



**RARE**  
resources  
S C O T L A N D



# 3 Using NHS Scotland



Rare Resources is a collection of information guides for families who have recently received a diagnosis of a genetic or rare condition, are on the journey to a diagnosis, or have been told their child's condition is so rare they might not get a diagnosis.

The Rare Resources guides have been developed in collaboration between Genetic Alliance UK and families in Scotland. The guides provide links to reliable sources of information and support, and contain 'top tips' from other families.

Rare Resources contains the following guides:

1. Genetic, rare and undiagnosed conditions explained
2. The journey to diagnosis
3. Using NHS Scotland
4. Support and information for parents and carers
5. Support and information for your child
6. Information directory detailing support services available in Scotland

The Rare Resources guides can be downloaded from [bit.ly/rrgeneticallianceuk](https://bit.ly/rrgeneticallianceuk)

If you have an questions about our Rare Resources guides, please contact us on 0300 124 0441 or [contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)

### **3.1 Using NHS Scotland**

### **3.2 What does NHS Scotland provide for children?**

### **3.3 How to access NHS services for your child**

### **3.4 Who does what in the NHS?**

### **3.5 What to expect from medical appointments**

### **3.6 Managing appointments**

### **3.7 Keeping records**

### **3.8 Participating in research**

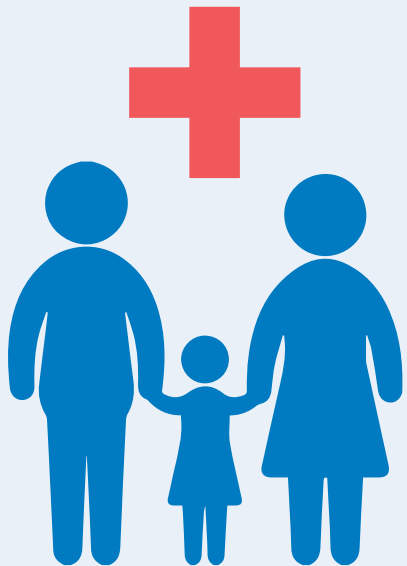
### **3.9 Finding research opportunities**

### **3.10 How to access treatment for your child**

### **3.11 Your healthcare rights**



# 3.1 Using NHS Scotland



**For many families, having a child with a genetic, rare or undiagnosed condition means using NHS services in Scotland with greater regularity.**

For many families, this might be a new experience.

**'I remember all the jargon the doctors in the hospital used – It was like learning a new language.'**  
Workshop participant

This section provides information on the NHS in Scotland and how to make the most of your appointments.

**NHS Scotland is the publicly funded healthcare system responsible for the care of people in Scotland.**

NHS Scotland provides most of the health services your child will access and is responsible for GP, hospital and specialist services.

**'Before I had my daughter, we hadn't really had to use the NHS for anything other than a few GP appointments. I now feel like I know every person and every corner of our hospital!'**  
Workshop participant

NHS Scotland is divided into 14 geographical Health Boards, which have the responsibility for running the NHS in their local area.

Details of each NHS Scotland Health Board can be found on the NHS Scotland Health on the Web (SHOW) website.  
[bit.ly/rrscothealthontheweb](http://bit.ly/rrscothealthontheweb)

Most NHS treatment is free, including all prescription costs, but there are some things for which there may be charges (i.e. dental treatments).

NHS Scotland provides details on charges and advice on how to obtain financial support if you need it, in their leaflet 'A Quick Guide to Health with Health Costs'.  
[bit.ly/rrhealthcosts](http://bit.ly/rrhealthcosts)

# 3.2 What does NHS Scotland provide for children?



## NHS Scotland is responsible for providing care for children with genetic, rare or undiagnosed conditions in Scotland.

This includes GP appointments, appointments with specialist clinicians, visits to NHS regional genetic centres and a wide variety of other services.

NHS Scotland also commissions specialist services for rare conditions, including services for genetic and undiagnosed conditions.

The services available for genetic, rare or undiagnosed conditions are varied and wide ranging.

