access, professionals you might meet and what to do if you are unhappy with the service being provided.

You can find more information on the **NHS Choices** website at www.nhs.uk. **NHS Choices** is the 'front door' to the NHS on the internet and provides information to help you:

- keep yourself and your family healthy
- find out about medical conditions
- find NHS services in your area
- know your rights and how to make complaints.



Getting information about your child's condition or treatment

If you want to find information about your child's condition or disability there are various places you can look.

The **NHS Choices** website provides information on a range of conditions and treatments – see www.nhs.uk.

Contact produces a wide range of information on specific conditions and syndromes, some very rare – see www.contact.org.uk or call the Contact freephone helpline on 0808 808 3555.

Great Ormond Street Hospital 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.

Medicines for Children is a partnership by the Royal College of Paediatrics and Child Health (RCPCH), Neonatal and Paediatric Pharmacists (NPPG) and WellChild. Their leaflets give practical and reliable advice about giving medicine to your child and cover many of the medicines that are prescribed or recommended to children by health professionals. See www.medicinesforchildren.org.uk.

Primary care: GPs, health

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Warning – medical information on the internet

Many people use the internet as a source of medical information but information found there is not always reliable.

Contact produces a short guide, *Sources of medical information on the internet*, which will help families judge if a website provides relevant, quality information.

You can download this by going to www.contact.org.uk and typing 'finding reliable medical information' into the search bar.

Or for a free copy, please call the Contact freephone helpline on 0808 808 3555.

visitors, dentists, opticians

Primary care is the local healthcare that we receive from General Practitioner (GP) practices, NHS walk-in centres, dentists, pharmacists and opticians. Primary health care provides the first point of contact in the healthcare system.

It is the route by which we most commonly access other parts of the NHS, for example, hospital care.

GP practices (GPs)

Your GP is often the first doctor you talk to if you have any concerns about your child. GPs usually work in GP practices as part of a team, which can include:

- nurses

- healthcare assistants
- practice managers
- receptionists, and other staff.

Your GP practice can provide a wide range of services including:

- advice on health problems
- examinations
- treatment for common ailments
- prescriptions for medicine
- health checks
- vaccinations.

They might refer your child to be seen by other health professionals if more specialist knowledge is needed.

GP practices keep a medical record for all their patients, which includes information about any medical conditions, tests and prescribed medicines. If your child is seen by other specialists, they should keep your GP informed about the results of any tests they carried out and recommended treatment.

You can find out how to register with a GP by going to the [NHS Choices](http://www.nhs.uk) website, www.nhs.uk.

What if my local GP practice refuses to register my child?

A surgery can refuse an application to register you or your child if you don't live in the surgery area or if it is not accepting new patients. If they do, they must have reasonable grounds and you must be given reasons in writing. If this happens, you can try registering with a different GP, or you can complain to [NHS England](http://www.nhs.uk).

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 in a practice you may be able to see another GP at that surgery.

If you are unhappy about the service provided by your GP practice, or disagree with the way your GP wants to treat a health problem, it is best to try to speak to them about it before deciding to change GP. If you feel uncomfortable about this you can always ask to speak to the GP practice manager instead.

Health visitors and the Healthy Child Programme

Shortly after having a baby you will receive a visit from a member of the Healthy Child team, usually a health visitor. A health visitor is a nurse who has undertaken extra training to work with families in the community. The Healthy Child team is led by a health visitor, and includes people with different skills and experience, such as nursery nurses, children's nurses and Early Years support staff. They will work closely with your GP and local Sure Start Children's Centre.

The Healthy Child Programme is delivered by this team to all children between the ages of 0 to 5. The programme includes a series of appointments where your child's development will be reviewed and they will be given vaccinations. The team can also give practical advice on day-to-day matters such as feeding, sleep and teething.

Appointments for this will be offered to you in either your GP surgery, local clinic or Children's Centre. Some reviews may



be done in your home. The reviews are also an opportunity for you to ask questions and discuss any concerns you may have.

