

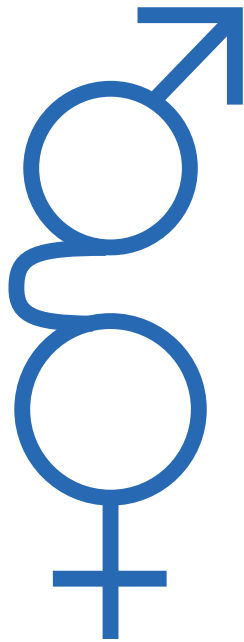


**GENETIC
INTEREST
GROUP**

*Working to benefit
all people affected
by genetic disorders*

Genetics? What's it got to do with me?

For older brothers, sisters and their parents



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Introduction

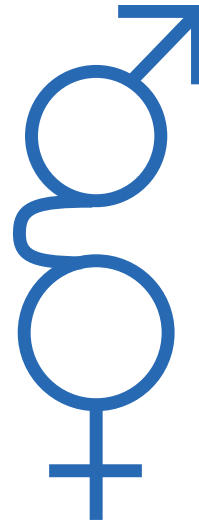
This resource pack is for the brothers and sisters (siblings*) of people affected by a genetic disorder. It is also for their parents.

There is a lack of information aimed specifically to help unaffected brothers and sisters in families understand and deal with what it means to have a genetic disorder running in the family – this pack is one attempt to fill that gap.

The pack is also aimed at parents as they have an important role to play in how their very young and older children receive information about, and deal with, a genetic disorder in the family.

The pack consists of two booklets:

- This booklet is for older brothers, sisters and their parents. It deals with issues faced by siblings which may not always be recognised by parents and health professionals. Because having a gene for a genetic disorder in the family affects everyone in the family in one way or another, this booklet explains the ways in which genetics may affect the lives of all family members. It also provides information on how to get further advice and support.
- The second booklet is for younger brothers and sisters; it deals with issues faced by children from an early age. Parents may also find this booklet helpful in gaining an insight into their children's perception of their situation, and as an aid to discussing some, possibly so far unrecognised, feelings and issues. It is hoped that older siblings may find it helpful to read this booklet as well, to examine some of the feelings that they may have experienced when younger, and which may still be with them.



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*Working to benefit
all people affected
by genetic disorders*

*Written by
Dr Aamra Darr*

*In the rest of this booklet, the term 'siblings', meaning brothers and sisters, will also be used – simply because it is a shorter way of saying 'brothers and sisters'.

Setting the scene

Siblings and genetic disorders

When a child is diagnosed as having an inherited condition, the immediate focus of health professionals is on helping the affected child, and on supporting the parents, as his/her carers.

For the parents, caring for a sick child can quite often be emotionally and physically demanding. There can be a risk that the needs of the other brothers and sisters may be overlooked. As well as that, the support that siblings provide to the affected child – and their role as co-carers with their parents – may have been ignored.

Just as parents require information and support in dealing with a disability in the family, siblings are also in need of information and support. Many families in this situation have told us that:

- Siblings need time for themselves and to be given time by their parents, from a young age;
- Siblings need to be valued within the family as carers and to be helped in that role;
- Siblings need information on the genetic condition affecting their brother or sister in order to understand it for themselves, and its implications for their lives, and to deal with wider perceptions of the condition and disability in general; and
- Siblings need to be able to meet other siblings in a similar situation, if they wish to.

The diagnosis of an inherited disorder in a family member means that siblings may also be at risk for the same condition or may be carriers of the condition, which they need to think about if they have children.

It can mean apprehension about developing relationships with the opposite sex, knowing that they will need to inform partners about their genetic status if they want to start a family.

The knowledge of one's genetic status may also have other implications; for some people it may make it difficult to get life insurance, for example.

- Siblings need information on genetic testing and what it means in terms of their lives, in order to make informed choices about whether to be tested or not;

Brothers and sisters without the genetic disorder can end up being overlooked

Siblings need information and support too – and their role as carers needs to be recognised and valued

Brothers and sisters should be allowed to make informed choices about whether to be tested or not

What are the issues?

- Siblings need support from professionals and parents to understand and deal with genetic information and its implications; and
- Siblings need to meet others to discuss the above issues, air their concerns and work out solutions.

Families and genetic disorders

The issues that face siblings of people affected by genetic disorders do not exist in isolation; they arise because they are all part of a family at risk from a genetic disorder, including a family member who is personally affected. Consequently, the level of information and support (or the lack of it) offered to parents and other adults in the family by professionals has a direct impact on how the unaffected brothers and sisters are able to understand and manage their situation from an early age.

The needs of parents, affected individuals and siblings for information, advice and support have a considerable overlap as all the members of a family need to be aware of the facts and issues surrounding a particular disorder. They all need information on the support services available. In the case of children and young adults, parents and professionals have a particular responsibility to provide appropriate information and support.

In order to inform and support siblings effectively, it is very important that parents and professionals examine their role in providing that support and make sure that everyone is working together.

The people who take on a caring role may not be just the parents and brothers and sisters, but also grandparents, aunts, uncles and friends.

Everybody in the family needs information and support

WELL-INFORMED FAMILIES are in a stronger position to cope and support each other, and to get the services they are entitled to. They are also more equipped to influence the wider society – such as people at school, college/university and the workplace – in how they deal with genetic conditions and any associated disability.

2 What are the issues?

Genetics: it all seems so complicated!

That germs can cause disease is common knowledge; how genes work, and how genetic disorders come about, is not. All families need some help in understanding genetics, and especially the condition that affects their family and what it will mean for each family member.

Ask your family doctor, the hospital doctor that looks after your brother or sister, or the genetic counsellor at your Regional Genetics Centre to explain to you the condition that affects your family, plus all the implications for you now, and in the future, if any. Keep asking until you feel you understand as much as you need (or want) to.

There's a list of articles and books which simplify the subject at the end of this section. Here's some general background to get started.

Genetic disorders

Some diseases are caused by germs in the air, water or food. Others are due to the gradual wearing-out of the body's organs and tissues. Genetic disorders are caused by faults in the genes.

The genes are the instructions for how the body grows, develops, and runs itself. There are many thousands of genes in every human body. They are made up of the substance DNA and are found in the nucleus or 'control centre' of each cell in the body, as 46 tiny thread-like objects called chromosomes.

A new baby receives, or inherits, a combination of genes from its mother and father. In most babies the genes are normal, and the baby is healthy. But in a few babies one or more genes are faulty. They provide the wrong information for the body to grow and run itself. These babies have genetic disorders.

In most countries about one baby in 30 has a genetic disorder. Many genetic disorders can be treated by operations or drugs or eating special foods, so that the affected babies can grow up normally. Many are not treatable yet, although we hope that one day they will be, as science discovers more about how genes work and what they do in our bodies.

Types of genetic disease

There are many hundreds of genetic disorders. Most of them are very rare. One group of disorders are called

All families need some help in understanding genetics

Further reading

If you want to know more about genetics, try the following publications:

'Amazing Schemes Within Your Genes'

Dr Fran Balkwill and Mic Rolph
Harper-Collins Publishers Ltd

'Genetic Engineering'

Jenny Bryan, 1995, Wayland
Publishers Ltd

'The Cartoon Guide to Genetics'

Larry Gonick and Mark Wheelis,
1991, Harper Perennial

The Genetic Interest Group has articles on a variety of subjects related to genetics. Give us a call. We'll send them to you free of charge. Please send an s.a.e.

