



**GENETIC
INTEREST
GROUP**

*Working to benefit
all people affected
by genetic disorders*

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

For younger brothers and sisters

This is me

Hi, my name's Adam. I'm 14...



AT SCHOOL today, the teacher asked us what we thought had the greatest effect on our lives. Somebody said friends, somebody said whether he does well with his school work, somebody said the weather – and somebody even said whether he's wearing his labels or not!

But then we had a long discussion... and decided it was life at home that affected us the most.

When things are good at home other things seem to go well. When life's difficult because of brothers and sisters and because of parents, life can be a bit tough, to say the least.

But when problems get sorted out everything bounces back again, doesn't it?... and it feels good – until the next time!

Sometimes it's easier to talk to friends... but then, if you have a row with a friend, there are always other friends to go around with. You can't swap your brothers and sisters,

though – they're with you for life.

It's quite a strong bond, really... they'll always be a part of you, no matter how old you are, or where you go – and whether you like it or not!

That's life, I suppose... what happens in the family, the fun things *and* the difficult things, they affect all of us.'

My sister's got a genetic condition

‘**MY LITTLE SISTER’S** called Sophie. She’s seven and she’s got this condition that’s genetic. She was all right for a while when she was born, but since she was about 10 months she’s been in and out of hospital.

Mum and Dad seemed to run round her all the time. I ended up having to help quite a lot as well.

Before, I didn’t used to talk about how I felt because I thought they’d think I didn’t care about my sister, but I do. Mum and Dad always seemed to be too tired to listen to me, or to do the things I wanted to do. I used to want to tell Mum something that had happened at school and she’d say “Wait a minute, I need to see to Sophie”. It was like *I didn’t exist* and they were just Sophie’s Mum and Dad. I felt jealous, but I also felt guilty for feeling that way.

It was about a year ago that it all came out. Mum and Dad had asked me what was wrong because I’d been getting angry at every little thing in the morning and then I was really quiet. They’d asked me before, but then they always had to run off and see to Sophie before I could tell them, or I was fed up and wouldn’t talk.

This time, I blurted it all out and told them that I thought they didn’t care about me and they cared only about Sophie. I told them that I love her as well... she’s my sister... but I needed them to do other things for me and I needed them to help me... things that *I* like, not just things for Sophie. Anyway, it all came out in bits over the next few days. I wanted them to listen to problems I had with some of my friends, I wasn’t sure I wanted to go on the school trip they’d booked me in for, and I wanted help in choosing my subjects at school... there was so much I’d been keeping inside. It was such a relief to let it all out!

I thought they’d think I was bad and selfish and didn’t care about Sophie. But they didn’t. They were just so pleased and relieved to get me talking, and they were

sorry they hadn’t done it earlier. Mum was *really* sorry because she has a brother with the same condition as Sophie, and she used to feel just the same way as I did when she was younger! Only she’d forgotten how it had felt because she was so busy with housework, working and looking after Sophie... and me too, I suppose!

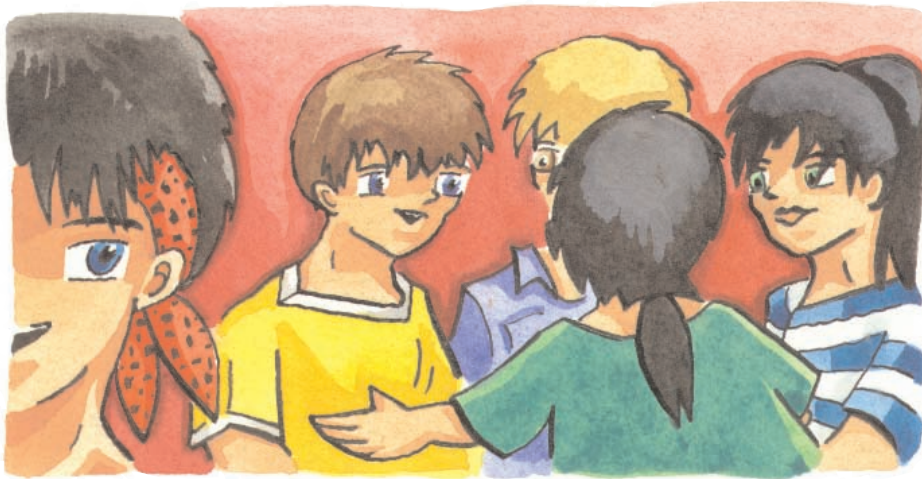
We talk a lot more now, and we organise our days differently so that we all get to do what we want to do, and I get to spend more time with Mum and Dad. Feels good.

