



## **Expert Parent Frequently Asked Questions**

### **1. What do I need to do to access the health service for my child?**

Every British resident has the right to access health care but there are some things you should do to make sure you can access the right service at the right time.

You need to register with a GP to be able to access a wide range of health services, when your child is born you will be given your baby's NHS number and a "pink card" or FP58 form that is used to register your baby with a GP. If you are not registered with a GP and don't have a "pink card" or NHS number for your child then you can still register and all the information about finding your local GP is available on NHS Choices.

<http://www.nhs.uk/chq/Pages/1095.aspx?CategoryID=68&SubCategoryID=158>

GP's cannot refuse to register you or your child unless they have reasonable grounds to do so. Reasonable ground may be that you live outside the Practice's catchment area or the practice is not accepting any new patients. If you cannot register with a GP for this reason you can register with a different GP in your area. If you still cannot do this you need to contact your local Clinical Commissioning Group who will register you with an available GP in your area. You can find your Clinical Commissioning Group using the NHS Choices website.

<http://www.nhs.uk/Service-Search/Clinical-Commissioning-Group/LocationSearch/1>

In addition to seeing your GP there are other ways for your child to access health services, you may be able to attend a children's health centre/clinic in your local area for simple health services and support, and if you have a health emergency you can attend the nearest Accident and Emergency (A&E).

However if your child is ill or you have a serious concern but it is not an emergency you should take them to your GP.

## **2. How do I get my child to see a specialist?**

If your child has a more serious health problem or impairment than your GP or local children's health centre/clinic may not be able to provide the right treatment by themselves. In this case your child may need to see some of the many different types of health professionals that work in the NHS. These more specialist health professionals work in what is called secondary or tertiary care.

To see a specialist who works in secondary or tertiary care you need to get a referral from a health professional who works in primary care, this will normally be a GP but can be a different professional, e.g. your child's care is coordinated by a paediatrician they will be making referrals to other specialists.

If you think your child needs to see a specialist make an appointment with your child's GP and discuss your concerns and ask for a referral to an appropriate health professional. The GP will discuss your options with you and make a decision about what further action is appropriate, including which services to refer your child on to.

Use the Expert Parent Guide to working with your GP to help you prepare for this.

## **3. I have not been able to get a referral to see the specialist?**

In most cases if you think your child needs a referral to a specialist then seeing a GP will mean your child is referred to a specialist, either for treatment or diagnosis.

However, sometimes this might not happen, the GP may not agree that your child needs a referral to a specialist and may suggest another course of action. If this happens it is important you talk with your GP about their opinion and explore what options are available and which is best for your child. Have evidence about why you are concerned about your child's health and why you believe a referral is necessary, and if the GP's course of action does not address this ask for a subsequent appointment.

If you are still not happy and believe that your child is not getting the appropriate treatment then there are things you can do. You have a right to ask to see a different GP at the surgery who may agree that a different course of action is needed, or you even change GP practice altogether and register somewhere else.

If you are unable to get a referral from any GP in your area and are not satisfied with the explanations given by your GP then you can think about whether you have ground to make a complaint to the NHS.

The Expert Parent Programme has tips about how you can get the best out of your appointments with health professionals and how to get the outcomes you want for your child.

## **4. I am not happy with the result of seeing a specialist, what can I do?**

In most cases seeing a specialist will result in a course of action that you, the specialist and when appropriate, your child agree with. It is important you understand what the specialist has said and you are involved in the decision making process.

If this has not happened and you are not happy with the decision of the specialist and do not think you're child is getting the right care then there are things you can do.

You can go back to the professional who referred you to the specialist, in most cases this will be your GP, but it maybe someone else, and discuss the outcome of your appointment with the specialist. Explain clearly why you do not think the outcome of the specialist appointment is right for you and try and agree what options are available going forward and whether you can be referred to a different specialist.

The Expert Parent Programme has tips about how you can get the best out of your appointments with health professionals and how to get the outcomes you want for your child.

## **6. How do we get access to services related to education?**

For most of your child's health needs the NHS will be responsible for meeting them, as set out above. However there are some circumstances where it may not solely be the responsibility of NHS to meet these need but instead are determined by local arrangements between the health service, the council and schools. This is normally the case when the service is not purely a health service but is also related to your child's education.

Speech and Language Therapy is an example of this type of service, where responsibility for providing it is determined by different areas between the health service, schools and the local authority. This means arrangements for accessing Speech and Language Therapy will be different in different areas according to how these local arrangements determine who is responsible for providing elements of the service. Education related services such as Speech and Language Therapy may be access by:

- Self referring you child to a primary care speech and language service: In most cases you should be able to access a SaLT service without requiring a GP referral, although your GP should be able to help you identify the right service. The details of this provision and how it can be accessed should be on your local Clinical Commissioning Group
- SaLT services can be provided by the local authority through a school based assessment that identifies that your child has additional communication needs.
- Long term SaLT services may be obtained when it is included in a statement of Special Educational Needs

These local arrangements mean you need to find out what the policy is in your local area, but the health service still to meet your child's clinical needs and these arrangements should not prevent your child from accessing the support they need.

There is specialist information about Speech and Language Therapy in the resources section of the Expert Parent Website

#### **4. My child has a complex long term health condition, how will his care be organised?**

For many children with serious or complex long term health conditions, that has been diagnosed, or is in the process of being diagnosed, their medical care will be organised by a paediatrician, a doctor that specialised in children's health or a consultant paediatrician that is an expert in a specific area of children's health. This care will probably be based in a local or regional hospital, although some element may take place in a community setting or in the home.