What are the issues?

chromosome abnormalities. Patau's syndrome and Edward's syndrome are two examples of such disorders. Babies born with them usually have physical abnormalities and die very soon.

Another group of genetic disorders are the *single-gene abnormalities.* Here only one gene is faulty, but it may cause serious problems. Huntington's disease is one example. The person is healthy until about 35 years of age, but then he or she begins to make twitchy, jerky, uncontrollable movements; the brain is also affected and memory and thinking powers fade. There is no treatment.

Other single gene abnormalities include muscular dystrophy, which affects only boys, where the muscles become weak and waste away. Another is haemophilia which also affects only boys, when the blood does not clot properly. In these disorders the body cannot make

Glossary of terms used in genetics

Genetics is riddled with technical terms. Here are some of them, simplified:

Carrier A person who has one faulty and one working copy of a gene for a recessive genetic disorder or for a characteristic. Carriers of most recessive disorders are themselves unaffected because the working copy of the gene overrides the faulty copy, but they can pass on a copy of the faulty gene to their children

Cell The smallest living part of any living thing. We all have millions of cells which do many different jobs

Chromosome A thread-like structure found in the nucleus of human, animal and plant cells. It is made up of DNA (which carries the genes) and protein. Humans have 23 pairs of chromosomes, including a pair of sex chromosomes

Dominant If a faulty gene is dominant, it will show an effect even though there is a working copy of the gene on the other chromosome. A person only needs to inherit a faulty gene for a dominantly inherited condition, from one parent, to develop the disease

DNA Deoxyribonucleic acid: A substance in nearly all living things that forms the structure of genes. In humans, animals and plants, the DNA is found in the chromosomes

Enzyme A protein which helps chemical reactions to take place in cells

Gene A section of DNA that carries the instructions for making an enzyme or other protein

Gene therapy Attempting to cure genetic

diseases by placing a normal 'healthy' gene into cells that have a faulty version of that gene

Genetic code The way in which messages for protein are 'written' in DNA

Genetic engineering The deliberate alteration of a living thing by modifying its DNA and changing its genetic make-up

Geneticist An expert in the study of genes and heredity

Genome All the genes of an organism

Hormones Substances in humans, plants and animals that help cells to function properly

Mutation A change in the structure of DNA. Such changes can be passed on to the next generation. A few mutations are beneficial, but others can cause genetic disorders

Nucleus The central part of human, animal and plant cells; it controls a cell's functions and contains the chromosomes

Protein A large molecule made of hundreds or thousands of amino acids. Proteins are essential to all living things

Recessive If a faulty gene is recessive, it will usually show no effect unless the same recessive gene is faulty in both of a pair of chromosomes. A person who inherits two faulty copies of the gene (one from each parent) will have the disorder. A person who only inherits one faulty copy of the gene will be a carrier and could pass the faulty gene onto any children he/she may have

X-linked Refers to the inheritance of a particular characteristic or disorder from a gene carried on the X (or female sex) chromosome. Also known as sex-linked inheritance.

2 What are the issues?

certain chemicals it needs, because the genes that carry the information for making them are missing or faulty.

Tay Sachs disease, tuberous sclerosis, thalassaemia, sickle cell and cystic fibrosis are also single gene abnormalities. Some of these can be treated with drugs which control some of the symptoms, even if they don't bring about a cure.

A third group of genetic disorders consists of *multifactorial abnormalities*. This means several genes are faulty. Other diseases such as diabetes and cancer are affected partly by genes in that, for some people, their genes may make it more likely that they have a higher risk of getting these diseases. But it needs something else in their environment or lifestyle to trigger off the condition.

As genes are passed from parents to children, so are the disorders – but only sometimes. Inheritance is complicated, and the way genes work means that in some cases neither parent has a genetic disorder but their child does have one. Or, one parent may have a genetic disease but the child does not inherit it. Sometimes a disorder skips a generation; a grandparent and grandchild have it, but not the parents in between. Some disorders affect only girls, or only boys.

Medical geneticists and genetic counsellors are experts on genetic diseases and inheritance. In the case of some single-gene and chromosome abnormalities they can work out the chance of a baby having a genetic disorder. To do this they need to test family members, including grandparents, aunts and uncles, and other relatives. Couples who wish to have children but who think that a genetic disease runs in their family can go to a genetic counsellor at a Regional Genetic Centre for advice on the risks (see page 25 for a list of all the Regional Genetic Centres in Britain).

A number of disorders can be detected by special tests before a baby is born. Parents at risk can have tests during the mother's pregnancy. If the result is positive, they can ask for a termination of the pregnancy, if they so wish.

In many cases a child is born with a genetic disorder where no disorder can be traced in the family for generations. This is because of a change, or mutation, in the genes. We do not know yet how most mutations happen. Because of mutations, however, genetic disorders are always likely to be with us.

Inheritance is complicated, and its effects vary depending on the genetic disorder involved

Couples who wish to have children but who think that a genetic disease runs in the family can go either to their GP or a genetic counsellor for advice

What are the issues?

One of my family members has a genetic disorder – will that affect me?

If one of your family members, who is a blood relative, actually has a genetic disorder, then there is a possibility that you may have inherited the same faulty gene. There is also a possibility that you may *not* have inherited the same faulty gene.

Genetic disorders caused by defects in single genes are inherited, or passed on, in three different ways: as dominant disorders; as recessive disorders; or as x-linked disorders. The way in which the disorder that affects your family is inherited may mean that you could have inherited the same faulty gene and could also pass it on to your children.

For some disorders it is possible to have a genetic test to find out if you have inherited the same faulty gene.

If you wish to find out whether the genetic disorder that runs in your family has any implications for you, ask your family doctor, the hospital doctor that looks after your brother or sister, or the genetic counsellor at your Regional Genetics Centre to explain the condition that affects your family to you, plus all the implications for you now and in the future, if any. They will be able to arrange for you to have a test, if one is available.

There are three main ways that a genetic disorder can be passed on

Family dilemmas

It can be difficult to discuss with each other the genetic condition that affects your family and the possibility of some of you being a carrier or of developing the condition yourself in later life. It can be a difficult subject for parents and their children because of the fear of what they don't know. Actually talking about the concerns and sharing them usually makes everything easier to deal with – when everyone involved feels ready to bring things out into the open.

Remember that a genetic disorder in the family is no-one's fault. It's just one of those things that happen. There's a chance that you may not be a carrier at all (see the previous page).

If you wish to find out whether you are a carrier of the genetic disorder that runs in your family, contact your family doctor, the hospital doctor that looks after your brother or sister, or the genetic counsellor at your Regional Genetics Centre.

Tell him or her that you would like to discuss this subject

A PARENT

'My children are getting older and I don't know if any of them carry the disorder that runs in our family or not. I don't know how to begin to talk to them about it, although I know that it's important that we do. I don't want to worry them. I already feel guilty about one of our children inheriting the disorder from us.'