I guess if you’re reading this *you* must have a brother or sister who has a genetic condition. So, how’s it been for you? Take it from me, you should tell somebody how you feel... it really helps.’



...and this is
Sophie.

What about support groups?



Talking to other people can help.

MUM AND DAD go to a support group for this condition that Sophie's got. They meet other parents there in the same situation. They get to talk and share information, and it helps them knowing they're not alone. Whole families go...

I never used to go... I had enough of it at home. But about seven months ago Dad told me there was a group for the brothers and sisters of someone who has a genetic condition, so I went along. There were loads of brothers and sisters there. I got talking to some of them and I couldn't believe what they were telling me. Some of them had felt exactly the same way about their brother or sister as I had about Sophie... you know, lots of love and wanting to help – but getting so *annoyed* with her too. So, I wasn't the only one.

I feel okay about all the negative feelings now, because there are lots of good feelings

and good times too. Like I said, because Mum and Dad and me and Sophie talk about things more now, it's much better.

But getting back to this group, there were lots of other things I learned... lots about genetics and how it could affect me... lots about getting more information and advice.

We got some help from some people to put some information together for brothers and sisters, like you and me. It's on this page and the next one. Check it out. Hope it's useful.'

In the other booklet that came with this one, there's a list on page 31 of all the support groups (with addresses and phone numbers) attached to the Genetic Interest Group. One of them might be for people with the condition that affects your family.

A few support groups also run groups for brothers and sisters, and some put on things for brothers and sisters at their annual conferences. Give

them a ring or write to them, if you're interested. They're there to help you.

If there isn't a group for the condition that affects your family, get in touch with an organisation called 'Contact a Family'. They have a list of nearly all the support groups in Britain. Phone them on 0171 383 3555 and ask to speak to the Information Officer. You can also write to them at:

Contact a Family, 170
Tottenham Court Rd, London
W1P 0HA.

If there isn't a support group for brothers and sisters for the condition that affects your family and you'd like to start one, then Contact a Family can also give you advice and help on getting it started. The Information Officer will put you through to someone who can help.

Where else can I get information?

APART FROM getting together as a group, there are lots of other ways of getting information and keeping in touch with what's going on.

And anyway, some people don't want to be part of a group for whatever reason, and that's fine. I certainly didn't until now. So if that's how you feel, then there's no reason to miss out on getting answers to some of your questions. And there's nothing to stop you finding other brothers and sisters in the same situation as you, without actually having to go out and meet people.

The Internet's brilliant for this. If you don't have a computer at home yet, there's bound to be one you can use at your school, college or library. Haven't used it before? Ask someone! It's easy, once you get going.

Check out Sibkids (by and for kids) at <http://www.chmc.org/departmt/sibkids.htm> – it's especially for siblings!

Some of the support groups have their own websites, and loads of others plan to get

Contact a Family produce a really good factsheet called 'Siblings and special needs'. It's full of good tips and really easy to read. Contact them at: Contact a Family, 170 Tottenham Court Rd, London W1P 0HA. Telephone 0171 383 3555. Fax 0171 383 0259. If you can use e-mail, they're at info@cafamily.org.uk

The Genetic Interest Group produces a regular newsletter. You might find that interesting too. Get in touch: The Genetic Interest Group, Farringdon Point, 29-35 Farringdon Rd, London EC1M 3JB. Telephone 0171 430 0090. Fax 0171 430 0092. E-mail: 101366.760@compuserve.com

Some support groups and other organisations run telephone helplines. If you want to speak to somebody in confidence, you can contact someone who may be able to help through a helpline. There's more information on telephone helplines on page 12 in the other booklet.



