contact a family
for families with disabled children

Living with a rare condition

Information for families

Incorporating The Lady Hoare Trust

Introduction

This guide is for parents and carers whose child has been diagnosed with a rare condition or who think their child may have a rare condition. It contains information on:

- what is a rare condition?
- getting a diagnosis
- what help and support you can expect
- meeting other parents
- top tips.

About the series

Around the time of diagnosis, families can go through a range of emotions. The 'About Diagnosis' series by Contact a Family deals with topics that may be useful to parents who are trying to get a diagnosis for their child. Each guide contains useful information and signposts to further sources of support for parents. The other guides currently available in our 'About Diagnosis' series are:

- *Developmental delay*
- *Living without a diagnosis.*

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Colour key to reading this guide:
Organisations in blue in this guide are listed in 'Useful Organisations' on p13. Words in brown in this guide are explained in the 'Glossary' on page15. The colour key will not work if you print this guide out in black and white. Call our helpline for a full-colour copy while stocks last.

What is a rare condition?

You may have been told by a doctor that your child has a rare condition. The European Union (EU) says a condition is rare if it affects fewer than five people in every 10,000. EURORDIS, a support organisation for people living with a rare condition in Europe, estimates that there are between 6,000 and 8,000 known rare conditions, and this number will increase as new rare conditions are identified.

Rare conditions can affect both children and adults and can occur at any time of life. Most rare conditions are life-long and some are known as 'progressive' (may get worse over time). In some cases, rare conditions can be life threatening.

How rare is rare?

Although each rare condition affects a small number of people in the population, the total number of people affected by rare conditions is quite large. Rare Disease UK estimates that there are 3.5 million people living with a rare condition in the UK. Most rare conditions (around 75 per cent) affect children.

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

If your child has a rare condition, you may feel quite alone. You may be told that your child is the only one in the country to be affected by the condition. However, there may be other families in the UK, or in other countries, that have a child who is affected by the same condition. With access to the internet becoming more common, and international **support groups**, it is now possible to get in contact with others who can relate to what you are going through.

> "Try to enjoy your child. It is easy to focus on all their problems and forget to enjoy watching them grow up." Parent

Why rare conditions can be hard to diagnose

It can take some families a long time to get a diagnosis for their child's rare condition. For some people, this can be frustrating and very upsetting, so it can be helpful for parents to talk to professionals to better understand why an early diagnosis is not always possible. There are several reasons that may delay a quick diagnosis for a rare condition:

- Some conditions have similar general symptoms; for example, muscle weakness, tiredness, pain, vision problems, and dizziness or coughing. Doctors are trained to look at common causes of symptoms before they consider rare conditions.
- Referral to specialists takes time. It can be difficult to get an appointment with some specialists who deal with rare conditions. Sometimes you may have to wait three to six months for an appointment.
- Some symptoms of rare conditions are unusual – if the specialist examining your child isn't familiar with the condition causing their symptoms, then your child is likely to be referred to another specialist.
- Identifying the condition can be difficult – you may see several specialists before you finally find one who knows something about your child's symptoms and condition.
- Your child may have a rare condition, but their symptoms do not fit those usually associated with the condition.
- Your child may not have all the symptoms that are commonly seen with the condition.

You can find more about this in our guide *Living without a Diagnosis*. Call our freephone helpline on 0808 808 3555 for a free copy.

Some helpful hints for appointments
Some parents find it helpful to make a list of all the features their child displays and examples of things they find difficult to take to appointments. You can use a log of your child's development progress to show areas where they may be behind other children.

The Early Support website has a Development Journal which allows you to log your child's progress (see 'Useful organisations' on page 13).

Parents have told us that it helps to make a list of questions to ask before they go to appointments. This helps them to remember what they want to ask the specialist. It can also be helpful to have a friend or relative come along to appointments, as they can help make sure you ask all the questions on your list and take notes for you.

What to do if you are not happy
If you feel strongly that all the ways of getting a diagnosis for your child have not been explored, you can ask for a second opinion. You may have a niggling feeling that your child is very similar to other children with a particular condition but other professionals aren't recognising it.

Support groups for the condition may be able to help you find information and the right specialists to make a diagnosis. If after seeing a consultant doctor or specialist you would like a second opinion, you can go back to your general practioner (GP) and ask them to refer your child to a different specialist. Try to avoid being confrontational but be firm. You can take along the list of things your child finds difficult to help explain the reason why you are asking for the referral. If your GP will not help you get a second opinion, you can ask to see another GP at the same, or a different practice. Contact a Family can also offer support and advice if you are unhappy with your child's care.