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 look on the **NHS Choices** website. You can also search online at 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

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www.cafamily.org.uk

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 to [NHS England](#)) 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 telling you where to go.

You could also call [NHS Direct](#) on **0845 46 47**. Over the next few months the 0845 4647 service is being replaced by NHS 111.

Community Dental Services (CDS)

The Community Dental Service (CDS) provides treatment for disabled people including those 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 GP or local dentist. More information about NHS dentist services can be found by going to the [NHS Choices](#) website at www.nhs.uk



and selecting 'Dental services'.

The [National Autistic Society](#) has useful information about dental care and preparing your child for an appointment.

Opticians (also known as optometrists)

When you visit an optician, you'll have your sight tested by an ophthalmic practitioner, who will check the quality of your vision and eye health. They can also prescribe and fit glasses and contact lenses. They are trained to recognise abnormalities and signs of any eye disease and if necessary they will refer you on a specialist doctor or eye surgeon for further advice and treatment.

All children's sight tests are free under

the National Health Service. More information about NHS optician services can be found by going to the **NHS Choices** website at www.nhs.uk and selecting 'Eye care services'.

Children can consider their own visual experience to be 'normal', so might not complain about visual symptoms such as blurred vision or eye strain. It may not be possible for a disabled child to express that something is wrong with their vision due to language difficulties, so it's important they have regular eye tests.

Instead of going to an optician your child might be able to have their eyes tested at the local eye hospital, depending on their needs and the services in your local area. Talk to your optometrist, optician, GP or paediatrician who can advise you about the most appropriate arrangement for an eye test.

The **National Autistic Society** has useful information about eye care and preparing your child for an appointment.

Secondary care: hospital, community and CAMHS services

Your child might be referred to see health professionals or services who have more specialist knowledge. These are often referred to as a secondary care, as you are usually (but not always), referred to the service having first been seen by another professional such as a GP, doctor or nurse.

These services might be provided in

your local hospital or elsewhere in the community, such as a health centre, children's centre, school or in your home.

If your child is referred to see someone and you are not sure what their role is, do ask the person making the referral – or the specialist when you first meet them.

Here is a list of services often accessed by disabled children.

Child and Adolescent Mental Health services (CAMHS)

The Child and Adolescent Mental Health Service (CAMHS) specialises in supporting the psychological and emotional needs of children and young people.

Child development team/centre

Child development teams are led by paediatricians working closely with physiotherapists, occupational therapists and speech and language therapists. They assess and review a child's needs and devise treatment programmes to encourage and support their development. They might also require input from psychologists, either as part of the team or from the Child and Adolescent Mental Health Service (CAMHS).

Community nursing

Community children's nurses support disabled children at home and within community settings. This includes those who are technology dependant, such as children who need tube feeding and gastrostomy care. They also play an

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important role in making sure a child's health needs are supported safely in nursery or school.

Continence service

The local continence services can see children if there are problems with toilet training. Children can usually be provided with free continence equipment once they reach a certain age – usually around four years old. In some areas health visitors, community nurses and/or learning disability nurses can also prescribe continence equipment and give parents advice on toilet training.

Dietician

A dietician can advise on food, diet and nutrition if a child is reluctant to eat certain foods, or needs to be on a special diet, or has difficulties chewing and/or swallowing.

Educational psychologists

Educational psychologists assess a child's learning and provide advice to parents and education staff on appropriate interventions to support learning and improve behaviour.

Learning disability team

Learning disability teams work with children and adults who have a learning disability and their families.

Occupational therapy

An occupational therapist pays particular attention to hand-eye coordination, perception and manipulative skills. They can advise and provide suitable aids to help with everyday activities such as feeding, dressing, toileting, bathing and play for younger children, plus writing skills for older children.

Paediatrician

A paediatrician is a doctor who specialises in looking after babies, children and young people. A paediatrician can coordinate and liaise with other agencies involved in the management, care and education of the child and family.

Physiotherapy

A physiotherapist helps in the management and development of movement skills. There are a number of ways in which children can be helped. These may include exercises to strengthen weak muscles and games to improve coordination and motor skills.