Check out the Web!

one soon. Call the group looking after the condition that affects your brother or sister, and ask them if they've got a website address. You can have all the information you need right there on your screen, without going anywhere near a support group!

And you don't have to actually go to support group meetings to get a regular newsletter from them. A few groups produce one especially for young people like us. Some produce booklets for children which are really good because everything is written so simply and it makes it easy for everyone to understand.

You can send off for a booklist and choose the ones you want. You just have to contact them and ask for one to be sent to you.'

Genes and you

‘NOW, ONTO GENES and all that stuff!

What we look like – the way our body is put together – is decided by the kind of genes we have. It’s our genes that decide things like the colour of our hair and our eyes, or how tall we might grow. The study of genes is called genetics.

Most illnesses come from outside, from things around us in the environment like bugs and germs and viruses. Genetic disorders come about because of the genes we have inherited.

Our genes come from our parents (which is why many of us look a bit like other people in our families) and our parents’ genes come from our grandparents – and our grandparents’ genes come from our great grandparents – and so on. A great long line of people have passed on their genes to us, and to our brothers and sisters. And sometimes along with all the good things that get passed along, we can get some genes that make life difficult too.

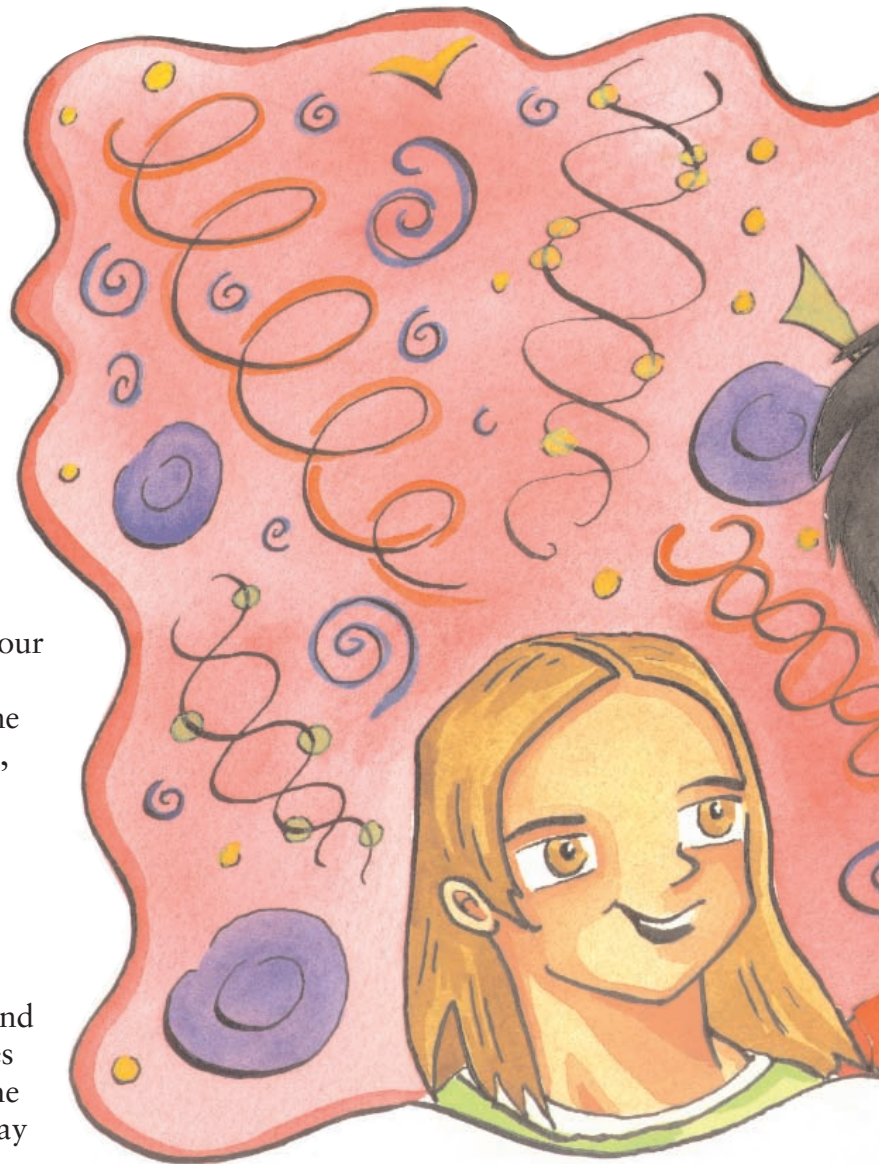
There are times, though, when a genetic disorder isn’t passed on through parents and grandparents. It happens because the genes get mixed up when a baby is made. But the person who’s got the faulty gene in this way *can* end up passing it on to his or her own children.