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Getting information on your child's condition

It is important to remember that children with the same condition can be affected in varying severity – some children may be mildly affected and some severely affected. It is a good idea to take any information about the condition that you find along to your next appointment with your specialist to discuss how it applies to your child. You might find it useful to keep a diary to note anything, no matter how minor, that you think might be relevant to share with specialists.

If your child's condition is not well known, it can be difficult to get reliable, easy to understand information about it. The internet has lots of sources of information but not all of it is reliable. Below we list some organisations that will have reliable, easy to understand information for families.

Contact a Family

We have information on more than 400 conditions on our website www.cafamily.org.uk/medical-information and details of UK support groups. Even if a condition and support groups are not listed on our website, we may have information on our internal records. Call our freephone helpline on 0808 808 3555 to ask about this.

Conditon support groups

Condition support groups sometimes produce medical information for families and professionals. Contact a Family can give you details of support groups for rare conditions. Call our freephone helpline on 0808 808 3555.

Other sources of information on rare conditions

Orphanet

Web: www.orpha.net

The Orphanet website has information about orphan drugs, specialised centres for rare conditions, laboratories that offer diagnostic tests, and clinical trials taking place in Europe.

NORD

Web: www.rarediseases.org

The National Organization for Rare Disorders (NORD) website's Patient Information Centre has an 'Ask the Nurse' and 'Ask the Genetic Counsellor' service. They also have a database of rare conditions and patient support organisations.

Working with health services

Local services

These services will include your GP, a paediatrician at your local hospital and other services your child might receive near your home such as physiotherapy, speech and language therapy and

occupational therapy. You may find that professionals in your local health services do not know much about your child's rare condition. It may be helpful to get a letter from your specialist to explain how your child is affected by their condition and what they need support with.

If you have found reliable information on your child's condition, you may want to take a copy along to appointments and leave it with local health professionals. Give professionals a sensible amount of time to read and digest the information. A busy professional may not have time to read a document when you give it to them. You could offer to go back at a later date to discuss the needs of your child.

Specialised services

If professionals suspect that your child has a rare condition and there is not the expertise in local health services to help, you may be referred to a specialist. At specialist hospitals you are more likely to meet a specialist who has seen other children with the same condition. An example of a specialist hospital is Great Ormond Street Hospital for Children.

Families tell us they like to see a specialist who knows about their child's condition, but this may involve a lot of travelling to get to specialist centres.

For some rare conditions, specialist clinics have been set up. This means that people affected by the condition can see all the specialists they need to in one place.

> "When they said that my daughter had a rare condition that would affect her growth, I was stunned. I started to panic, wrongly assuming that she would never go to school, have a boyfriend, or get married."
> Parent

Some parents find that they are able to effectively manage their child's follow-up care by using specialist services when necessary, but attending local services for routine assessments, check-ups and tests. It is important to let your specialist centre and local health care centre know about your plan to do this. Information will need to be clearly communicated between both places.

It is important to work in partnership with health and other professionals to get the best support in place for your child. Your expertise on the condition and the needs of your child is important to this partnership.

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Access to medicines

For medicines to be used to treat conditions they must be approved for use – also known as getting a licence. To get approved for a certain use, the medicine must be tested in a number of trials to show it is safe and effective.

Using medicines when they haven't been approved for a certain group of people, or for a certain condition, is called 'off-label' use. This means that the main use of the treatment is something else, but doctors think it may benefit another group of patients. Medicines for children are quite often used off-label because trials have only been carried out with adults.

As a parent of a child with a rare condition, you may have found out some information on off-label medicines that could help your child. If you think your child would benefit from an off-label medicine, take the information along to your child's specialist and discuss it with them.

Orphan drug development – what is it?
Orphan drugs are developed for the purpose of treating a rare condition. The EU introduced orphan drug status because usually drug companies are not interested in developing a drug for so few patients, as the cost of development outweighs the profits they make. Orphan drug status comes with financial benefits for the drug companies as well as other assistance and support from the EU to develop the new medicines.

> "Try not to focus on the milestones your child has not reached. Focus on those they have." Parent

Getting involved in research

For many rare conditions there is no cure, meaning that the effects of the condition cannot be completely reversed. But there may be treatments and therapies that reduce the symptoms your child experiences. Your child's specialists can advise on treatments to help manage symptoms. Condition support groups may also have useful information.