2 What are the issues?

with your family, but aren't sure of how to go about it. Genetic counsellors, particularly, are trained to offer you advice and support in this situation.

Ask for an explanation of the condition that affects your family, plus all the implications for you now and in the future, if any. They will be able to arrange for you to have a test, if one is available.

If there is a support group for the condition that affects your family, speak to other parents or brothers and sisters in the group, to see how they started to discuss the subject.

SISTER OF SOMEONE WITH A GENETIC DISORDER

'My brother's got a genetic disorder. I didn't know this before, but I recently read in a leaflet I picked up that I might have inherited some bit of it... though I'm not sure what... and that it could have an effect on my children, if I have any. I don't know whether I should tell my boyfriend about it or not. We've never talked about it in the family. I don't know why. It's a worry that's at the back of my mind. I want to do something about it,

Getting information and finding support

General sources of information

There are a number of sources. Try them all! Keep trying them until you feel you've got what you need (or, at least, everything that's available).

Speak to your family doctor (GP) and ask for leaflets and information about relevant organisations. It may be that your GP doesn't know much beyond the basics about the condition that affects your family. Be patient – remember, as genetic conditions are rare, this may be the first time he or she has come across it. Check out the other sources.

Contact the genetic counsellor at your Regional Genetics Centre. These centres are part of the National Health Service and their services are free. In some cases, your family doctor may need to make the appointment for you. Genetic counsellors are trained to provide information and support to families at-risk for a genetic disorder in their region; this is their specific responsibility. Ask them to put you in touch with a support group. The addresses and telephone numbers of all the Regional Genetics Centres in Britain are on page 25.

If a member of your family has a genetic disorder and visits a doctor at the hospital, you can also speak to him or her.

Contact the Genetic Interest Group (GIG), on 0171 430 0090. GIG is a national charity working to benefit all people affected by genetic disorders. Staff can provide you with information on support groups for rare as well as common genetic conditions. We also have a list of publications on issues affecting at-risk families and a quarterly newsletter, which are available free of charge. For more information about GIG's aims and activities plus the list of publications, see page 15. Staff will happily call you back if you are making a long-distance call.

Get in touch with Contact a Family (CaF) on 0171 385 3335. CaF is a national charity which supports families who care for children with disabilities and special needs, including those who have, or are at-risk for, a genetic condition.

CaF's work ranges from offering advice and information to individual families and providing links between them, through national, regional and local support groups, to publishing information which would be helpful to

The genetic counsellor at your Regional Genetic Centre will be able to help you

Get in touch with the Genetic Interest Group

An organisation called Contact a Family offers a wide range of help and advice

3 Getting information and finding support

families and professionals, and bringing the views of the families to politicians and the wider public. See page 16 for the range of information and help available from Contact a Family.

Find a support group through the Genetic Interest Group or Contact a Family. Many support groups have been started by parents who felt isolated when they were told their child had a genetic disorder. Those parents identified others in a similar situation and arranged meetings where they could share experiences and knowledge, and offer each other support.

There are support groups located all over the country, started by parents

Quite often, parents have said that they have gained tremendous strength through being in contact with other parents. The first aim of all support groups, large or small, is to offer support to families.

There's a list of the support groups for families at risk for a genetic disorder affiliated to the Genetic Interest Group on page 31. New ones are cropping up all the time, so do ring GIG (0171 430 0090) to find out if the condition that affects your family is not listed. Remember, if contacting GIG means you have to make a long-distance call, staff will be happy to call you back.

Some of the larger, more established groups have a helpline and regular newsletter. Some have newsletters especially for young people. They also publish information sheets and booklets for children, siblings and parents on issues such as organising help at home, opportunities for holidays, leisure activities and other issues relevant to the family. Some arrange conferences and seminars where families and professionals can get together, or run support groups and events especially for brothers and sisters. So there's a lot happening out there. Contact the group relevant to your family for the information.

Some groups produce newsletters and run helplines as well as holding meetings

Some groups also run support groups and events especially for brothers and sisters. Contact a Family can provide you with information on almost every support group in the country.

If your most local group is still too far away, why not get together as a family and start one that would be closer? There's lots of help available if you wish to do that. Get in touch with a Parent Adviser at Contact a Family. Parent Advisers offer information, advice and support to families who have children with special needs. They are also there to listen if you want to talk something through, if that is all you want to do.

You could start up a support group yourself

Getting information and finding support

However, at times *you may not want to get involved with a support group*. If that's how you feel at the moment, you can still send off for information leaflets and newsletters, or keep in touch through the Internet.

Newsletters are a great way of keeping up-to-date on the latest developments in terms of treatment, upcoming events, and help and information currently available. Contact the organisation or support group for people with the same condition as your family. Some produce newsletters especially for young people. They are usually free, but some groups do ask you to pay a small charge. Why not ask for information leaflets at the same time!

Helplines are run by a number of support groups and other organisations. Helplines allow you to speak to people in confidence, knowing that they have some experience of the issues you are dealing with. If you want to talk through an issue, someone is at hand to listen. If you have a question and don't know who to ask or where to look, you will be able to get assistance through a helpline. If you are making a long-distance call, do ask people to phone you back. All the reputable helplines are listed in the Telephone Helplines Directory. There should be a copy at your local library. There's more information on the Telephone Helplines Directory on the page opposite.

There are a number of telephone helplines you can call

The Internet is another great way of accessing information. Not everyone may feel confident about using the Internet, but it really is simple once you've learnt a few basic instructions. Through the Internet you can access information about genetic disorders, services available, events, and a whole lot more. A number of support groups and other organisations connected with genetics are in the process of acquiring their own website, and there are websites specially for siblings too (see page 14 for more information).

If you don't have a computer at home, there should be one at your local school, college or university – or go along to your local public library. Someone at the enquiries desk should be able to give you help on how to use the Internet facility.

Telephone helplines

Helplines are run by a number of support groups and other organisations. Helplines allow you to speak to people in confidence knowing that they have some experience of the issues you are dealing with. If you want to talk through an issue, someone is at hand to

Your nearest public library should have a Telephone Helplines Directory

3 Getting information and finding support

listen. If you have a question and don't know who to ask or where to look, you will be able to get help through a helpline. If making a long-distance call, do ask people to phone you back.

The Telephone Helplines Association publishes a Telephone Helplines Directory (your local library should have a copy in the reference section – ask at the enquiries desk) which is a national source of information about national, regional and local helplines. Helplines listed in the directory offer a non-commercial, confidential and non-judgmental service, which includes advice, information, counselling, listening, befriending and signposting to other services. The Directory is a major source of information for advice workers and many other professionals working in the fields of social welfare and health, and for the general public.

The Directory is a major source of advice for professionals – and it can help you too

There are 22 subjects covered by the Directory, which include:

- Children and young people;
- Carers;
- Family and parents;
- Health;
- Disability;
- Mental health; and
- Legal.

You can contact the organisation at:
 Telephone Helplines Association
 Resource Information Service
 The Basement
 38 Great Pulteney St
 London
 Tel: 0171 494 2408

All the information in the directory is also available on the Telephone Helplines Association's website at <http://www.helplines.org.uk>

The Internet

Not everyone may feel confident about using the Internet, but it's simple once you've learnt a few basic instructions. The Internet gives you speedy access to lots of up-to date information. Through this service you can get information about genetic conditions, services available, events and lots, lots more.