Some of these illnesses show up when you’re still a baby or a little kid. Others wait until you’ve grown up before they appear.

The best thing to do is to get all the facts from the doctors looking after your brother or sister. Discuss it with your Mum and Dad or someone else that you trust.

Some people in the family may not be affected at all, but may still have the gene for the condition which can be passed on their children.

And that could go for me – and you as well.



But there’s also the chance that we may not have inherited the gene at all!

The only way of really knowing is to have a genetic test. You can get a genetic test for quite a lot of disorders, though not all of them yet. Again, discuss it with Mum and Dad or someone else that you trust.

One really important thing I’ve learned is that a genetic disorder isn’t anybody’s fault. It’s not our parents’ fault, not our brother or sister’s fault, and it’s definitely not your fault either – but we all know it can be hard to live with.

It doesn’t seem fair if a brother or sister has a genetic disorder. But that doesn’t mean anyone’s to blame. It just happens to some people.’



If you want to learn more about genes and genetics – it takes time to get your head round everything – there’s a section in the main handbook on how genetic disorders are inherited, on page 8. There’s more stuff on genetic testing on the same page.

Or you could check out ‘The Cartoon Guide to Genetics’ (by Larry Gonick and Mark Wheelis, published in 1991 by Harper Perennial) which makes the whole thing a lot easier to understand. Contact the Genetic Interest Group (telephone 0171 430 0090) and they’ll send you some stuff to read. There’s also a list of publications in the other booklet.

Genetic disorders can be passed down through a family so that some of you end up getting it, but others don’t.

It’s nobody’s fault. It just happens to some people.

Helping each other

‘THINGS ARE NEVER the same once someone in your family is found to have a genetic disorder, are they?

I knew Mum and Dad were pretty upset and worried about something to do with Sophie. I didn't know what had happened. It was awful not knowing. I felt really left out. Then they told me after a few weeks that Sophie wasn't well, it was serious, and it was important to help her.

I was about eight then. I didn't really understand. I remember wanting Mum and Dad to hug me a lot.

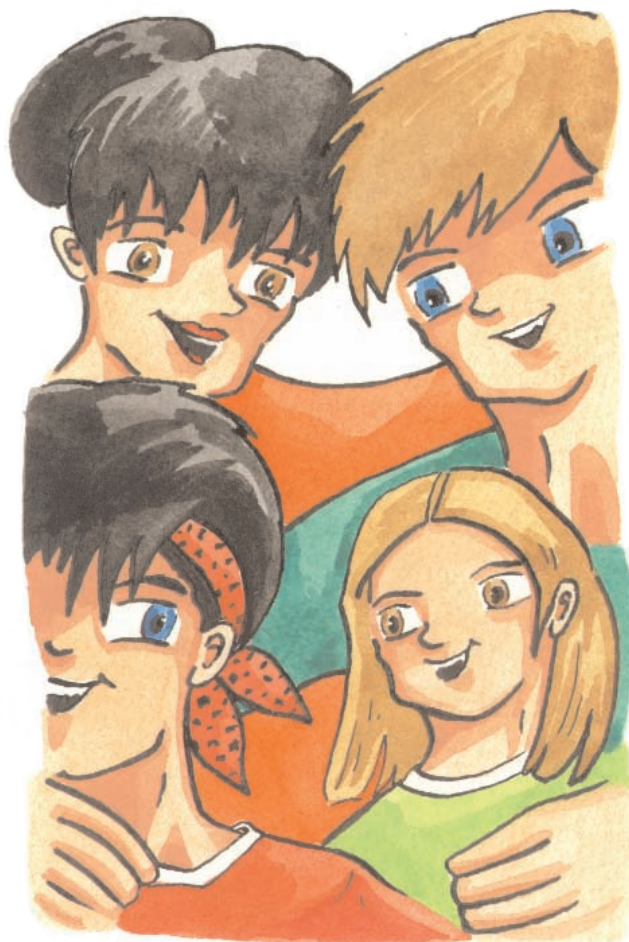
Now I'm older I can understand a bit more. Parents don't stop loving you, they just get really tired and have a lot on their plate. They weren't angry with me, though it can feel like it sometimes!