Speech and language therapy

Speech and language therapists can work with parents to develop communication skills. If a child cannot talk they can help them explore other ways to communicate such as Makaton signing (a language programme that uses signs and symbols to help people communicate). They can also provide help where there are physical issues with eating, drinking and safe swallowing.

Wheelchair and equipment

Wheelchair and equipment services support the child in home and at school. Wheelchairs for children will need regular reviewing to monitor the child's growth and make sure it is providing good postural support.

Continuing care – for children with complex needs

NHS continuing care is support provided for children and young people under 18 who need a tailored package of care due to their complex health needs. Professionals working with a child or young person should offer them an assessment if it seems they could have continuing care needs. If you think your child should be assessed for NHS continuing care, talk to a health or social care professional who works with them.

They can arrange a holistic assessment which may include other services such as education and social services.

The assessment process is led by a nominated children and young people's health assessor and reports may be obtained from services already involved with your child.

The assessment considers what daily support a child might need with:

- behaviour that challenges
- communication
- mobility
- nutrition, food and drink
- continence and elimination
- skin and tissue viability
- breathing
- drug therapies and medicines

- psychological and emotional issues
- seizures.

You should get a decision about your child's eligibility within 28 working days of them being referred.

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, please see the NHS Choices website www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/continuing-care-children.aspx.



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Top tips from parents

Health appointments

If your child finds it difficult to wait, is anxious about going to new places or meeting new people, then taking them to visit the doctor or hospital can be extremely stressful for yourself and your child.

Here are some tips which other parents have found useful in this situation:

- try and get appointment times at the start of clinics when there is likely to be less of a wait
- if your child does not like to be in crowds of people, explain the problem to the receptionist and ask if there is a quieter room where they can wait
- write on a postcard what might be difficult for your child and give it to the receptionist, so you do not have to say it out loud for others to hear
- ask the receptionist to let you know if there is going to be a long wait, so you can take your child for a walk and come back later
- ask if you can wait in the car outside and be called on your mobile when the doctor is nearly ready to see you
- if possible, try to get appointments with the same doctor/health professional on subsequent visits, so they get to know your child's additional needs and you do not have to keep repeating your story
- before they examine your child explain to the doctor what might stress your child or trigger behaviour

that challenges, and suggest strategies that might help.

Hospital admission

If you know your child is to be admitted to hospital telephone the hospital to let them know your child has additional needs. Ask for a pre-admission meeting with a senior nurse on the ward where your child will stay to discuss your child's additional support needs. If your child has a learning disability ask if the hospital has a learning disability nurse and try to speak to them as well. They can be very helpful in liaising with hospital staff to make sure the stay is less stressful for your child.

Write down all the things that your child might find particularly stressful and how they are likely to respond. Take this with you. It is also useful to take this with you if your child has to go to hospital in an emergency.

Some hospitals have their own hospital 'passports' which can be used to communicate your child's needs to hospital staff.

"I wait in the car until the doctor is ready to see me – the receptionist rings me and we walk straight in."

Personal health budgets

From April 2014, anyone receiving NHS continuing healthcare will have a right to ask for a personal health budget. This can be used to pay for a wide range of items and services, including therapies, personal care and equipment. This will allow you more choice and control over the health services and care your child receives.

From September 2014, after the Children and Families bill becomes law, some children with SEN will be eligible for a single assessment plan to support their needs for health, education and social care. If eligible, the personal health budget element will be combined with their personal budget for social care and/or education.

For more information see www.personalhealthbudgets.england.nhs.uk/

Tertiary care: highly specialised services

If your child has a very complex or very rare condition they might be referred onto what are called specialised services.

These are usually provided at large hospitals called regional 'centres of excellence' such as Great Ormond Street, Alder Hey, and Bristol Children's hospital.

Children have to be seen in these centres for certain conditions and treatments, for example cystic fibrosis, congenital heart disorders, complex neurological disorders, metabolic disorders, and some rare conditions.