Websites created by support groups are springing up all the time

A number of support groups and other organisations connected with genetics are in the process of acquiring

Getting information and finding support

Here are some websites we've come across:

<http://www.cafamily.org.uk> (Contact a Family)

<http://www.drpaula.com> (chromosome, general)

<http://www.nb.net/~tbon/trisomy/trisomy.html> (MUMS – Mothers United for Moral Support)

<http://waisman.wisc.edu/~rowley/mums/home.htm> (Rare Genetic Diseases in Children)

<http://mcrcr2.med.nyu.edu/mur-php01/homenew.htm> (The Alliance of Genetic Support Groups)

The Genetic Interest Group will soon be acquiring a website. Give us a ring in the near future to find out the website address.

their own website. There are websites specifically for siblings too. If you don't have a computer at home, there should be one at your local school, college or university, or try your local library. There'll be someone there to show you how to access the Internet. Ask at the enquiry desk.

A word of caution about information on the Internet. Some information may have been put there by individuals. There is no guarantee that this information is medically correct or applicable to your situation. It is best to get information from organisations that you know have some expertise in the field of genetics or special needs.

Especially for siblings!

Check out Sibling Support in Cyberspace – it's at <http://www.chmc.org/departmt/sibsupp>. This World Wide Web site is packed full of information of interest to siblings, parents, extended families and professionals working with special needs persons. It also gives you access to SibNet, which is the first ever listserv (online discussion group) for the adult brothers and sisters of people with special needs. This is a list of people forming an online community, connected through e-mail, dedicated to adult sibling issues. It is a place where young adults and adult brothers and sisters can share information and discuss issues of common interest. It is also a relevant site for parents, service providers and others interested in the well-being of siblings.

There's a website for younger brothers and sisters on page 5 of the other booklet. Do check it out, especially as younger members of the family may need some help to get started

3 Getting information and finding support

Genetic Interest Group (GIG)

GIG is the only charity concerned with all genetic disorders, and is an alliance of over 120 charities and voluntary organisations which support children, families and individuals affected by genetic disorders. GIG aims to:

- Raise professional and public understanding of genetic disorders;
- Ensure high quality services for people affected by genetic disorders;
- Bring patient views to policy and ethical debates on issues concerning human genetics; and
- Promote dialogue between professionals and service users.

GIG:

- Co-ordinates and communicates member views to Government, the health service and other agencies on genetic issues;
- Holds regular conferences, seminars and other events which bring service users and professionals together to discuss topics of common concern;
- Puts people in touch with support groups and other services;
- Produces a regular newsletter called '*GIG Today*', carrying information on issues and policy developments, new initiatives, services and the work of support groups;
- Provides information, training and support to its members; and
- Trains GPs, midwives and other health professionals.

GIG's own helpline is open Monday to Friday from 9am to 5pm, on **0171 430 0090**. You can ring GIG on any issue concerned with genetics. A member of staff will deal with your enquiry or provide you with details of someone else who can. You can send off for a free copy of '*GIG Today*'. If you would like to see our publications list, we'll send it to you absolutely free of charge. Please enclose an s.a.e.

GIG is a national alliance of more than 120 different charities

Contact GIG at this address:

Genetic Interest Group
Farringdon Point
29-35 Farringdon Road
London EC1M 3JB

Tel: 0171 430 0090
Fax: 0171 430 0092

Our E-mail address is:
101366.760@compuserve.co

Getting information and finding support

Contact a Family (CaF)

CaF is a national charity which supports families who care for children with disabilities and special needs, including those who have, or are at-risk for, a genetic condition. Contact a Family's specific aims are:

- To encourage families living in the same area to form local self-help groups;
- To form national networks of families whose children suffer from rare disorders; and
- To provide an information service for families and professionals.

CaF can give you information on almost any support group in the country, and if you wish to start a parent or sibling support group, their Parent Advisers will be able to offer you advice on how to go about it.

Contact Line is CaF's helpline, on 0171 383 3555. It provides a listening ear for all callers, whether parent, carer, relative or professional worker, plus information and advice.

Contact a Family produces a range of very informative and useful materials you can send off for, including:

- Posters;
- Group Action Pack (on setting up support groups);
- Conference papers;
- A quarterly magazine, called *'Share an Idea'*;
- A publications list; and
- Factsheets.

The factsheets are a particularly good (free!) resource for carers and families, as they are packed with useful and practical information and advice.

Contact a Family
170 Tottenham Court Road
London W1P 0HA
Tel: 0171 383 3555
Fax: 0171 383 0259
E-mail: info@cafamily.org.uk
Website: <http://www.cafamily.org.uk>

CaF has a national network of families, all helping each other

CaF Factsheets currently available include:

'Siblings and Special Needs'

'Living Without a Diagnosis'

'Holidays – A Guide for Parents Planning a Holiday with a Disabled Child'

'Planning for the Future – The Transition from Child-Based Services to Adult Services'

'Child Disability Benefits and Other Sources of Help'

'Caring for Children with Disabilities and Special Needs – A Guide for Students and Professional Workers'

'A Parents' Guide to Statements of Special Education Needs'

4 Getting help on specific issues

Carers – that means brothers and sisters too!

The **Carers' National Association (CNA)** is the national voice of carers in the UK. It has a nation-wide network of branches and groups which support carers and provide an opportunity to share experiences and information. The CNA's work involves:

- Raising awareness of the needs of carers at all levels of government and society and ensuring action is taken to support them;
- Helping carers become more aware of their own role and status in the community; and
- Providing information, advice and support to carers, enabling them to make their own choices about providing care.

The CNA provides information in the following areas:

- General leaflets;
- Benefits claim packs;
- Information booklets;
- Publications for professionals; and
- Information packs for students and professionals.

Specifically for young carers the CNA has the following:

- *'Under 18? Know about young carers?'* This leaflet for young carers explains how to get help from Social Services;
- *'Young Carers Information Pack'*. Aimed at 12 to 18-year-olds this pack is full of helpful advice and information; and
- *'Link'*. A quarterly newsletter for young carers between 10 and 18.

The Carers' National Association can offer brothers and sisters a considerable amount of help

Contact the Association at:
 Carers' National Association
 Head Office
 Ruth Pitter House
 20-25 Glasshouse Yard
 London EC1A 4JS
 Tel: 0171 490 8818
 Fax: 0171 490 8824
 Email: Internet@ukcarers.org.
 Website: <http://www.carersuk.demon.co.uk>

The Association also has a helpline called **CarersLine**.

Getting help on specific issues

It's the best starting point if you want to contact them. Call 0345 573369 (local rate call) Monday to Friday, 10am to 12noon and 2pm to 4pm.

There are a couple of other useful publications available from CNA:

The London Directory of Organisations Supporting Black and Minority Ethnic Carers lists a broad range of agencies supporting black and minority ethnic carers in London, and gives important information of what actual services are provided, languages spoken, publications, opening hours and so on. The directory is a guide and reference document for black and minority ethnic carers as well as for professionals involved with the relevant communities in London. It is available from:

Carers' National Association (London)

11 John St

London WC1N 2EB.

