

SIBLINGS



INFORMATION FOR PARENTS OF DISABLED CHILDREN



contact

“Having Alex has promoted more family activities, and a more affectionate relationship between us all.”

Parent carer

CONTENTS

SPOTLIGHT ON SIBLINGS	5
WHAT'S IT LIKE BEING THE SIBLING OF A DISABLED CHILD?	6
COMMON ISSUES THAT SIBLINGS EXPERIENCE	8
SIGNS THAT SIBLINGS MAY NEED MORE HELP	11
HOW PROFESSIONALS CAN HELP	13
TOP TIPS FROM PARENTS	14
SIBLINGS AND THE LAW	17
A FEW WORDS FROM SIBLINGS	18
SOURCES OF SUPPORT	20
AN ADULT SIBLING REMEMBERS	22

“They are very tolerant of others. They are educators of their peers and very often defend other children against bullying/comments.”

Parent carer



SPOTLIGHT ON SIBLINGS

Most of us grow up with one or more brother or sister. How we get on with them can influence the way we develop and what sort of people we become. As young children we may spend more time with our brothers and sisters than with our parents, and relationships with our siblings may be the most important and meaningful we have.

Nearly all children, whatever their disability, spend most of their time with their family. So it is not surprising that some parents want to talk about the importance of siblings and the ups and downs of their daily lives, and to seek advice about handling any difficulties that may arise.

This guide is about supporting the brothers and sisters of children who have a disability or long-term illness. It is written for parents and for those working with families who have a disabled child. Every child and family is different and not all the points mentioned here will apply to every situation. The issues discussed are those brought up most often by parents and brothers and sisters themselves. Many of the ideas in this guide have come from parents and professional workers who have attended workshops about siblings run by Contact in recent years.

“It’s the same as in any brother or sister relationship, only the feelings are exaggerated.”

Sibling

WHAT'S IT LIKE BEING THE SIBLING OF A DISABLED CHILD?

Studies about siblings of disabled people have tended to report a mixed experience. They often report a close relationship but there can be some difficulties. Sibling relationships in general tend to be a mixture of love and hate, rivalry and loyalty. In one study a group of siblings of disabled children were reported as having stronger feelings about their brother and sister – either liking or disliking them more – than a matched group did about their non-disabled brothers and sisters.

Often, having to put the needs of the disabled child first seems to encourage an early maturity in brothers and sisters. Parents may worry that siblings have to grow up too quickly but they are often described as very responsible and sensitive to the needs and feelings of others. Some siblings say that their brother or sister has brought something special to their lives.

“Tom makes me laugh and a stronger more thick-skinned person. He also makes me more acceptant of people and not judge them by how they look.”

Sibling

SEEING THE SIBLING'S POINT OF VIEW

Sometimes parents try hard to do what seems best for a brother or sister, only to find out later that their efforts were not appreciated. One mother stressed that parents need to realise how different a child's view of life can be. She would try to leave her elder son at his friend's house while she took his younger brother to therapy appointments, believing that he would find playing with his friend much more enjoyable than hanging around the hospital. But when he was older, he told her that he had felt his brother was going off with her to have fun, while he felt left behind. Wanting to protect your other children from too much of a 'caring' role is natural, but it can be helpful to keep the lines of communication open so you can understand the brother or sister's point of view and avoid misunderstandings. It can be a difficult balancing act, but something that parents need to be aware of.

Whatever your situation, we encourage all parents to consider accessing the support for siblings described in this guide.

"My daughter has had to learn to be very thoughtful about other people less able than herself."

Parent carer



COMMON ISSUES THAT SIBLINGS EXPERIENCE

Most siblings cope very well with their childhood experiences and sometimes feel strengthened by them. They seem to do best when parents, and other adults in their lives, can accept their brother or sister's disability and clearly value them as an individual. Avoiding family secrets, as well as giving siblings the chance to talk things over and express feelings and opinions, can help them deal with worries and difficulties that are bound to arise from time to time.