A full list of specialised services can be found in 'The Manual' on the [NHS England](http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf) website at www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf. As specialised services are only provided in a few centres, it can involve families having to travel long distances to access them.

Your child might receive all their treatment at the regional hospital or arrangements might be put in place so your local hospital provides some of the care with advice from the specialised centre. This is sometimes called 'shared care'. Attending the local hospital for routine check ups and treatments can be much less disruptive to family life than having to always travel to the tertiary centre.

In some areas, teams from the specialised service come out and run clinics at the local hospital, so families do not have to travel so far. This is not always possible as it will depend on the number of children in the area accessing the service as well as equipment needed.

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. This part of the guide sets out what your family's rights are when using the NHS, and what to do if you are unhappy with the service you receive.

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Getting help with health costs

Although treatment on the NHS is free at the point of delivery, there may still be some costs (for example medicine, spectacles, your journey to hospital).

Children under the age of 16 and in full-time education up to the age of 19, pregnant women and women within one year of giving birth are entitled to free prescriptions for medicine, free dental treatment and eye check-ups.

If you have a low income, you may be able to get help with NHS costs through the NHS Low Income Scheme (LIS). The scheme covers:

- prescription costs
- dental costs
- eye care costs
- healthcare travel costs
- wigs and fabric supports.

For more information about this visit the [NHS Choices](#) website or telephone our helpline.

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

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.

The Mental Capacity Act 2005 governs decisions made on behalf of adults when they do not have mental capacity. The Act says that a person must be presumed to have mental capacity unless it is established that they lack mental capacity. The Act also says that a person 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.

This means people may lack capacity to make some decisions for themselves, but will have capacity to make other decisions. For example, they may have capacity to make small decisions about everyday issues such as what to wear or what to eat, but lack capacity to make informed decisions around consent about major life-changing events, such as undergoing a major surgical operation.

When a person is not able to make all their own decisions, the Act makes it possible for others to act in the person's best interests for many everyday decisions. This will include family members and carers making decisions about what happens in the family home, doctors making medical decisions and

care workers making decisions about care offered by a care service.

Where doctors act as decision maker, you must be consulted in any best-interests decision taken for your child. You should also let them know your child's view as far as you are able.

If there is disagreement, and you are not happy about a best-interests decision taken for your child, there are several options:

- involve an advocate to act on behalf of your child to make the decision
- get a second opinion
- hold a formal or informal 'best interests' case conference
- attempt some form of mediation
- pursue a complaint through the organisation's formal procedures.

If this fails, an application to the Court of Protection can be sought for particularly difficult decisions, or situations where there is serious disagreement between family members and services.

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.

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.

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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. If a parent fails to allow treatment, they could be prosecuted for neglect.

Who has parental responsibility

Parental responsibility includes the right to consent to medical treatment on behalf of a child and the disclosure

of information held by healthcare professionals about a child.

For children in England, whose births were registered from 1 December 2003, parental responsibility rests with both parents, provided they are named on the birth certificate, regardless of whether they are married or not.

For children whose births are registered prior to these dates, the father would only automatically have parental responsibility if he was married to the mother. Otherwise, he could acquire parental responsibility through a Parental Responsibility Agreement with the mother or a Parental Responsibility Order through the courts. A married step parent or civil partner may also obtain parental responsibility in this way.

You can read more about this at www.gov.uk/parental-rights-responsibilities.

If parents are divorced, both parents retain parental responsibility for the child. If the child is the subject of a Care Order, the local authority has parental responsibility which is shared with the parents. If the parent asks for the child to be taken into care, parental responsibility remains with the parents.

Further information

Mencap Mental Capacity Act: resource pack, from:

www.mencap.org.uk

Type 'Mental Capacity Act resource pack' into the search bar.

The Mental Capacity Act 2005

Code of Practice provides guidance to anyone who is working with and/or caring for adults who may lack capacity to make particular decisions: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act.

Patient UK – Consent to Treatment in Children (Mental Capacity and Mental Health Legislation)

www.patient.co.uk/doctor/consent-to-treatment-in-children-mental-capacity-and-mental-health-legislation.