Tel: 0171 404 2900

Fax: 0171 404 9552

Price: £15 including p&cp.

'After Age 16, What Next? Services and Benefits for Young Disabled People'

This is a comprehensive book covering such subjects as money matters, services, mobility, work, training and community care. It is available free to young people with special needs and their parents and carers. It's priced at £4 (including p&p) for all others.

Available from:

The Family Fund Trust

PO Box 50

York YO1 2ZX.

Support for minority ethnic carers

Parents and other carers in employment

If you're a working parent or a working brother or sister who is a carer, it can be even harder to make time for everything you would like to do. Balancing responsibilities at home and at work, possibly on a tight budget, is no easy task.

It may be worth your while contacting an organisation called **Parents at Work**.

Parents at Work (PAW) is a charity campaigning for issues relevant to working parents; issues that are also relevant for other carers in the family. PAW produces a newsletter, runs conferences, publishes information materials and offers advice. It also runs a publication

Parents at Work campaigns nationally for people who need to work as well as caring for family members

4 Getting help on specific issues

specifically for parents of children with disabilities and special needs, called **'Waving *not* Drowning'**.

PAW runs a quarterly newsletter (also available on audiocassette), available free of charge. Its helpline on 0171 588 0802 is available between 9am and 5pm Wednesday to Friday, for you to discuss any aspect of balancing work with caring.

Parents at Work also produces a series of factsheets to help you balance work and home. Factsheets on the following topics are available:

- What type of childcare;
- Childminders;
- Nannies and mothers' helps;
- Au pairs;
- Nurseries;
- Maternity rights; and
- Flexible working.

For copies, phone the information line on 0171 628 3578 or send an A4 s.a.e. to:

Parents at Work
45 Beech St
London EC2Y 8AD
Tel: 0171 628 3565
Fax: 0171 628 3591

'Waving *not* Drowning' is a contact directory which lists working parents of children with disabilities or special needs so that they can contact each other for mutual support. The directory is only sent to people whose names appear in it. For copies phone the information line or send an A4 s.a.e. to the address above.

The Nigel Clare Network Trust (NCNT) helps families to help themselves avoid the diagnosis of a child's special needs becoming the prognosis of financial hardship. The NCNT was set up to offer practical help and raise awareness and understanding amongst families, employers and professionals. The Trust is all about helping families take control of their own lives, and it provides in-depth financial and career counselling for families, and runs workshops in various parts of the country.

'More needs than most', a book by Mairi Putt, one of the founders of the NCNT, draws on the experiences of hundreds of families. It details the financial difficulties that families may experience, and is full of useful ideas to help them plan ahead. It is available from Parents at

PAW produces factsheets and a newsletter

*Working parents of children with disabilities can contact and help each other through the 'Waving *not* Drowning' programme*

Getting help on specific issues

Work. You can contact the Nigel Clare Network Trust at:

The Nigel Clare Network Trust
85, Moorgate
London EC2M 6SA
Tel: 0171 256 8313

Publications for you and your employer

Increasingly, parents are wanting greater flexibility in their work patterns to enable them to combine work with family life, particularly so if they are also caring for a child with a disability.

There are a number of books and guides that can help carers in the workplace

'*An Employee's Guide to Flexible Working*' (£3.99 including p&cp) sets out a range of options: job-sharing; teleworking; term-time working; and annualised hours. It lists the pros and cons of each, and helps you think through how you might approach your boss. Available from Parents at Work.

'*Managing Flexible Working*' (£4.99 including p&cp) explains how flexible working can benefit employers, and provides a step-by-step guide to help managers through the issues. Available from Parents at Work.

Making life easier for ourselves and for the family

Some genetic conditions can be debilitating, either physically or mentally, or both. Providing constant care for someone with disabilities can often be overwhelming for parents, brothers and sisters. Parents can be too exhausted to give sufficient time to themselves or to their other children. In recognition of the variety of needs in this type of situation, a number of organisations have organised play schemes or respite care, special facilities which allow families to create leisure time for themselves as individuals and as a family.

When caring for somebody who needs constant attention just becomes too exhausting, you need a break

Contact a Family has produced an excellent factsheet called '*Holidays*'. It provides information on organisations that provide holidays and holiday accommodation for families and children with special needs, plus holiday advice, equipment and sources of finance.

If you are stressed out by looking after a family member who needs a lot of care, then this factsheet is a must for equipping yourself with all the information to organise a break. At the same time, you could ask Contact a Family to send you their other factsheets (see page 16 for the full list). They're all free and packed with useful information. You can get hold of them at the following address:

4 Getting help on specific issues

Contact a Family
170 Tottenham Court Rd
London W1P OHA
Tel: 0171 383 3555
Fax: 0171 383 0259
E-mail: info@cafamily.org.uk
Website: www.cafamily.org.uk

Contact your local **Social Services Department** for details of local respite-care facilities. They may have Befriending or Family Link schemes to offer short-term breaks to families, via local volunteers. The phone number will be in the telephone book.

Social Services may have a scheme that will help the family recharge its batteries

What about the future?

For brothers and sisters with a sibling who needs a lot of looking after, the anxieties about their role in their sibling's life can begin from an early age. During adolescence, there is a growing awareness of the choices available as each individual gets older, and of the need to make these choices.

Brothers and sisters who have taken on a caring role from a young age need to decide how that role will fit into their future, if at all. It is clear to young people in this situation that their parents are getting older and won't be with them forever. So, who will take over their responsibility? Which brother or sister? How will it affect each one's life and the lives of their families? What about the financial arrangements?

As parents age, the siblings of a disabled brother or sister have to decide how to handle the future

Each family situation has its specific concerns. What is common to all is the need to share those concerns and make some decisions as a family to ensure the wellbeing of all and not to sweep anger, resentment and worry under the carpet – hoping the feelings will go away. Financial provision for the future eases a number of problems for families with a disabled person. You can get help from the following organisations:

- The **Disability Law Service**, a law and advisory charity for disabled people and their families. Send an s.a.e. (9 by 6 inches) for its information sheet '*Setting Up a Will or Trust for People with Disabilities*'
Their address is:
The Disability Law Service
2nd Floor, High Holborn House
52-54 High Holborn
London WC1V 4RL
Tel: 0171 831 8031

Getting help on specific issues

- **MIND**, the mental health charity. It can send you free details of solicitors who specialise in trusts and wills, in your local area.
MIND infoline
Tel: 0181 522 1728 (in London)
Tel: 0345 660 163 (outside London)
- **MENCAP** produces a useful booklet for parents, *'Leaving money by will to people with learning disabilities'*. Cost: 50p.
Public Liaison Unit
MENCAP
Golden Lane
London EC1Y 0RT
Tel: 0171 454 0454

When death threatens a family

Different genetic disorders have different effects; some people are mildly affected whilst others need a lot of treatment to survive.

For some, sadly, there may be little treatment or cure, and death early in life is inevitable. A number of organisations offer support to families in such situations.

A number of organisations offer help where genetic disorders lead to death

The **Child Bereavement Trust (CBT)** offers support and counselling for grieving families. The CBT has a publications catalogue that includes booklets, videos and cards. Some of these resources are specifically for children, some for parents and families.