This lead health professional will be responsible for coordinating your child's health care, liaising with other specialist health professionals and deciding on the appropriate treatment. They should involve you and your child in this process, make sure you understand all the options available, provide information about other sources of support and advice and listen to your thoughts and wishes when discussing available options.

Even if a secondary specialist is responsible for coordinating your child's health care you should still register them with a GP surgery and build a relationship with their GP. The GP can provide more accessible, local health services for less serious health issues so you can avoid unnecessary trips to hospitals to see a paediatrician, and they should be able to help you understand what other services are available in your local area that you paediatrician may not be aware of.

GPs will also play an important role in your child's transition from the children's to the adult health system, and building a relationship can help make this a smoother process.

#### **5. Funding, where does the money come from for my child's treatment?**

It is set out in law that the NHS is paid for through general taxation and is free at the point of delivery. This includes NHS services delivered by private companies and charities.

The way money is allocated and spent in the NHS is a complicated process called commissioning, where professionals called commissioners decide what services are needed, how they should be organised and how they should be paid for. Where the money comes from will depend on the type of treatment your child receives.

The Department of Health is given the money by Parliament to run the NHS, in 2012/13 this was around £108.9 billion. The Department of Health then delegates most of this money to NHS England, the body responsible for the day to day running of the NHS in England. NHS England then gives £65 billion to Clinical Commissioning Groups who spend it on the health care services that are needed by their local population.

NHS England is responsible for commissioning some highly specialized services itself, so if your child needs specialized health services, normally delivered in a specialist centre like a large regional hospital, this will be paid for directly by NHS England.

Very rarely there may be a situation where there is a dispute over whether the NHS in your areas will pay for a certain treatment. This will normally be the result of one of these reasons;

- The specialist treatment is not approved to be bought by health service commissioners by senior decision makers in the Health Service and National Institute for Clinical Excellence.
- The specialist treatment is not available in your local area because the health commissioning organisation chooses to buy a different service or product to meet your child's needs.
- There is a disagreement between the health service and the local authority about who is responsible for a certain aspect of a care package

In some circumstances the NHS may have a policy that does not correspond to the law, such as when an area has a blanket policy on not providing a certain treatment without taking individual circumstances into account, or it is not providing a treatment that has been approved by a NICE Technical Appraisal.

In these situations the legality of what the NHS is doing will depend on the specific circumstances of each individual case and you should get in contact with an organisation that can provide help and support in specific cases. There is more information in the Expert Parent Guide to Rights.

## **7. What is NHS Continuing Care for Children?**

If your child has long term complex health needs they may be eligible for a children's continuing care assessment. In this process their needs will be assessed against 10 areas by a team led by health professionals from the local Clinical Commissioning Group, but it may include other professionals from the local authority and education services.

If the professionals decide your child's meets the necessary threshold in their assessment then the CCG and local authority will work together to put a package of funded care in place to meet your child's needs. Government guidance recommends that wherever possible, NHS continuing care for a child or young person should be provided in their own home but it can also take place in schools or medical settings like hospitals.

If you are not happy with the decision of the Continuing Care Assessment, or are unhappy with the support put in place then you can use the local NHS Complaints procedure (see below)

## **8. What are my legal rights?**

Patients, parents of patients and members of the public all have legal rights in relation to the Health Service. These rights come from a number of different sources including specific laws that set out what the NHS must do, Equalities and Human Rights legislation that prevents the NHS unfairly discriminating against patients and the public, including disabled children, International Treaties that set out the commitments the UK Government has a responsibility to meet and other laws relating to how public bodies must behave.

The NHS Constitution is a document that brings these rights together in one place, it does not create the rights but sets out what rights already exist and what they mean.

You can access [the NHS Constitution here](#) and [the NHS Constitution handbook, that sets out what these rights mean in more detail here](#), and the Expert Parent Programme guide to your rights to when using the NHS. If you don't not think that the NHS has respected these rights then you may be able to use the Constitution to help resolve the situation by working together with your local health service to make sure it meets the standards set out in the NHS Constitution. If this is not successful then you may be able to make a complaint against the NHS, see below.

## **9. How can I complain and get redress?**

If you do not think that your rights have been met or you are unhappy about the service you have received from the health service then you have the right to complain. The NHS has a complaints process that you need to follow when making a complaint. At the local level every NHS body will have its own complaints process that should be available on their website, it is important that you follow this process in the 1<sup>st</sup> step on making a complaint. This will help resolve the complaint at the earliest opportunity and is also important if you decide to pursue your complaint further. If you are not happy with the outcome of your complaint to the provider of the care then you can move your complaint to the next level, which is complaining to the body that Commissioned the service. The end point of this process if you are unable to resolve the issue with the NHS's own complaints structure is the Parliamentary and Health Service Ombudsmen, and in specific cases, Judicial Review.

When making a complaint it is important to keep a record of every step of the process, collect evidence, to think about the outcome you want from the complaints process and seek expert help and advice.

The Expert Parent Programme has a simple guide to the complaints process and who can help you in the resources section of the Expert Parent website.

## **10. How to have your voice heard in the system**

As a patient, parent of a patient or a member of the public you have the right to get involved in the running of the health service in your local area.

There are a number of ways to get involved in the health system in your local area. Local health organisations like Clinical Commissioning Groups and NHS Hospital Trusts have patient and public participation forums as part of their duty to engage with patients and the public. These bodies provide information and engagement regarding issues and decisions facing the NHS organisation.

There is also a body in every local authority area called Healthwatch, these are independent bodies commissioned by Local Authorities to represent patients and the public's voice in the local health and care system. Healthwatch cover all health issues and services in their local area, including children and young people, and should be able to provide information and advice about local services, support and provide information and advice about the complaints process.

The Expert Parent Programme has a simple guide about how to get involved in the local health system in your area.