Gay and lesbian couples who have children

Since December 2005, the Civil Partnership Act has 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.

Looking at your child's health records

Parents do not have an automatic right to see their child's medical records. Young people with capacity do have the legal right to access their own medical records. If a child is capable of understanding the nature of a request to see their records, their consent must be sought before giving their parents access. As a child gets older, it is more likely that evidence of their agreement will be required.

Parents would normally be allowed to see their children's records if their child lacks capacity, and it is not against the child's interest for the parents to be given the information. If the medical record contains information given by a child or young person in confidence, it will not be disclosed to their parents, unless the child or young person consents.

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](#) on page 25).

NHS Summary Care Records

The NHS in England is introducing NHS Summary Care Records, which is an electronic record which contains information about the medicines you take, allergies you suffer from and any bad reactions to medicines you have had.

Having this information stored in one place makes it easier for healthcare staff to treat you in an emergency, or when your GP practice is closed.

Almost half of the population of England now have a Summary Care Record. When Summary Care Records are coming to

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your area you will receive an information pack. This pack will explain the changes to your records and help you choose whether you would like a Summary Care Record or not, before one is made for you. Further information is available at the NHS Care Records Service at www.nhs.uk/carerecords or call our freephone helpline.

Getting a referral

Most patients now have the right to choose which hospital provider they are referred to by their GP. This legal right, which was introduced in April 2009, lets patients choose from any hospital provider in England offering a suitable treatment that meets NHS standards and costs.

A choice of hospital is available for most patients and in most circumstances. Exceptions include emergency and urgent services, cancer, maternity and mental health services. If you need to be seen urgently by a specialist (for example, if you have severe chest pain), your GP will send you where you'll be seen most quickly.

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. For further information, visit www.chooseandbook.nhs.uk.

NHS Choices provides more information on patients' choices of hospital. See www.nhs.uk/choiceinthenhs/yourchoices/hospitalchoice/pages/choosingahospital.aspx.

Further information about choices following a referral can be found at the Patient UK website 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.

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 a long 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 are unhappy

If you are unhappy with the way the service is run or the care provided, you might not want to make a complaint but do try and let the organisation know what you are unhappy about.

Hospitals and other service providers are expected to gather feedback of patients' experiences to help monitor how well their service is provided, and identify areas that need improving.

This provides a way for you to give feedback – both good and bad – about the services received – without going through a formal complaints process.

Giving this feedback helps the organisation understand what went wrong so they can prevent the same thing happening to someone else.

Since April 2013, patients have been asked whether they would recommend hospital wards and A&E departments to their friends and family if they needed similar care or treatment. This means every patient on these wards will be able to give feedback on the quality of the care they receive.

You can also rate and comment on a service through **NHS Choices** and the **Care Quality Commission** website at www.cqc.org.uk.

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www.cafamily.org.uk



Patient Advice and Liaison Services

The Patient Advice and Liaison Service (PALS) is a confidential service provided by NHS organisations including hospitals, mental health services, community services and clinical commissioning groups.

They can help if you:

- don't know what's happening
- want information but don't know where to get it
- want to resolve a situation but don't want to complain
- want to complain but not sure how
- want to speak to someone but not sure who.

You can find their contact details on **NHS Choices** at www.nhs.uk.

Making a complaint

If you are not able to resolve matters through discussion, you have the right to complain. Every NHS organisation has a complaints procedure. To find out about it, ask a member of staff, look on the hospital or trust's website, or contact the complaints department for more information.

You can complain to the organisation who provided the service you are unhappy with.

Alternatively you can complain to the organisation responsible for commissioning – or purchasing – that service:

NHS England commission all primary care services such as GPs, dentists, opticians. They also commission tertiary care – very specialised services usually provided at regional hospitals or centres.