Research and trials
Some families may consider becoming involved in research or clinical trials for treatments for rare conditions. The decision to take part will be individual for each family. Always try to find out as much unbiased information as possible before deciding to take part and make sure you inform your child's specialist about what you have found. NHS Choices have some information on clinical trials and questions to ask before getting involved. The healthtalkonline website has interviews with parents talking about how they found out about trials, why they decided to take part, or why they did not take part.

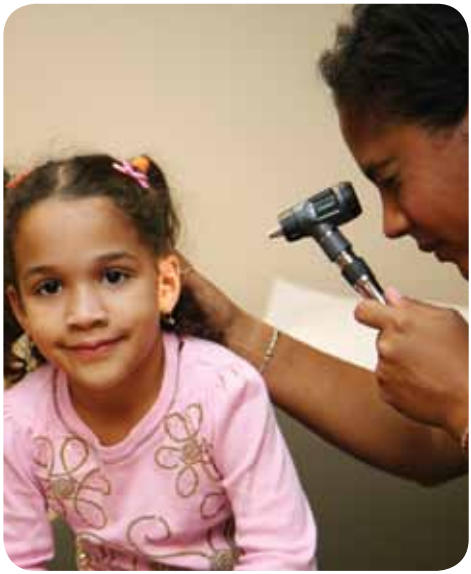
You can find information about ongoing clinical trials on the NHS Choices website, or search on the Orphanet website. Some support groups have information about ongoing research. It is worth asking the relevant condition support group about this.

Buying drugs and treatments online
This may be very tempting, especially if a treatment claims to be successful and is not available in the UK. It's worth noting that the evidence for the treatment working may not be reliable. In addition, there is no guarantee that the drugs you are buying online are what they say they are because they don't have to undergo the same strict checks as prescribed medications in the UK.

Experimental treatments
Many families will come across information about experimental treatments in their search for treatments for their child. An example of this is gene replacement therapy for a genetic condition – where a changed (or mutated) gene is replaced by a functioning gene.

It is important to discuss any information you come across with your specialist. These types of treatments are still fairly new, so scientists and medical professionals are gathering information about them. Experimental treatments may not be available on the NHS and even if they are, there will usually be very strict guidelines on how they are used.

You may be keen to have an experimental treatment used on your child but professionals may not agree,



maybe because they are unproven or too expensive to be used. If you are looking for information about these kinds of treatments, get impartial advice from a not-for-profit organisation and discuss it with the specialist treating your child. Drug companies offering miracle cures may not always be genuine and the cost of treatment can be very high.

Treatments abroad
Some families may look into accessing specialist treatments abroad. This can often be very costly and the success of treatments can vary. In some cases, the NHS can fund treatment within Europe

(continues on page 11)

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Top tips

Parents can find the number of professionals and appointments they have to attend overwhelming. These tips from parents who have 'been there' can help you to manage your diagnosis journey.

- Make a list of all the ways your child is affected by their disability or condition to show doctors at appointments, or people in schools or nurseries.
- Create a communication passport for your child (see page 11). This can be taken to appointments and they are a quick and easy way of passing on information to the specialist about your child.
- Get a diary or a big wall calendar with space to mark appointment times.
- Keep copies of all letters, appointments, and test results in a folder. Keep a note of all the phone calls you make as well.
- Prepare the questions you want to ask at an appointment beforehand. Write these all down in an appointment notebook and take it along with you.
- Take a friend or relative to your appointment to make notes while you talk. It can be hard to remember what you are told, especially if you are upset.
- If you find reliable information about your child's rare condition, take a copy to local services that may not be familiar with the condition, such as your GP, social worker or physiotherapist.
- Work with health and other professionals to get the best help and support for your child. Your expertise on their condition and the needs of your child is likely to be really important to this partnership.
- Use a mixture of local services and specialised services that suit the needs of your family best – this will reduce stress, time and expense by not making long unnecessary journeys. Make sure that you let professionals know this is your plan.
- If you feel that you need to see a specialist, or if you think you may have somehow got 'lost in the system', don't be afraid to phone and find out. Ask to speak to the doctor's secretary to find out what is happening with your child's appointment.
- Don't be afraid to ask your specialist questions that are concerning you, however silly or insignificant you think they may seem. Support groups may also be a useful source of information about everyday issues
- If possible, try to stick with the same professionals so that your child gets a good level of care all the time from people that understand their needs.

Economic Area countries (EEA). See the NHS Choices website for more details. Treatment not funded by the NHS will have to be funded privately by the family.