ISSUE	SUGGESTED WAYS OF RESPONDING
Limited time and attention from parents	<ul style="list-style-type: none"> • protect certain times to spend with siblings, for example bedtime, cinema once a month • organise short-term care for important events such as sports days • sometimes put the needs of siblings first and let them choose what to do
Worry about bringing friends home	<ul style="list-style-type: none"> • talk over how to explain a brother or sister's difficulties to friends • invite friends round when the disabled child is away • don't expect siblings to always include the disabled child in their play or activities
Teasing or bullying about a brother or sister	<ul style="list-style-type: none"> • recognise that this is a possibility and notice signs of distress • ask your child's school to encourage positive attitudes to disability • rehearse how to handle unpleasant remarks
Embarrassment about a brother or sister in public	<ul style="list-style-type: none"> • realise that the behaviour of non-disabled family members can cause embarrassment sometimes • find social situations where the disabled child is accepted • if old enough, split up for a while when out together
Guilt about being angry with a disabled sibling	<ul style="list-style-type: none"> • make it clear that it's all right to be angry sometimes – strong feelings are part of any close relationship • share some of your own mixed feelings at times • siblings may want to talk to someone outside the family

ISSUE	SUGGESTED WAYS OF RESPONDING
Why them and not me?	<ul style="list-style-type: none"> • emphasise that no-one is to blame for their brother or sister's difficulties • come to terms yourself with your child's disability • encourage siblings to see their brother or sister as a person with similarities and differences from themselves • meet other families who have a child with a similar condition, perhaps through a support organisation
Concerns about the future	<ul style="list-style-type: none"> • talk over plans for the care of the disabled child with siblings and see what they think • if your child has a genetic condition, find out about opportunities for genetic advice if siblings want it • encourage them to leave home when they are ready
Stressful situations at home	<ul style="list-style-type: none"> • encourage siblings to develop their own social life • a lock on a bedroom door can ensure privacy and avoid possessions being damaged • get professional advice about caring tasks and handling difficult behaviour and include siblings in it • try to keep the family's sense of humour
Restrictions on family activities	<ul style="list-style-type: none"> • try to find family activities that everyone can enjoy, for example swimming, picnics, etc • see if there are holiday schemes the sibling or disabled child can take part in • use help from family or friends with the disabled child or siblings
Protectiveness about a very dependent or ill sibling	<ul style="list-style-type: none"> • explain clearly about the diagnosis and expected prognosis – not knowing can be more worrying • make sure arrangements for the other children can be made in an emergency • allow siblings to express their anxiety and ask questions

SIGNS THAT SIBLINGS MAY NEED MORE HELP

If a sibling is finding it hard to cope, they may need more help if they:

- ***show changes in behaviour after their brother or sister has a hospital stay***
- ***keep asking questions about brother or sister that you can't answer, for example "what if" questions***
- ***get easily annoyed with their brother or sister***
- ***complain more than usual or try to get your attention***
- ***feel very sad, angry or jealous***
- ***are reluctant to talk to you***
- ***avoid spending time with friends***
- ***find it hard to get homework done or are falling behind at school***
- ***are being teased or bullied***
- ***are doing too much care***
- ***are getting hurt by their brother or sister.***

If you feel your non-disabled child or children would benefit from some extra support, see the next section and page 20 *Sources of support*.

Local authorities also have duties to support disabled children and their siblings, see page 17.

"T's disability affects their opportunities and as a family restricts many activities that we would like to do. Her brother can get very resentful which is very difficult to manage."

Parent carer



HOW PROFESSIONALS CAN HELP

Any of the agencies a family is in touch with can play their part in supporting siblings, whether health, social services, education or the voluntary sector. Increased awareness by professionals of the other children in a family, and recognition of their particular situation, can help these siblings to feel that they are part of what's going on.

Some of the ways this might happen include:

- ***professionals speaking directly to siblings to provide information and advice***
- ***listening to the sibling's point of view – their ideas may be different to those of their parents***
- ***trying to understand the particular rewards and difficulties they encounter and how these may affect their daily lives***
- ***offering to refer siblings to someone outside the family to talk things over with in confidence***
- ***providing support that is flexible enough to accommodate the needs of siblings as well as the disabled child and their parents.***

“It helped to know that I’m not alone with a disabled brother or sister.”

Sibling

TOP TIPS FROM PARENTS

These tips from parents who have 'been there' may help.