The Child Bereavement Trust
The Harleyford Estate
Henley Rd
Marlow
Buckinghamshire SL7 2DX
Tel: 01628 488101

The Compassionate Friends (TCF) is a nationwide organisation of bereaved families. It supports other bereaved parents and their immediate families through a national helpline, one-to-one visiting, group meetings, telephone and/or letter contact, a wide range of leaflets, and a quarterly newsletter. These can be ordered from:

The Compassionate Friends
National Office
53 North Street
Bristol BS3 1EN.
Tel: (Admin and fax) 0117 966 5202
National office and helpline, tel: 0117 953 9639.

4 Getting help on specific issues

The Compassionate Friends' extensive postal library has over 1,000 book titles plus articles. There are many books for siblings of all ages and these are incorporated in the library list, costing £2.50. Audio tapes and videos are also available on loan. The list and other items can be obtained from:

Catharine Pointer
77 Rectory Lane North
Leybourne
West Malling
Kent ME19 5DH

If you write to Catharine stating your circumstances she can help in making a selection from the books, articles and audio/video tapes which would be relevant for you. Four items can be ordered in each mailing at a cost of £3 plus post and packing. There is a reduced price for full-time students and low-income families. You can also order the booklist from the national office on 0117 953 9639.

SIBBS (Support in Bereavement for Brothers and Sisters) is supported by The Compassionate Friends. SIBBS has a support network and publishes a newsletter (also available on audiocassette) four times a year. The '*SIBBS Newsletter*' publishes your letters, poems and drawings, as well as any other items you think will help other bereaved brothers and sisters. Contact SIBBS on:
Tel: 0117 953 9639
E-mail: info@sibbs.demon.co.uk

Cruse Bereavement Care is a national charity offering help to all who are bereaved, young and old, men, women and children. Cruse offers personal and confidential help to bereaved people and those who care for them through:

- Counselling – the opportunity to talk through feelings in confidence with a trained counsellor, who has the knowledge and understanding of the process of grief;
- Information on many aspects of bereavement, including practical and financial matters; and
- Social support groups – which offer support and companionship.

Cruse also has a list of publications:

- About bereavement;

The Compassionate Friends can select the right materials to suit your circumstances

Cruse offers help and counselling for people who are trying to cope with a death in the family

Getting help on specific issues

- Losing a partner;
- Practical information;
- Comforting the bereaved; and
- Help for bereaved children.

You can get in touch with Cruse Bereavement Care at:

Cruse House
126, Sheen Rd
Richmond
Surrey TW9 1UR.
Tel: 0181 940 4818
Fax: 0181 940 7638

The Children's Liver Disease Foundation produces four leaflets on the issues of bereavement. These are:

- *'Children and Bereavement'*;
- *'The Death of a Child'*;
- *'I'm Sorry Your Child Has Died'*; and
- *'When a Child Dies'*.

The leaflets all handle a painful topic with sensitivity. They are available free with s.a.e. from:
The Children's Liver Disease Foundation
1st Floor, 138 Digbeth
Birmingham B5 6DR.

Books dealing with grief and loss

The following books are available from PARC (Paediatric Aids Resource Centre) at: PARC Edinburgh, Dept of Child Life and Health, 20 Sylvan Place, Edinburgh EH9 1UW

'What do we tell the children? Books to use with children affected by illness and bereavement'

Price: £5 (plus £1 p&cp). This is a collection of 156 books that deal with grief and loss.

There are four interactive booklets for 3 to 7- year-olds, each with a simple story line encouraging children affected by parental illness to talk through worrying issues with a trusted adult:

'Maybe Another Day'

As a result of chronic illness, Lucy's Mum is not always able to do as much with Lucy. Lucy needs reassurance that she is not to blame for Mum's illness and that Mum's love is constant.

'Missing Mum'

This booklet helps prepare for separation. Lucy stays with an aunt when Mum has to spend some time in hospital.

'Getting to Know Sandra'

This focuses on preparing Lucy for going into respite care. Lucy and Mum visit a carer.

'Tell Me Again What Happens'

This concerns Mum's death and the planning of future care for Lucy. Lucy, her family and friends say goodbye to Mum at the funeral. Lucy has been prepared and knows where her home will be.

Throughout the books there are blank pages where children can draw or write about their own personal experiences. Each book costs £2.50 each, or £9 for the set.

Some of the telephone numbers given are for the hospitals in which the genetic centres are based. Ask to be put through to the Genetics Centre. Then ask for the genetic counsellor.

S.E. Thames Regional Genetics Service

Division of Medical & Molecular Genetics
8th Floor Guy's Tower
Guy's Hospital
LONDON SE1 9RT
Tel: 0171 955 4648 /9
Fax: 0171 955 4644
(Catchment area: Kent, E. Sussex, Bromley, Greenwich, Bexley, Lambeth, Southwark, Lewisham)

S.W. Thames Regional Genetics Service

St Georges Hospital Medical School
Cranmer Terrace
LONDON SW17 0RE
Tel: 0181 767 8150
Fax: 0181 725 3444
(Catchment area: S.W. London, Surrey, W. Sussex)

N.E. Thames Regional Genetics Service

Mothercare Unit of Clinical Genetics & Fetal Medicine
Institute of Child Health
30 Guilford Street
LONDON WC1N 1EH
Tel: 0171 242 9789 x 2647
Fax: 0171 831 0488
(Catchment area: Barking, Havering, Brentwood, Baidon, Thurrock, Bloomsbury, City & Hackney, Enfield, Hampstead, W., N.E., & Mid Essex, Southend, Waltham Forest, Tower Hamlets, Redbridge, Newham, Haringey, Islington)

N. Thames Regional Genetics Service

Clinical Genetics
Royal Free Hospital
Pond Street
LONDON NW3 2QG
Tel: 0171 794 0500 x 5163
Fax: 0171 830 2917
(Catchment area: New River, Edgware, Barnet, Whitechapel, Newham)

N.W. Thames Regional Genetics Service

Kennedy Galton Centre
Northwick Park & St Marks NHS Trust
Watford Road
HARROW
Middlesex HA1 3UJ
Tel: 0181 869 2795
Fax: 0181 869 3106
(Catchment Area; Hertfordshire, Bedfordshire, Barnet, Hillingdon, Brent & Harrow, Ealing, Hammersmith, Hounslow, Kensington, Chelsea, Westminster, Ashford)

East Anglia Regional Genetics Service

Department of Clinical Genetics
Box 134
Addenbrooke's Hospital NHS Trust
CAMBRIDGE CB2 2QQ
Tel: 01223 216 446 or 01223 217 027
Fax: 01223 217 054
(Catchment area: Cambridgeshire, Norfolk, Suffolk, parts of N. Essex, Hertfordshire, Lincolnshire, Bedfordshire)

Oxford Regional Genetics Service

Department of Clinical Genetics
The Churchill Hospital
Old Road, Headington
OXFORD OX3 7LJ
Tel: 01865 226 000
Fax: 01865 226 011
(Catchment area: Oxfordshire, Northamptonshire, Buckinghamshire, Berkshire, Swindon)