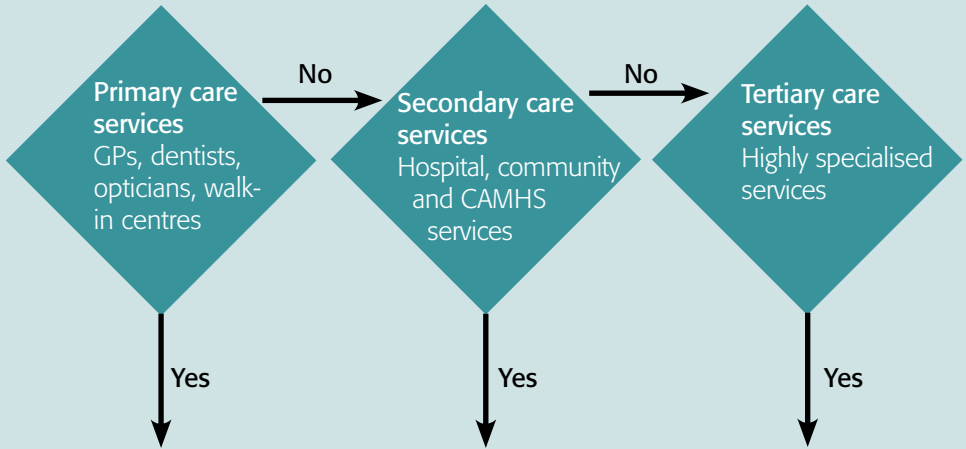
Clinical Commissioning Groups commission all secondary services, such as local hospital and community services.

This first stage of the process is called local resolution, and most cases are resolved at this stage.

Your local **Healthwatch** can provide information about the complaints process and help you access an independent advocacy service to support you through the complaints process.

Advocacy services can simply provide information to help people understand the complaints process and manage their own complaint, or provide more in depth support such as supporting you to write letters or attend a meeting.

Who to talk to if you want to complain



Ask for a copy of their complaints procedure, which will explain how to proceed.

If you are not happy with their response contact [NHS England](#).

[NHS England](#)

Tel: 0300 311 2233 or email: england.contactus:@nhs.net.

Ask for a copy of the organisation's complaints procedure which will explain how to proceed.

The local [Patient Advice and Liaison service](#) (PALS) might be able to assist.

If you are not happy with their response you can contact your local clinical commissioning group.

Contact details for clinical commissioning groups can be found on the Contact website at www.contact.org.uk.

organisation's complaints procedure which will explain how to proceed.

If you are unhappy with their response contact [NHS England](#).

[NHS England](#)

Tel: 0300 311 2233 or email: england.contactus:@nhs.net.

Ask for a copy of the [Freephone helpline: 0808 808 3555](#)
www.cafamily.org.uk



How your complaint should be resolved

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

Once your complaint has been made, it should then be resolved speedily and efficiently and you should also be kept informed as far as is 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 someone from an independent advocacy service.

The response to your complaint must be sent to you within 6 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.

Serious complaints: further courses of action

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.

Judicial review

You might be able to make a claim for judicial review if you believe you have been affected by an unlawful act or if you urgently need to challenge a decision. An example of this could be decisions over the treatment of your child which you do not think are in their best interest. You can call our freephone helpline for information about legal advice services in your area.

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. See www.avma.org.uk.

The Care Quality Commission

welcomes feedback from people about their experience of health and social care services. Although they cannot respond to individual complaints they will make use of this information when carrying out inspections to make sure services are meeting standards. See www.cqc.org.uk or call 03000 616161.

How the NHS is run

This section provides a brief overview of how the NHS works in England. More detailed information on this topic can be found on the **NHS Choices** website at www.nhs.uk.

The NHS Constitution

This establishes the principles and values of the NHS in England. It sets out rights to which patients, public and staff are entitled, and pledges which the NHS is committed to achieve. It also sets out the responsibilities which the public, patients and staff owe to one another to ensure that the NHS operates fairly and

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

effectively. See www.gov.uk and search for 'The NHS Constitution for England'.

Guide to the Healthcare System in England

This guide explains organisations in the healthcare system and how they work together and includes the Statement of NHS Accountability. The guide will be updated annually. See www.gov.uk and search for 'Guide to the healthcare system in England'.