You will need to think carefully about whether treatment abroad is right for your child. Try to also get as much information as you can from a reliable, unbiased source before doing this. Support groups may be in touch with members who have had such treatments and it can be possible to speak to other families about their experience.

Not all treatments will be suitable for all children. It is important to discuss your intentions with your child's specialist in the UK as they may be able to offer some advice and may be involved in any follow-up treatment or care.

Working with education professionals

Getting support for your child at nursery or in school may be more difficult if your child has a rare condition. You might find it helpful to ask your child's specialist or paediatrician to write a letter to the school listing your child's support needs. You may also want to take any reliable information you find on your child's condition for education professionals to read. Some rare condition support groups have leaflets for schools that you can find on their websites.

A child with additional needs is entitled to get help in the education setting based on their needs and not their diagnosis.

The main point of contact for a parent whose child has special educational needs (SEN) is the early years or school's special educational needs coordinator (SENCO). To find out more about SEN call Contact a Family's freephone helpline on 0808 808 3555.

Communicating your child's needs

If your child has a rare condition, you may struggle to communicate their needs to health or other professionals that work with your child. This may be because professionals do not know a lot about the rare condition. Parents often say it is frustrating to continually repeat their child's life story.

A communication or hospital passport is a booklet that you can use to pass on crucial information about a child or young person with additional needs. It contains information about their condition, medications, likes and dislikes and

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essential information if an emergency happens. For example, The Foundation for People with Learning Disabilities has a good template for a communication passport in their booklet *An ordinary life.* If your child doesn't have a communication passport, then Bristol Children's Hospital produces a good communication passport that you can adapt for your child. See the useful organisations section for contact details.

Meeting other parents

National condition support groups
As a parent of a child with a rare condition, you may want to meet other families that are going through similar experiences.

In the UK, there are many support groups that help families with a child affected by a particular condition. Condition support groups may:

- provide information on the condition
- support families and professionals who work with them
- link families together
- run activities for families, including family fun days
- run medical conferences
- fundraise for research
- advertise research.

At Contact a Family we have details of more than 400 condition support groups on our website and hundreds more on our database. Search on the medical information section of our website at www.cafamily.org.uk/medical-information.

Local parent support groups
Many areas in the UK have a local parent support group, where families of children with all kinds of additional needs come together for mutual support and contact.

If your child has a rare condition, it is unlikely that another child in a local support group would have the same condition. However, a lot of the issues you face on a day-to-day basis will be familiar to other parents and they will have practical advice to share.

Local groups have the advantage of meeting regularly, which can be important in providing a support network if you need one. You can call Contact a Family's freephone helpline to get information on local support groups.

How Contact a Family can help you

Contact a Family is a UK-wide charity providing advice, support and information

to families with a child with additional needs or rare medical condition.

We provide medical information on many conditions, including rare conditions. See www.cafamily.org.uk/medical-information or call our freephone helpline on 0808 808 3555.

We can put you in touch with condition specific support groups and local support groups and other families through our online family linking scheme – MakingContact.org at www.makingcontact.org

Where there is no UK support group, we offer a one-to-one family linking scheme for rare conditions, where possible.

We also support groups of parents and carers that set up and run local and national support groups.

> "There was a mum who lived nearby whose daughter had Down syndrome. I got more information and support from her about getting local services for my child than anyone else." Parent of a child with Pallister-Killian syndrome

Useful organisations

Bristol Children's Hospital
Web: www.uhbristol.nhs.uk
Bristol Children's Hospital has a good template for a hospital passport, which can also be used in other settings. Visit the Bristol Children's Hospital website and search for 'passport'.

Children Living with Inherited Metabolic Diseases (Climb)
Freephone helpline: 0800 652 3181
Email: info.svcs@climb.org.uk
Web: www.climb.org.uk
Climb is a UK organisation working on behalf of children, young people, adults and families affected by metabolic disease. It provides condition specific information and advice and support to families, including linking families together. They also fund educational and primary research programmes and investigate treatments and medical services.