Whatever the problem is, it doesn't go on for ever. Now, when Mum and Dad get upset I go over and give *them* a hug. It's really surprising how much better they feel after that.

Sometimes it all gets on my nerves and I want to get away from it all, so I go off and see my friends or do something else that I enjoy. I don't see why I should have to sit there when it all gets me down. Mum and Dad tell me it's the best move I make!

There are some good times too, though, aren't there? Especially now! Mum and Dad made a real effort to work out ways of how we could do things so that we could all have fun times together *and* separately.

They got in touch with the local Social Services Department to see if they organised any services that would help our family. Get in touch with your local Social Services Department. See what's on offer. You'll find their number in the phone book.'



We all need a hug sometimes.

I'm a carer, too

I'VE HEARD a number of people refer to my Mum and Dad and other parents as 'carers', because they have to care for their children who have a genetic disorder. It was a surprise when somebody called **ME** a carer, when I was talking about how I help Sophie or help Mum and Dad round the house because they need to see to Sophie.

It got me thinking, though. Of course, I'm a carer, too! I do my bit (sometimes, only when I have to – but still, I think I do enough). It just hadn't occurred to me to think of it like that. Yes, I'm definitely a carer along with Mum and Dad.

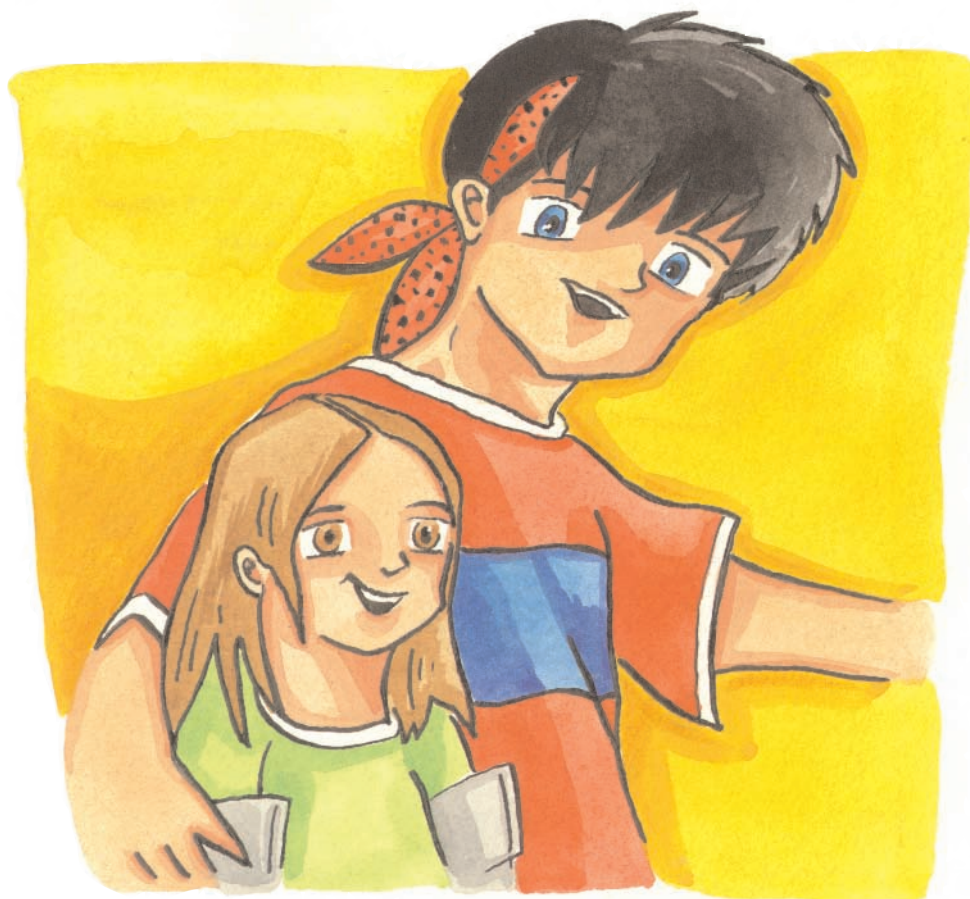
There's an organisation called the Carers' National Association that deals with issues that are relevant to young carers like you and me. They've got a number of things useful for us:

- A *'Young Carer's Information Pack'* aimed at people who are 12 to 18 years, full of helpful advice and information.

- A leaflet called *'Under 18? Know about Young Carers?'*, which helps explain how to get help from Social Services.
- A quarterly newsletter for young carers between 10 and 18 called *'Link'*.

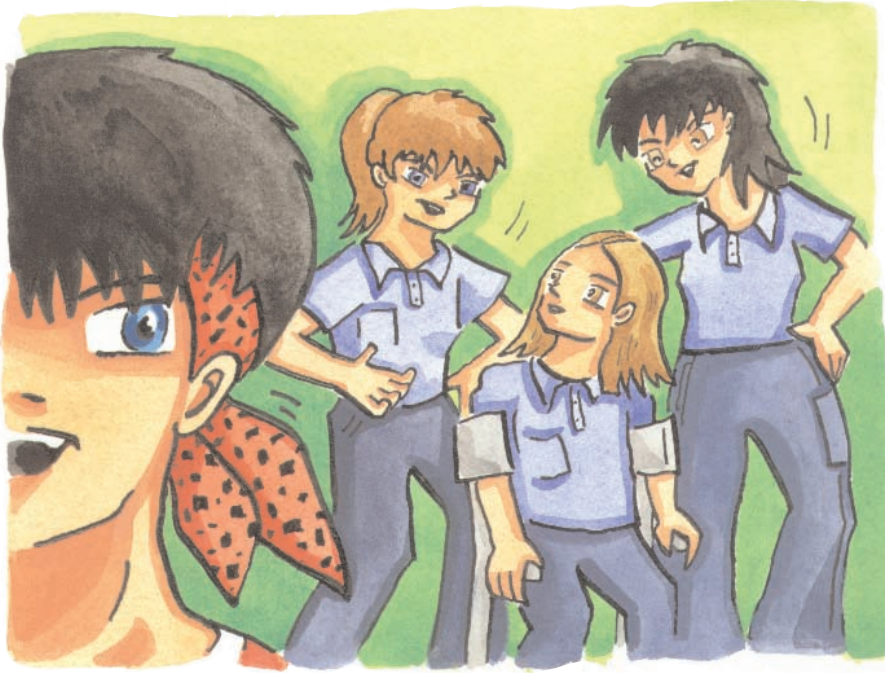
Here's where to get in touch:

Carers' National Association, Head Office, Ruth Pitter House, 20-25 Glasshouse Yard, London EC1A 4JS. Telephone 0171 490 8818. Fax 0171 490 8824. You can e-mail them at internet@ukcarers.org, and their website is at www.carers.demon.co.org.



**Hey –
you're a
carer!**

Disability and your school



**School
can be
hard for
disabled
kids.**

‘SOPHIE DOESN’T need a wheelchair. But there’s a girl, Anita, in another class at school, whose brother does. He sometimes comes to school with his mother when they come to pick up Anita. People used to stare at her brother and a group of kids joked about him and made nasty comments. Anita ended up crying. She was really upset.