The [National Services Division \(NSD\)](#) is responsible for the national commissioning for very specialist services that cannot be provided at a local or regional level.

These services are generally concerned with the diagnosis and/or treatment of rare conditions.

The diversity of rare conditions and the specialist knowledge required to diagnose and treat them mean that it is not always possible to have a service for a rare condition available near to home.

Sometimes a specialist can't be found in Scotland and a child will have to travel to another part of the UK to access specialist care.

National Service Division is responsible for the commissioning of specialist services from elsewhere in the UK and ensuring that Scottish people are able to access them.

There are also [National Managed Clinical Networks \(NMCNs\)](#) that link together health professionals, patients, third sector organisations and other partners to improve access to services for people who often have complex or rare conditions.

For example, the Children with Exceptional Healthcare Needs NMCN exists to strengthen specialist services for children in Scotland with complex and exceptional healthcare needs.

# 3.3 How to access NHS services for your child

## The role of your Family Doctor

Your GP, or family doctor, will likely be the first person you go to if you think your child has a health issue. GPs are doctors who have completed training in general practice. However, they may not be an expert in your child's genetic, rare or undiagnosed condition. They should coordinate your child's care with other health professionals.


If you have concerns about your child's development or their health, or if you think your child needs to access a particular NHS service, it is a good idea to discuss this with your GP or your health visitor in the first instance.

**You may wish to make a list of your concerns and any particular symptoms or patterns of behaviour that you have noticed so you can talk them through.**

You can also video them or take photos to take along to the appointment.

Your GP or health visitor will discuss your concerns with you. It is likely that they will also examine your child and discuss options with you. This may include referral to other services, such as a paediatrician, specialist clinician, a physiotherapist or speech therapist.

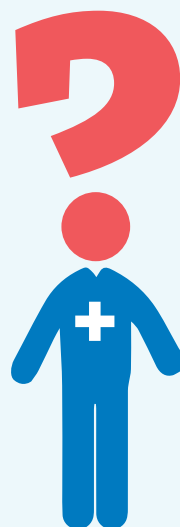
In the section '3.4 Who does what in the NHS?' you will find some general information about services that are available and the range of specialist clinicians.



## Top Tips From Parents

If you suspect that your child has a particular condition, don't be afraid to tell your GP or Health Visitor – you may be right and your GP may not have thought about it.

# 3.4 Who does what in the NHS?



## Healthcare Professional

## Description

<b>Allied Health Professional (AHP)</b>	A health professional that is not a doctor or nurse. For example, physiotherapists, occupational therapists and speech and language therapists.
<b>Clinical Nurse Manager</b>	A nurse responsible for the management of a ward or a unit.
<b>Clinical Nurse Specialist</b>	A nurse who has undertaken specialist training to become an expert in one area of healthcare.
<b>Clinical Support Worker (or auxiliary nurse)</b>	A person who works closely with healthcare professionals, helping to provide patients with a high standard of care.
<b>Consultant</b>	A consultant is a senior doctor who practises in one of the medical specialties.
<b>District Nurse</b>	A nurse that looks after patients in the community.
<b>General Practitioner (GP)</b>	A doctor based in the community who treats patients with minor or chronic illnesses and refers those with serious conditions to a hospital.
<b>Genetic Counsellor</b>	A health professional trained to provide support, information and advice about genetic conditions.

Having a child with a genetic, rare or undiagnosed condition might mean having to see a number of different healthcare professionals. There are many different types of healthcare professional working within the NHS in Scotland.