Early Support
Tel: 0207 843 6000
Email: earlysupport@ncb.org.uk
Web: www.councilfordisabledchildren.org.uk/earlysupport
Early Support is a way of working, underpinned by 10 principles that aim

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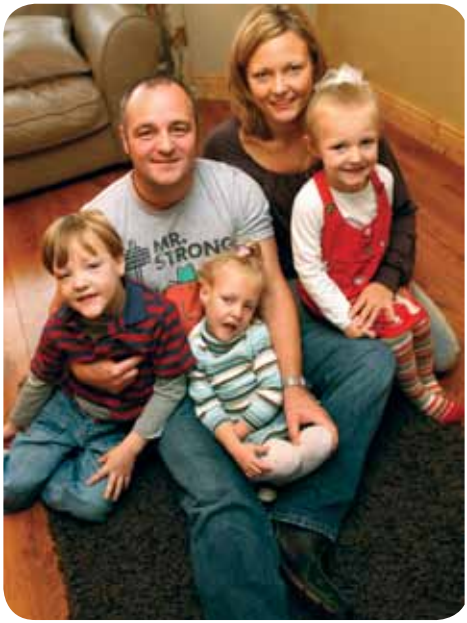
to improve the delivery of services for children and young people with additional support needs and their families. It enables services to coordinate their activity better and to provide families with a single point of contact and continuity of care and support through key working. Early Support has lots of information on their website, including booklets on behaviour and sleep. They also produce the Early Support Development Journal.

EURORDIS
Tel: 33 (1) 56 53 52 10
Email: eurordis@eurordis.org
Web: www.eurordis.org
EURORDIS is an alliance of patient organisations and individuals active in the field of rare diseases. Their website has information on rare diseases, orphan drugs, other patient experiences, training resources and news.

Foundation for People with Learning Disabilities
Web: www.learningdisabilities.org.uk
The Foundation works to influence government and local authority policies and services so that they better meet the needs of people with learning disabilities, their families and carers. The Foundation's report *An ordinary life* has a good communication passport template.

Genetic Alliance UK
Tel: 0207 704 3141
Email:
contactus@geneticalliance.org.uk
Web: www.geneticalliance.org.uk
The Genetic Alliance UK is an umbrella body that represents many individual patient organisations. The Alliance runs several projects, including Syndromes



Without a Name (SWAN) UK and has lots of information on genetics testing and services, including a list of all UK regional genetics centres.

Healthtalkonline
Web: www.healthtalkonline.org
Healthtalkonline is the award-winning website of the DIPEx charity. Healthtalkonline shares in more than 2,000 people's experiences of over 60 conditions and illnesses. In particular, they have a channel of parent stories from parents who have taken part in clinical research.

National Organization for Rare Disorders
Email: via website
Web: www.rarediseases.org
National Organization for Rare Disorders

(NORD) is a federation of voluntary health organisations dedicated to helping people with rare conditions. Their Patient Information Centre has an 'Ask the Nurse' and 'Ask the Genetic Counsellor' service. They also have a database of rare conditions and patient support organisations.

NHS Choices

Web: www.nhs.uk
NHS Choices has a wide range of health information including A-Z of conditions and a search function to check services near you like GPs, dentists and hospitals. It also holds information about clinical trials and a section on services, rights and paying for treatments abroad.

Orphanet

Email: via website
Web: www.orpha.net
Orphanet is the largest rare condition website in Europe. As well as information on conditions, it has information about orphan drugs, specialised centres for rare conditions, laboratories that offer diagnostic tests, and clinical trials in Europe. Orphanet also lists European patient organisations for rare conditions.

Rare Disease UK

Tel: 020 7704 3141
Email: info@raredisease.org.uk
Web: www.raredisease.org.uk
Rare Disease UK (RDUK) is the national alliance for people with rare diseases. It was established by the Genetic Alliance UK, the national charity of over 140 patient organisations supporting all those affected by genetic conditions. RDUK has been lobbying the government for an effective rare disease strategy for the UK.

Unique

Tel: 01883 723 256
Email: info@rarechromo.org
Web: www.rarechromo.co.uk
Unique is a source of information and support to families and individuals affected by any rare chromosome disorder and the professionals who work with them.

Unique links families with children affected by rare chromosomal conditions to other families with similar diagnoses for mutual support and provides family friendly, medically verified condition information leaflets.

Glossary

Additional needs

This term is used to refer to any child or young person who has a condition, difficulty, challenge or special educational need, whether diagnosed or not, who is likely to need additional support beyond universal services available to children or young people of the same age.

Clinical trials

A clinical trial is a particular type of clinical research that compares one treatment with another. It may involve patients or healthy people, or both. For example, a drug trial may test the safety of a drug in people and how well tolerated it is. Also the effectiveness of the drug may be compared to other available drugs.

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Communication or hospital passport
A communication or hospital passport is a booklet that is used to pass on crucial information about a child or young person with additional support needs. It contains information about their condition, medication, likes and dislikes and essential information for an emergency situation.