Department of Health (DH)

The Department of Health (DH) is the government department responsible for developing government policy relating to health. This includes public health, the NHS and social care.

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. See www.nice.org.uk.

Commissioning NHS services

NHS commissioners pay other organisations to provide NHS services to patients to agreed standards such as those set by the Department of Health and the National Institute for Health and Clinical Excellence.



NHS England

NHS England is responsible for commissioning some NHS services including:

- primary care services, including GPs, pharmaceutical services, dental services, ophthalmic services (for example) NHS sight tests and optical vouchers
- some services for members of the armed forces and their families
- services for prisoners or people in custodial settings
- some specialised services needed by people with very complex conditions, or required by only a small number of patients. These services are usually provided in a few hospitals and can require highly specialist skills and equipment.

NHS England has 27 area teams responsible for commissioning primary care services across England. Ten of these are also responsible for commissioning highly specialised services. See www.england.nhs.uk.

NHS England also has a role to improve health outcomes for people in England by:

- providing national leadership for improving the quality of care
- overseeing the operation of clinical commissioning groups.

Clinical commissioning groups (CCGs)

Clinical commissioning groups (CCGs) are responsible for purchasing all local health services, except for primary care services commissioned by NHS England. CCGs are formed from a group of GP

practices in a particular geographical area. Some local authorities have one CCG for their whole area. County councils or large cities are more likely to have more than one CCG.

Contact details of clinical commissioning groups can be found on the Contact website – or call the Contact freephone helpline.

Both NHS England and CCGs have a duty to involve their patients, carers and the public in decisions about the services they commission.

Providers of NHS services

NHS providers are paid by NHS commissioners to provide NHS services to agreed standards such as those set by National Institute for Health and Clinical Excellence (NICE).

NHS services are often but not always provided by NHS trusts. They are sometimes provided by private healthcare organisations, community groups or charities.

NHS trusts

There are a wide range of NHS health trusts managing NHS care in England, including hospital, community and mental health services.

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk



Getting involved in improving 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. Across England parents have been setting up forums to work with local authorities and health services to improve services.

Most NHS trusts have achieved foundation trust status and all NHS trusts are expected to become foundation trusts by 2014. Foundation trusts have much more financial and operational freedom in running their services, but they remain within the NHS and its performance inspection system.

Contact has been supporting the development of these parent forums across England. For information about forums in your area please call our helpline on 0808 808 3555 or visit our website:
www.contact.org.uk/parentcarerparticipation.

NHS trusts include:

- **acute trusts** – manage hospitals and can provide services in the community, for example through health centres, clinics or in people's homes. Some also provide specialised services at regional or national centres for more specialised care
- **mental health trusts** provide health and social care services for people with mental health problems
- **ambulance trusts** – there are 12 ambulance services in England, providing emergency access to healthcare. The NHS is also responsible for providing transport to get many patients to hospital for treatment. In many areas, it is the ambulance trust that provides this service.

Patient Advice and Liaison Services (PALS)

As well as helping patients and carers resolve concerns as quickly and as stress-free as possible, PALS also helps the NHS to improve services by listening to what matters to patients and suggesting changes.

All NHS trusts and clinical commissioning groups offer a PALS service. You can find their contact details on the **NHS Choices** website.

Healthwatch

Healthwatch gathers and represents the public's views on health and social care services. Healthwatch England works at the

national level and is helping set up local Healthwatch organisations. Their aim is to take local experiences of care and use them to influence national policy.

Local Healthwatch began to work on 1 April 2013. There is a local Healthwatch organisation in every local authority area in England. To find yours see www.healthwatch.co.uk. They:

- have the power to visit and view services
- influence how services are set up and commissioned by having a seat on the local health and wellbeing board
- produce reports which influence the way services are designed and delivered
- provide information, advice and support about local services
- pass information and recommendations to Healthwatch England and the Care Quality Commission.

Care Quality Commission

The Care Quality Commission (CQC) monitors and inspects hospitals, care homes and care services to check that they are meeting national standards. You can read their inspection reports on their website. If you have experienced poor care, or know that poor care is being



provided somewhere you can report it to them, anonymously if you wish. You can also tell them when you feel you have received good care. See www.cqc.org.uk.