<b>Genetic Nurse</b>	A registered nurse with special education and training in genetics.
<b>Health Visitor</b>	A qualified and registered nurse or midwife who has chosen to gain additional training and qualifications. They mainly work in the community with children from birth to five years old and their families.
<b>Midwife</b>	A qualified health professional that cares for women throughout pregnancy, birth, and during the postnatal period, as well as caring for newborn babies.
<b>Occupational Therapist (OT)</b>	An AHP who promotes health and wellbeing through the use of particular activities as an aid to recuperation or self-management of a condition.
<b>Paediatrician</b>	A medical practitioner specialising in the physical, mental, and social health of children from birth to young adulthood.
<b>Pharmacist</b>	A health professional who is an expert in medicines and their use. They advise medical and nursing staff and provide information to patients.
<b>Physiotherapist</b>	A health professional who helps people affected by injury, illness or disability through movement and exercise, manual therapy, education and advice. They provide advice on pain management.
<b>Practice Nurse</b>	A nurse who works in the community, usually in a GP surgery or local health centre.
<b>Speech and Language Therapist</b>	An AHP who addresses speech, language and communication problems.



# 3.5 What to expect from medical appointments



**For many families who have a child with a genetic, rare or undiagnosed condition, managing lots of different medical interactions can be an emotional, confusing and sometimes stressful experience.**

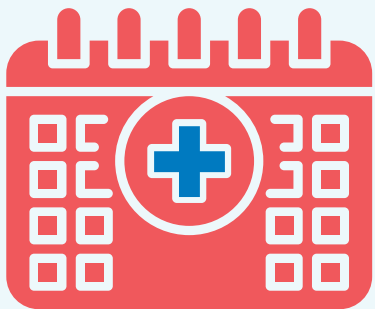
Some of the things you might experience include:

- Having lots of appointments to attend
- Having to visit different hospitals or health services
- Having to spend a lot of time in hospitals
- Having to have many different health care professionals involved in your child's care
- Having to repeat your child's symptoms and needs to different health professionals
- Having to 'learn the language' that health professionals use and understand medical jargon
- Having to learn how to provide healthcare for your child
- Having nurses, carers and therapists providing care in your home
- Your child may need to be referred to a clinical specialty and a specialist consultant. For example, a child with a rare condition affecting their immune system may be referred to immunology (the clinical specialty) to see a consultant immunologist (a specialist in immunology)

You can find explanations of different medical specialities in the Rare Resources Information Directory.



# 3.6 Managing appointments



**Families who have a child with a genetic, rare or undiagnosed condition may have to attend many different healthcare appointments.**

## **Prepare for your appointments**

Have a think about what it is you want to discuss and what questions you want to ask. Write down any questions you want answered before you go and take them with you so you do not forget.

## **Keep records**

Keep records of the appointments you have, who they were with and short notes on what was discussed. This can be helpful to reflect upon and to discuss with others involved in your child's care.

## **Record your child's progress**

If your child has good days and bad days, it might be helpful to note these down and record what was different on these days. If possible, take a photo or a video to show your doctor.

This might help your healthcare professional better understand your child's condition or possibly spot a pattern or a clue that could lead to diagnosis.

## **Arrange appointments to suit you**

Try to arrange appointment times to suit you. If you receive an appointment letter with a time that is not convenient, don't be afraid to call and ask for a more suitable time.

## **Appointments in the morning can sometimes reduce the chance of a long wait**

Delays tend to get longer as the day goes on. Explore options for consultations by phone or by Skype to reduce the need for travel.

## **Explain**

If your child is scared about attending a particular appointment or having a particular procedure, think about how you can explain what is going to happen beforehand in a way that will reassure them.

In Glasgow Children's Hospital there is a 'Teddy Hospital' in the main reception area where a specialist play team can help your child understand more about being in hospital.



## 3.7 Keeping records

There can be a lot of paperwork involved when you have a child with a genetic, rare or undiagnosed condition. You may receive a lot of letters, test results and information from the various appointments that you have.

You may also choose to keep your own notes about how you think your child is progressing. All of this is extremely valuable information to you and the people involved in your child's care.

It is a good idea to keep this information together and somewhere safe so that you can easily access it. Some families keep their child's information in a ring binder or folder; others prefer to keep the information digitally on their phone or on an app.

Some families organise their paperwork by clinical specialty, others keep everything together in date order. How you wish to gather and store your child's information is up to you but it is a good idea to think of a way that works for you.



## 3.8 Participating in research

For many families of children and young people who have a genetic, rare or undiagnosed condition, research provides hope for an effective treatment or cure for their child's condition.