Wessex Clinical Genetics Service

Princess Anne Hospital
Coxford Road
SOUTHAMPTON SO16 5YA
Tel: 01703 796 166
or 01703 796 170
or 01703 798 537
or 01703 794 268
Fax: 01703 794 346
(Catchment area: Hampshire, Dorset, Isle of Wight, Salisbury)

Regional Genetic Centres

Devon & Cornwall Clinical Genetics Service

Department of Child Health
Royal Devon and Exeter Hospital (Wonford)
EXETER EX2 5DW
Tel: 01392 403 151/2 /5
Fax: 01392 403 158
(Catchment area: Devon, Cornwall)

Bristol Clinical Genetics Unit

Institute of Child Health
Bristol Royal Hospital for Sick Children
St Michaels Hill
BRISTOL BS2 8BJ
Tel: 0117 928 5652
Fax: 0117 928 5167
(Catchment area: Avon, Somerset, Gloucester, Cheltenham)

W. Midlands Regional Clinical Genetics Service

Clinical Genetics Unit
Birmingham Maternity Hospital
Edgbaston
BIRMINGHAM B15 2TG
Tel: 0121 627 2630
Fax: 0121 627 2618
(Catchment area: Staffordshire, Shropshire, Warwickshire, Birmingham, Hereford & Worcester, W. Midlands, Leicester)

Yorkshire Regional Genetics Service

Department of Clinical Genetics
Ashley Wing
St James's University Hospital
Beckett Street
LEEDS LS9 7TF
Tel: 0113 283 7070/1/2/3/4
Fax: 0113 246 7090
(Catchment area: N. Yorkshire, Bradford, W. Yorkshire, Leeds, Wakefield, E. Riding, Grimsby, Scunthorpe)

Sheffield Centre for Human Genetics

Langhill
117 Manchester Road
SHEFFIELD S10 5DN
Tel: 0114 271 7025
Fax: 0114 266 7333
(Catchment area: Doncaster, Worksop, Barnsley, Chesterfield, Rotherham, Sheffield, Buxton)

Nottingham Department of Clinical Genetics

2nd Floor H Block
City Hospital NHSTrust
Hucknall Road
NOTTINGHAM NG5 1PB
Tel: 0115 962 7728
Fax: 0115 967 7711
(Catchment area: Nottingham, N. Nottinghamshire, Lincolnshire, S. & N. Derbyshire)

Northern Region Genetics Service

19/20 Claremont Place
NEWCASTLE-UPON-TYNE NE2 4AA
Tel: 0191 222 7711 or 0191 227 5127
Fax: 0191 222 7143
(Catchment area: Cleveland, Durham, Tyne & Wear, Northumberland, Cumbria)

Mersey Regional Genetic Service

Royal Liverpool Children's Hospital
Alder Hey
Eaton Road
LIVERPOOL L12 2AP
Tel: 0151 706 4019
Fax: 0151 706 5851
(Catchment area: Liverpool, Wirral, Southport, St Helens & Knowsley, Warrington, Runcorn, Chester, Crewe, Isle of Man)

Chester Regional Clinical Genetics Service

Moston Lodge
Countess of Chester Hospital
Liverpool Road
CHESTER CH2 1UL
Tel: 01244 364 754
Fax: 01244 365 089
(Catchment area: Warrington, Halton, Crewe, S. Wirral)

Manchester Clinical Director for Medical Genetics

Department of Medical Genetics
St Mary's Hospital
Hathersage Road
MANCHESTER
M13 0JH
Tel: 0161 276 6262
Fax: 0161 248 8308

(Catchment area: Lancaster, Blackpool, Preston, Blackburn, Burnley, Chorley, Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford, Wigan)

Manchester Paediatric Genetics Unit

Royal Manchester Children's Hospital
Hospital Road
Pendlebury
MANCHESTER
M27 4HA
Tel: 0161 727 2335
Fax: 0161 727 2328

(Catchment area: Greater Manchester, Lancashire, Cumbria, Warrington)

Leicestershire Clinical Genetics Service

Leicester Royal Infirmary
LEICESTER
LE1 5WW
Tel: 0116 258 5736
Fax: 0116 258 6057

(Catchment area: Leicestershire)

Northern Ireland Regional Genetic Service

Department of Medical Genetics
Floor A, Belfast City Hospital
Lisburn Road
BELFAST
BT9 7AB
Tel: 01232 263 555
Fax: 01232 236911

(Catchment area: Northern Ireland)

Wales Institute of Medical Genetics

University Hospital of Wales
Heath Park
CARDIFF
CF4 4XW
Tel: 01222 744 028
Fax: 01222 747 603

(Catchment area: Wales)

W. Scotland Regional Genetics Service

Duncan Guthrie Institute of Medical Genetics
Yorkhill Hospital
GLASGOW
G3 8SJ
Tel: 0141 201 0365
Fax: 0141 357 4277

(Catchment area: Greater Glasgow, Argyll & Clyde, Ayrshire & Arran, Forth Valley, Lanarkshire, Dumfries & Galloway)

S.E. Scotland Regional Genetics Centre

Department of Clinical Genetics
Western General Hospital
Crewe Road
EDINBURGH
EH4 2XU
Tel: 0131 651 1012
Fax: 0131 651 1013

(Catchment area: Lothian, Fife, Borders)

N. Scotland Clinical Genetics Service

Department of Medical Genetics
Medical School
Foresterhill
ABERDEEN AB9 2ZD
Tel: 01224 840 749
Fax: 01224 662 839

(Catchment area: Grampian, Highland, Orkney & Shetland, Western Isles)

N.W. Scotland Cytogenetics Laboratory

Pathology Department
Royal Northern Infirmary
Ness Walk
INVERNESS
IV3 5SF
Tel: 01463 704 000 extension 3231
Fax: 01463 713 844

(Catchment area: Highland, W. Grampian)

E. Scotland Human Genetic Laboratories

Department of Pathology
Ninewells Hospital and Medical School
DUNDEE
DD1 9SY
Tel: 01382 632 035
Fax: 01382 645 731

(Catchment area: Dundee, Perth, N. Fife, Angus, Perthshire)

Useful publications

The following articles are all about the mixture of feelings that people have experienced through having a member of the family affected by a genetic condition, and how they have dealt with them. They are all available from the **Genetic Interest Group** free of charge (tel: 0171 430 0090). Please send an s.a.e.

'Family Matters: Siblings'

Karin Weatherup talks with brothers and sisters about how muscular dystrophy has affected their relationships. Originally published in 1990 in *The Search*, the magazine of the Muscular Dystrophy Group.

'Dear Daniel...'

Jennifer Cleaver writes about her brother Daniel who had muscular dystrophy. Originally published in *The Search* 1990.

'My Brother's Keeper'

Written by Rozemary Tozer in *Therapy Weekly*, May 1996.

'Child Talk'

By Alex Duncan, in *The Search*, Summer 1996, Number 21.

The following titles are taken from an interesting range of books on disability published by the **Letterbox Library**. You can send off for the complete list. If the titles are not in stock at your local library, you can always ask them to get them for you.