- **Talk about disability and additional needs from an early age.**
- **Talk openly and honestly about your disabled child's condition.** Assure siblings that no one is to blame, and stress that they are an individual with a personality with strengths and weaknesses like anyone else.
- **Try to find activities that the family can enjoy together, but try to set aside time and activities for each child individually.** This should ideally be at the same time each day/week, so that each child has something special. Arrange childcare for your disabled child so that you can do things with his/her sibling(s).
- **Don't miss siblings' important events (school play, sports day and so on).**
- **Praise all your children equally when they achieve something or make a big effort.**
- **Acknowledge siblings' negative feelings about their brother/sister (as well as the positive ones).** Talk about these feelings and about any guilt they may have about them. Explain that everyone gets angry with other family members sometimes.
- **Allow siblings to speak their mind even if it is difficult.**
- **Teach siblings fun activities they can do with their brother or sister.**
- **Give them choice about spending time with their brother or sister.** Don't expect siblings to always include their brother/sister in their play. Let them retreat to their bedroom, and when they get older let them lock the door.

- **Discuss how they can talk to their friends about disability, and how it affects their brother/sister.**
- **Limit the type and amount of care and support that siblings do.**
- **Make sure that the sibling's school knows what is happening at home.**
- **Don't be negative – siblings can gain and learn from their experiences.**
- **Give siblings permission to enjoy and live their own lives.** Don't let them feel too much responsibility for your disabled child. Discuss any anxiety they may feel about his/her future.
- **Talk to siblings in the teenage years about plans for the future.**
- **Don't put pressure on – don't have too high expectations of siblings.**
- **Celebrate siblings' achievements.**

“Her big brother of 7 years is very supportive – also because he treats her like an equal she (aged 4) is more determined to do what he is doing.”

Parent carer

“Some of S's friends have said horrible things about J - she found this very hard.”

Parent carer



SIBLINGS AND THE LAW

Social services and social work (in Scotland) are under a general duty to safeguard and promote the welfare of children in need. Disabled children, and potentially their siblings, are children in need under the Children Act 1989 if they are:

“unlikely to achieve or maintain a reasonable level of health or development, or whose health and development is likely to be significantly or further impaired, without the provision of services.”

There is similar legislation in Scotland, Wales and Northern Ireland. Local authorities have a general duty to make a range of services available to help children in need, which could include:

- ***occupational, social, cultural or recreational activities***
- ***home help***
- ***assistance to enable your child and family to have a holiday.***

IN ENGLAND ONLY

The right to assessments for siblings who provide care also exist under the Children and Families Act 2014. This Act places a duty on the local council to assess carers ‘on the appearance of need’. This includes parent carers as well as young carers.

Additionally, under the Care Act 2014 there are strengthened rights for brothers and sisters who provide care and are approaching the age of 18. Here the council must consider the young carer’s own interests and future endeavours, particularly in areas of study and work.

A FEW WORDS FROM SIBLINGS

“I would be a completely different person without her because she brings out the best in me. So although she can be hard work, she is my sister and she means a lot to me so I wouldn’t want her to be any different.”

Sibling



“There are the negative sides to having a disabled brother. He needs constant care and I often get roped into looking after him. This can be tiresome but I find ways of doing things with him that are more fun – such as pushing him on his bike.”

Sibling

“The positives outweigh the negatives and I never want him to be any different (except when he’s screaming in the middle of the night!).”

Sibling

“Looking after her has its plus sides especially when sitting with her gets me out of the washing up and cleaning my room!”

Sibling

“Ollie’s a great judge of character. My friends that accept Ollie for who he is and act naturally around him are always the friends that stick by me and aren’t false.”

Sibling

SOURCES OF SUPPORT

SIBLING SUPPORT GROUPS

Projects for young carers often include siblings and usually offer a mixture of individual and group support. You might also want to talk to the special educational needs coordinator at your child's school about the possibility of setting up a sibling support group in school.

The Children's Society

Has a map of young carers projects around the UK, which may offer siblings:

- ***the opportunity to meet other siblings and share experiences***
- ***learn new ways of coping***
- ***activity breaks***
- ***support groups***
- ***help with homework clubs***
- ***confidential one-to-one support***
- ***training – such as self-esteem and confidence building, first aid.***

They also have resources for professionals and schools with good practice around supporting young carers.

www.youngcarer.com/young-carers-services

Over the Wall

Runs free activity camps (climbing wall, abseiling, canoeing, archery, swimming, arts and craft, music, drama, sports and games) for children with a range of conditions, their siblings and families.