Research is fundamental in understanding genetic, rare or undiagnosed conditions.

Often families are unsure about what is involved in research. Genetic Alliance UK and SWAN UK have produced helpful resources which explain about research and innovation.

You can find more information about how to participate in research here:

Research and innovation:  
[bit.ly/rrresearchandinnovation](https://bit.ly/rrresearchandinnovation)

Genetic research studies:  
[bit.ly/rrgeneticresearchstudies](https://bit.ly/rrgeneticresearchstudies)

Exome and genome sequencing:  
[bit.ly/rrexomeandgenomesequencing](https://bit.ly/rrexomeandgenomesequencing)



## 3.9 Finding research opportunities

### Support Groups

Support groups are an excellent source of advice on condition specific research that is being carried out. It is a good idea to get in touch with a relevant support group to find out what information they have on available research opportunities.



### Speak to your specialist clinician

It is likely that your specialist clinician will be aware or possibly involved in research opportunities for your child. A good starting point is to ask your specialist clinician what research is available and how your child can be involved.

### SHARE

The SHARE register has created a database of up to one million people in Scotland prepared to be approached directly about possible participation in research. Through linkages to health records, this facilitates the identification and recruitment of people into clinical studies in Scotland.  
[bit.ly/rrshareregister](http://bit.ly/rrshareregister)

## 3.10 How to access treatment for your child

For many families, the day-to-day challenges of managing their child's condition are made worse by the absence of an effective treatment.

For most genetic, rare and undiagnosed conditions, no licenced treatment is available.

Where a treatment has been licenced for a rare condition, patients may struggle to access it due to the complex processes for making medicines available on the NHS.

**You may be aware of a particular treatment, or medicine, available for your child's condition. It is important to discuss this with your healthcare professional.**

Your health professional will consider whether the medicine will benefit your child.

If a medicine is needed, the healthcare professional will speak to you about your options.

Further information about how to access medicines on the NHS can be found in the leaflet 'Medicines in Scotland: What's the right treatment for you?' [bit.ly/rrmedicineinscotland](http://bit.ly/rrmedicineinscotland)



# 3.11 Your healthcare rights

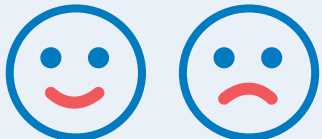
Sometimes families report that they are not happy with the service they receive from a medical professional. Sometimes this can be because families don't feel they have been listened to, or their wishes have been ignored.

In Scotland, the [Patient Rights \(Scotland\) Act 2011](#) gives all patients the right that the healthcare they receive will:

- Consider their needs
- Consider what would most benefit their health and wellbeing
- Encourage them to take part in decisions about their health and wellbeing
- Provide them with the information and support to do so

The Act also gives patients and families the right to give feedback, raise concerns or complain about the healthcare they have received.

Your Rights and Responsibilities are summarised in the Charter of Patient rights and Responsibilities.  
[bit.ly/rrpatientrightsandresponsibilities](http://bit.ly/rrpatientrightsandresponsibilities)



# The Patient Advice and Support Service (PASS)

The Patient Advice and Support Service (PASS) is an independent service which provides free, accessible and confidential advice and support to patients, their carers and families about NHS healthcare.

The service is provided by the Scottish Citizens Advice Bureau.

PASS promotes an awareness and understanding of the rights and responsibilities of patients and advises and supports people who wish to give feedback, make comments, raise concerns or make a complaint about treatment or care provided by the NHS in Scotland.

The service can:

- Help you understand your rights

- and responsibilities as a patient
- Provide information, advice and support for anyone who wishes to give feedback or complain about healthcare delivered by NHS Scotland
  - Provide practical help with making a complaint, including writing letters, making phone calls and supporting you in preparing for and attending meetings
  - Work with the NHS by using feedback to improve your healthcare and NHS service provision

You can access the Patient Advice and Support Service (PASS)  
[bit.ly/rrpatientadviceandsupport](http://bit.ly/rrpatientadviceandsupport)  
0800 917 2127





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