Letterbox Library
Unit 2D, Leroy House
436 Essex Rd
London N1 3QP
Tel: 0171 226 1633
Fax: 0171 266 1768

'Veronica's First Year' by Jean Sasso Rheingrover

A loving and positive portrayal of the relationship between Nathan and his little sister Veronica, who is born with Downs syndrome, with full page pastel

illustrations. Age 6-10. Price £7.99.

'Hero of Lesser Causes' by Julie Johnston Keely is convinced that her destiny is to fight for Great Causes, but her belief in herself is shattered when her brother contracts polio; can she inspire him to survive? Age 10+. Price £4.50.

'No Time At All' by Susan Sallis

At the stroke of midnight, a ghost train rushes out of the mist – and leads Matt and his disabled brother Sam into a gripping mystery, and into a new understanding of the meaning of death. A terrific read. Age 10 up. Price £2.70.

'Our Brother Has Downs Syndrome' by Shelley Cairo

This straightforward account, told with family snapshots, is still fresh and valid today in spite of some dated language. Age 4-8. Price £3.50.

The **National Children's Bureau (NCB)** has an extensive library of resources on disability and children's issues, particularly relevant to professionals working with children.

The Library and Information Service
National Children's Bureau
8 Wakley St
London
EC1V 7QE
Tel: 0171 843 6008

Here are some titles available from the NCB for parents and children:

'Brothers, sisters and learning disability: a guide for parents' by R. Tozer (1996)

Published by British Institute of Learning Disabilities (BILD), Kidderminster. This guide provides information and advice for families who have a child with a learning disability. It looks at the impact of a child with a learning disability on other children in the family and considers what parents can do to encourage acceptance and understanding.

'Contact a Family Factsheet: Siblings and special needs' by R Tozer (1996)

Published by Contact a Family, London.

This factsheet covers some of the issues that often arise for siblings of a child with special needs and ways parents have found of responding to them. It includes further reading.

'Family Matters: Siblings' by K Weatherup (1996)

Published by Search (Muscular Dystrophy Group) no. 11 (Sept) pp 8-11. These are interviews with siblings about how muscular dystrophy has affected their relationships.

'Children with special needs: a guide for parents and carers' by H. Woolfson

Published by Faber, London

Scope (formerly the Spastics Society) also has a list of books of interest to brothers and sisters. The address:

16 Fitzroy Square
London W1P 6LP
Tel: 0171 387 9571
Fax: 0171 383 3205

'Brothers and Sisters – A Special Part of Exceptional Families' by T.H. Powell and P.A. Gallagher (1993)

Published by Paul H Brookes Publishing Co, Baltimore. Siblings experience a bond unique to their relationship. A brother or sister is usually the first close friend and playmate a child has, and that relationship often outlasts all others. This book explores this affinity from the perspective of siblings with a brother or sister who has a disability.

'Brothers, Sisters and Special Needs' by D.J. Lobato (1990)

Published by Paul H Brookes Publishing Co, Baltimore. This book shows professionals and parents how they can help a child's understanding of disability or chronic illness develop in a healthy, adaptive direction during the pre-school and elementary school years.

'It Isn't Fair – Siblings of Children With Disabilities' by S.D. Klein and M.J.

Schleifer (1993)

Published by Bergin and Garvey, Westport, Connecticut. Selected and compiled from two decades of the *Exceptional Parent* magazine, this book reveals first-hand the myriad feelings of non-disabled brothers and sisters at all stages as they grapple with caretaking, frustration, powerlessness, jealousy, guilt, and worry about their special siblings.

The following articles are also available from Scope:

'My Life with Ursula – A Sister's Tale' by C. Clancy-Smith

In *Community Living*, Vol 9/4, pp 22-23, 1996.

'The School-aged Siblings of Children with Disabilities' by M. Coleby

In *Developmental Medicine and Child Neurology*, Vol 37/5, pp 415, (1995).

'Hey, I'm Here Too – A Guide for Brothers and Sisters of Children with Muscular Dystrophy' by I.M. Siegel

Published by Muscular Dystrophy Group, London.

'Living with Disability – The Experience of Siblings' by J.A. Reed

Published by National Children's Bureau in *Highlight*, Vol 118, pp 1-2, (1993).

'Kith and kids (on the experiences of siblings of children with disabilities and their needs)' by K. Sone

In *Community Care*, pp 16-17, (1995).

'Support for Siblings' by A. Flynn and M. Meakin

In *British Journal of Special Education*, Vol 16/1, pp 15-18, (1989).

'My Brother's Keeper – Sustaining Sibling Support' by R. Tozer.

'A Sibling Born Without Disabilities – A Special Kind of Challenge' by the Downs

Syndrome Association
In *Exceptional Parent* magazine (1991).

'Living with a brother or sister with special needs: A book for siblings' by Donald Meyer and Patricia Vadasy, 1996, 2nd edition
University Washington Press

'If Only I'd Known that a Year ago'
A revised guide to services for newly disabled people, their friends and families. The guide provides an overview of services and facilities with a contacts listing. Topics covered vary from accommodation, aids, equipment, benefits, education, employment health and care. RADAR, 12 City Forum, 250 City Rd, London EC1U 8AF. Tel: 0171 250 3222.

'Help Starts Here – A guide for parents of children with special needs'
This is an updated edition of the best-selling guide through the maze of services available to parents and children with special needs and professionals working with these families. It gives clear, concise information on financial help and the benefits system; play and leisure activities; growing up with a disability, leaving school and respite services.

'A Directory of Projects and Initiatives with Deaf People from Minority Ethnic Communities'

Compiled by A. Darr, L. Jones, W. Ahmed And G. Nisar.

Available from the Ethnicity and Social Policy Research Unit, University of Bradford, Bradford BD7 1DP. Tel: 01274 383 179 (voice), 383 178 (text). Fax: 01904 433618. E-mail: a.e.ross@bradford.ac.uk.
Price £5.

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ADD/ADHD Support Group (South London)
c/o 66 Forest Hill Road
LONDON SE22 0RS
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ALZHEIMER'S DISEASE SOCIETY

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**ANGELMAN'S SYNDROME SUPPORT
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**ANORCHIDISM SUPPORT GROUP
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THE ARTHROGRYPOSIS GROUP (TAG)

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A-T Appeal
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ATAXIA-TELANGIECTASIA SOCIETY

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ALPHA-THALASSAEMIA WITH MENTAL RETARDATION ON THE X-CHROMOSOME

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ADRENOLEUKODYSTROPHY

Attia Research Trust Into ALD
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BECKWITH WIEDEMANN SUPPORT GROUP

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BRITISH DIABETIC ASSOCIATION

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Careline: 0171 636 6112

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BRITTLE BONE SOCIETY PARENTS' SUPPORT GROUP

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CANCER RESEARCH CAMPAIGN

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 10 Cumberland Avenue
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 12 Hindley Crescent
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PEMPHIGUS VULGARIS NETWORK
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PROGRESSIVE SUPRANUCLEAR PALSY

PSP Europe Association
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RUBINSTEIN TAYBI SYNDROME SUPPORT GROUP

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SUPPORT AROUND TERMINATION FOR ABNORMALITY

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SUPPORT ORGANISATION FOR TRISOMY SOFT (UK)
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TREACHER COLLINS FAMILY SUPPORT GROUP
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