General Practitioner (GP)
This is your family doctor. They will be the first person to ask for medical help and advice. They can ask for your child to be seen by another specialist.

Genetic condition
A genetic condition is caused by changes (mutations) in genes (our body's blueprint) or chromosomes (the structures that DNA is strung onto). Genetic conditions will affect a person from birth. Some genetic conditions are passed down from the parents' genes, but others are always or almost always caused by new changes to DNA and chromosomes.

Gene replacement therapy
This is an experimental treatment where defective genes are replaced with healthy genes. These therapies are in the early stages of development and scientists and doctors are trying to get more information about how well they work. There are strict controls on these treatments and they will only be carried out in certain cases.

Metabolic disease
Metabolism is the process your body uses to get energy from the food you eat. A metabolic disease happens when abnormal chemical reactions in your body disrupt this process. When this happens, you might have too much of some substances, or too little of other ones that you need to stay healthy.

Off-label
A medicine becomes licensed for treating a condition once it has successfully undergone clinical trials. It can be difficult and expensive to run clinical trials for rare conditions. Doctors sometimes suggest prescribing 'off-label' medicines which they think might be beneficial, even though it has only been licensed to treat another condition, or patient group.

If your specialist is considering prescribing an unlicensed or off-label medication, they should inform you and discuss possible risks and benefits with you.

Occupational therapy
An occupational therapist pays particular attention to hand and eye coordination, perception and manipulative skills. They can advise and provide suitable aids for feeding, dressing, toileting, bathing and play in younger children and writing skills in older children.

Orphan drugs
Orphan drugs status was introduced by the European Union (EU) for the development of treatments for rare conditions. Usually, drug companies are not interested in developing a drug for so few patients, as the cost of development outweighs the profits they make.

Orphan drug status comes with financial benefits for the drug companies as well

as other assistance and support from the EU to develop the new medicines.

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. Physiotherapy may include exercises to strengthen weak muscles and games to improve coordination and motor skills.

Rare condition

The European Union says a condition is rare if it affects fewer than five people in every 10,000. Rare conditions can affect both children and adults and can occur at any time of life. Most rare conditions are life-long and some are known as 'progressive' (may get worse over time). In some cases, rare conditions can be life threatening.

Specialist

A specialist doctor (or consultant) is a senior doctor who practises in one particular area of health, such as a cardiologist for the heart, or a neurologist for conditions affecting the brain. Once specialty training has been completed, doctors are able to apply for consultant posts. Consultants have ultimate responsibility for the care of patients referred to them.

Specialist clinics

A specialist clinic for a rare condition is a place where you can get information and support from any professionals under one roof to save numerous appointments. Often rare condition support groups work closely with the specialist centres for that condition.

Special educational needs

Children with special educational needs (SEN) have greater difficulty in learning than others the same age. SEN includes communication, physical, sensory and emotional difficulties that require additional support to help a child reach their full potential.

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Special educational needs coordinator

A special educational needs coordinator (SENCO) is a member of staff at a school or in early years' settings who has responsibility for coordinating SEN provision.

Speech and language therapy

Speech and language therapy helps children learn to communicate, either through speech or other methods. Speech and language therapists can also help if there are problems with swallowing.

Social worker

A social worker can help children and families by advising them on practical and financial issues, telling them about local services and sometimes helping to arrange support.

Support groups

Support groups are run by families or parents that have a child affected by a condition or disability or by professionals with an interest in helping people. They are a forum for people to meet together and share experiences. They may be a national group for a specific condition or a local group for parents and families with a child with additional needs.

Written by Cheryl Lenny,
April 2013.

Social networking

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

Facebook
www.facebook.com/contactafamily

Twitter
www.twitter.com/contactafamily

Videos

You can watch videos on our YouTube channel at:
www.youtube.com/cafamily

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

Getting in contact with us

Free helpline for parents and families
0808 808 3555
Open Monday to Friday,
9.30am–5pm
Access to over 170 languages

www.cafamily.org.uk
www.makingcontact.or

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Tel **020 7608 8700**
Fax **020 7608 8701**
Email **info@cafamily.org.uk**
Web **www.cafamily.org.uk**

Other guides available

This guide is one in our series 'About diagnosis' for parents and carers concerned with the care of disabled children. The other guides in this series are:

- *Developmental delay*
- *Living without a Diagnosis*

Contact a Family publications can be downloaded from our website at www.cafamily.org.uk

Parents can call our freephone helpline on 0808 808 3555 and ask for a copy of any of our guides.

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