Anita’s parents must have felt really angry and hurt about the way some kids had reacted to disability, because they did something about it. They told the headteacher about a set of videos produced by SCOPE which deal with disability. One’s called *‘Land of the Droog’* which is for primary children upwards, and the other is called *‘Stand Up the Real Glyn Vernon’* for older people in the school. They both deal with disability and have notes for the teacher. The one we were shown really made our class think.

Many genetic conditions don’t cause people to need wheelchairs, or the disorder doesn’t affect the way they talk... but some do. So the stuff on disability is still useful to find out about if your brother or sister has a disability.

If you’ve got problems at school with how people behave towards your brother or sister, why not speak to your teacher about

getting hold of these videos? You can borrow them free from SCOPE at 12 Park Crescent, London W1N. Call them on 0171 636 5020, or you can fax 0171 436 2601.

A couple of questions... Are you being taught about genetics at school? Does your science or biology teacher know about the *‘Genes and You’* pack produced by the Genetic Interest Group? This is a complete pack to teach genetics to 14 to 16-year-olds. It’s free! Tell your teacher about it – all they have to do is ring 0171 430 0090.’

SCOPE also has a reading list of books on disability issues for children and young adults.

Letterbox Library stocks an excellent range of books dealing with issues of disability for young readers. Contact them and ask for the booklist called *‘Disability in Children’s Books’*. They’re at Letterbox Library, Unit 2D, Leroy House, 436 Essex Rd, London N1 3QP. Telephone 0171 226 1633. Fax 0171 226 1768.

Some of the support groups listed on page 31 of the other booklet produce leaflets or booklets especially for schools. Get hold of one by contacting the group and take it to school and show your teacher, or ask your Mum or Dad to do it.

When a brother or sister dies

AFTER THE LAST support group meeting for brothers and sisters, three of us were just sitting and chatting. There was me, Raj and Sue. Sue looked worried.

She's 17 and she's got a sister who's quite disabled, and needs a lot of looking after. The whole family used to help. But recently, her older sister got married and moved away and her brother's got a job in another city. Now it's Sue, her sister, and her Mum and Dad at home.

Sue told us she was worried because she felt confused about her future. She's got a place at college and wants to live away from home. But she feels guilty about accepting because her Mum and Dad would be left by themselves to cope with her sister. She loves her sister, but wants to lead her own life too.

We talked about it, and both Raj and I thought she should tell her parents and brother and sister how she felt. It's best to get it out in the open... definitely no point in bottling it up. So, that's what she's going to do. She felt better.

Raj, who's 12, then opened up and told us about his brother.

He's dreading the day his little brother Anil won't be there any more. Anil's slowly getting worse and the doctors have told them that, at the moment, there's no cure for his disorder and that he won't live many more years. Raj said it made him feel very sad, but he was glad his parents had told him.

All the family will miss Anil. Raj has a shoebox where he keeps special photographs of his brother to remember him by. He's written a poem for him, as well... he keeps that in there, too. It made Raj feel better to talk about it. Sue and I were glad we were there to listen.

For some families, it's really tough. At the moment, there isn't a cure for many genetic disorders, but a lot of them can be managed with treatment.'

There's a section on how one family planned for the future in the factsheet on Siblings and Special Needs produced by Contact a Family. Send off for one. Contact a Family, 170 Tottenham Court Rd, London W1P 0HA. Tel: 0171 383 3555. Fax: 0171 383 0259. Email: info@cafamily.org.uk



It can be painful thinking of the future.

Final words

I USED TO think that because I didn't have Sophie's genetic disorder, that genetics didn't have much to do with me. But it affects me and my life in lots of ways... it's a part of *my* life... just like other things (including other difficulties!) are a part of someone else's life.

I've learned a lot since that day when I'd had enough and I blurted out how I felt to my Mum and Dad. The most important things I've realised are that:

- A genetic disorder in the family is nobody's fault.
- How I feel and what I have to say is just as important as how anybody else in the family feels, and what they have to say.
- It's best to talk openly about worries and not bottle things up.
- Keeping in touch with what's going on makes me feel better.

Hope this booklet's been useful!

Bye...

ADAM