02392 477 110

www.otw.org.uk

ONLINE SUPPORT

Sibs

Charity supporting siblings of disabled children and adults. Runs workshops, training and events around the UK. Support, advice and information for young siblings, and for parents and professionals supporting siblings.

www.sibs.org.uk

YoungSibs

For siblings aged 6 –17. Information about different conditions and strategies for coping with sibling issues. Section for siblings to receive personalised responses to their questions. Safe online chat area for siblings under 18.

www.youngsibs.org.uk

BOOKS

We have a list of helpful books for siblings to read – or we can look for books for you. Please get in touch at:

info@contact.org.uk
020 7608 8726

There are also a number of books written for parents about supporting siblings. Search for ‘siblings of disabled children’ at online book stores. Sibs also has books on their website:
www.sibs.org.uk/parents

IF YOU KNOW THE NAME OF YOUR DISABLED CHILD’S CONDITION

Specific condition support groups often have information and booklets for affected children and their siblings. Please contact our helpline on 0808 808 3555 to find out if there is a support group for your disabled child’s condition. Alternatively you can search our A-Z Directory to find support groups at:
www.contact.org.uk/medical-information

FINANCIAL HELP/GRANTS

We have a list of charities which provide grants for families with disabled children on our website, or available from our helpline:
www.contact.org.uk/financial-support
0808 808 3555

Family Fund

Provides grants to families who are caring for a disabled child, which may ease the pressure on siblings:
01904 550 055
www.familyfund.org.uk

FOR BEREAVED SIBLINGS

The Compassionate Friends

Support for bereaved siblings and parents.
www.tcfsiblingsupport.org.uk

Hope Again

A free helpline and website for young bereaved people, run by Cruse.
0808 808 1677
www.hopeagain.org.uk

Winston’s Wish

Reading materials for children and parents on coping with serious illness and when someone has died.
Helpline 08088 020 021
www.winstonswish.org.uk

AN ADULT SISTER REMEMBERS

When I was just one year and four months old, my brother was born and he was diagnosed seven months later with a disability. We did not know what, so I've grown up from infancy with a disabled sibling – I have never known any different, which I guess makes it easier.

As a child I never really noticed any disability. Christopher couldn't talk but I had plenty of others to talk to, friends at school and family friends. We grew up in a small village which felt more like an extended family – Christopher, in turn, became more like an adopted brother to my school, everyone loved and accepted him for who he was so the early years of my life were fantastic and Christopher's disability went very much unnoticed for me.

MOVING TO SECONDARY SCHOOL

At 11 I started secondary school and I had the worry of knowing new friends may not welcome and accept my brother as people had previously. As it turned out, it needn't have been a worry as I had a brilliant group of friends who would ask questions out of intrigue, with the willingness to understand and accept Christopher as not just my brother, but as the person he was, too.

My brother's behaviour at home, as I hit my teenage years, became more challenging. As much as I love him, when given the option, I would always opt to go to a friend's house and stay over. Angry, adolescent drama is truly enough for any teenager, without problems at home. We all felt the stress.

THINKING ABOUT THE FUTURE

When we reached the time to start thinking about Christopher's future and residential care this obviously affected my parents more than myself. I had my own choices to make; what college did I want to go to, what

career did I want, what outfit do I wear to the party Friday night. My parents were deciding where to let their son live, to me, it was just my brother moving out. But they have always included me in choices for Christopher and I know they listen to me, as I have different concerns and priorities for him which they may not have considered. We work as a team which is how it should always be.

As someone with a disabled sibling, the worry embedded in all our minds is “what do I do once my parents are gone?” This is why you have to be involved as much as possible so that your parents are made aware of your fears as well as being aware of theirs.

There is no doubt in our minds that allowing Christopher to leave home was the best decision for him. When he returns home we make a conscious effort to make it a family time. There are still plenty more decisions to make for Christopher’s future, but as long as we remain a team and talk together, we can make sure we make the best choices for him.


ADVICE FOR BROTHERS AND SISTERS!


If there is any advice I could pass on to people growing up with a disabled sibling it is this. Try not to be embarrassed and worry what your new friends may think about your sibling, welcome them and introduce them as casually as possible, and once they see you are not afraid of people meeting them, they will not be afraid to get to know them. Your friends may well be just as afraid as this could be completely unknown to them.


You will need your friends when times are tougher, and if they know your sibling as well as they can, they can truly be there to support you. They are not as involved as your parents and will not judge you for any selfish feelings you may have. I know for sure when it comes to family, especially a disabled sibling, you will feel guilty on numerous occasions because of feelings you have. Friends will get you through it!


GET IN CONTACT


Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

 0808 808 3555

 info@contact.org.uk

 www.contact.org.uk

 twitter.com/contactfamilies

 facebook.com/contactfamilies

 youtube.com/contactfamilies

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We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

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