NHS Choices

You can comment on almost any NHS service, including hospitals, GP practices and dentists, and rate them on the **NHS Choices** website. They welcome feedback from friends, family members as well as patients.

Useful organisations

Action against Medical Accidents (AvMA)

Free, confidential advice and support to people affected by medical accidents. Can refer to their panel of specialist clinical negligence solicitors or other sources of support if appropriate. Write to them at: Action against Medical Accidents 44 High Street, Croydon Surrey CR0 1YB or call 0845 123 23 52, or see www.avma.org.uk.

Care Quality Commission

Checks whether hospitals, care homes and care services are meeting national standards. See www.cqc.org.uk.

Healthwatch

Local Healthwatch organisations provide information about services in your area and support people through the complaints process. See www.healthwatch.co.uk.

Information Commissioner's Office

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk



Upholds information rights, promotes openness by public bodies and data privacy for individuals.
Helpline: 0303 123 1113
www.ico.org.uk

National Autistic Society

Has useful information on how to make visits to doctors, dentists and opticians easier for people on the autistic spectrum. See www.autism.org.uk.

NHS Choices

Provides medical and health information, and information about local NHS services. Patients and carers can feed back their experience of services on their website www.nhs.uk.

NHS Direct

24 hour helpline for medical advice (being replaced by NHS 111 over the next year)
Tel: 0845 46 47 (24 hours a day)
www.nhsdirect.nhs.uk

NHS 111 – if operating in your area

Call the NHS 111 service if you need medical help fast, but it's not a 999 emergency. To check if it is operating in your area see www.nhsdirect.nhs.uk/en/About/WhatIsNHSDirect/0845areas.

NHS England

Contact if unhappy with primary care (GP, dentists, opticians, pharmacists; or tertiary services commissioned by NHS England, on 0300 311 2233 or email nhscommissioningboard@hscic.gov.uk.

Parliamentary and Health Service Ombudsman

The Ombudsman can investigate if you're unhappy with the outcome of a complaint.
Tel: 0845 015 4033.
www.ombudsman.org.uk

Patients Association

The helpline answers concerns from patients and relatives about any aspect of the healthcare system.
Tel: 0845 608 4455
www.patients-association.com

Written by Sheila Davies

Social networking

Contact is on Facebook and Twitter. Join us at:

Facebook

www.facebook.com/contactafamily

Twitter

www.twitter.com/contactafamily

Podcasts

iTunes users can listen to our podcasts at:

www.contact.org.uk/itunes

Videos

You can watch videos on our YouTube channel at:

www.youtube.com/contact

Support Contact

Help us continue to provide information, advice and support to ALL families with disabled children in the UK.

From cake sales, to running the London Marathon, or signing up to be a regular giver – there are many ways you can help.

Find out more on our website at www.contact.org.uk/fundraising
Call our fundraising team on 020 7608 8786, or email fundraising@contact.org.uk.

Or why not get involved in our campaign work across the UK? Visit www.contact.org.uk/influencing.

Your support will ensure we're here for families now and in the future.

Freephone helpline: **0808 808 3555**
www.contact.org.uk

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Open Mon–Fri, 9.30am–5pm

Access to over 170 languages

www.contact.org.uk

Contact Head Office:

209–211 City Road, London EC1V 1JN

Tel: **020 7608 8700**

Fax: **020 7608 8701**

Email: **info@contact.org.uk**

Web: **www.contact.org.uk**



Language Line
services

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children including:

- *Fathers* (UK)
- *Understanding your child's behaviour* (UK)
- *Grandparents* (UK)
- *Siblings* (UK)
- *Aids, equipment and adaptations*
- *The tax credits guide* (UK)
- *A guide to claiming Disability Living Allowance for children*

All our guides can be downloaded from our website www.contact.org.uk. Parent carers can call our freephone helpline and ask for a copy of any of our guides.

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London EC1V 1JN
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