

Siblings

Information for parents of disabled children in England,
Northern Ireland, Scotland and Wales



Introduction

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.

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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.

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. ”

What's it like being the brother or sister 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. As one grown-up sibling said, "It's the same as in any brother or sister relationship, only the feelings are exaggerated."

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 "Having Charlie has promoted more family activities, and a more affectionate relationship between us all."

According to one study, siblings of children with intellectual and developmental disability overall have

a slightly increased risk for problems with wellbeing and educational attainment.

Siblings who are also likely to experience an increased risk are:

- sibling young carers (that is, brothers and sisters who provide a significant amount of care to their disabled sibling)
- siblings whose brothers and sisters have behavioural problems.

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



Common issues 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.

Common issues	Ways of responding suggested by parents
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.
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.
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.

Common issues	Ways of responding suggested by parents
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 in which siblings can be included ● 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.
Guilt about being angry with a disabled brother or sister	<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.
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.
Protectiveness about a very dependent or ill brother or sister	<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.
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 ● find out about opportunities for genetic advice if this is relevant and what siblings want ● encourage them to leave home when they are ready.



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 is falling behind at school
- are being teased or bullied
- are doing too much care
- are getting hurt by their brother or sister.

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



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 in which 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 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. ”

Parents' top tips

- Talk about disability and additional needs from an early age
- Talk open and honestly to siblings about the child's condition
- Spend time each day with siblings one to one
- Acknowledge the negative feelings as well as the positive ones
- 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
- Limit the type and amount of care and support that siblings do
- Give siblings permission to enjoy and live their own lives
- Make sure that your sibling child's school knows what is happening at home
- Don't be negative – siblings can gain and learn from their experiences
- 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.





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 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.

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.

If there is any advice I could pass on to people growing up with a disabled sibling – try not to be embarrassed and worry what your new friends may think, 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 know your sibling. 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.

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

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.

My parents 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, I can safely assume that 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.



Siblings and the law

Social services and social work 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.

The rights to assessments for siblings who provide care also exist under the Children and Families Act 2014 (England only). 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 (England only) 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.



Call our freephone helpline for advice on accessing support and services for siblings.

Sources of support

Sibling support groups


Sometimes supporting a young person individually will be necessary as well as, or instead of, group work. Projects for young carers often include siblings in their work 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
- issue-based workshops
- counselling.


 www.youngcarer.com/young-carers-services

The Children's Society also has resources for professionals and schools with good practice supporting carers.

> 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 for siblings of disabled children and adults. Run workshops, training and events around the UK. Has support, advice and information for young siblings. Also for parents on supporting siblings and professionals.

 www.sibs.org.uk

> YoungSibs

Sibs online support service for siblings aged 6 –18 who have a brother or sister who is disabled or has additional needs. It has information about different conditions and strategies for coping with sibling issues. It also has a letters section for siblings to receive personalised responses to their questions, and a safe online chat area for siblings to talk to other siblings under 18.

 www.youngsibs.org.uk




Sibs also runs a moderated online support and discussion forum for siblings of disabled people aged 18 or over.

 adult-siblings-forum.sibs.org.uk

> Carers Trust

Runs a dedicated website for siblings/young carers including discussion boards and chat rooms.

 <https://babble.carers.org>

Books

The Contact library has a book list for siblings – or we can look up books for you.

 library.team@contact.org.uk

 020 7608 8726.

There are a number of books written for parents about supporting siblings, some general, and some for parents of children with specific conditions.

If you search for 'siblings of disabled children' on popular online book stores they will come up. Sibs also has books on their website


 www.sibs.org.uk/parents

If you know the name of your disabled child's condition

Specific disability support groups often have information and booklets for affected children and siblings.


It is not possible to list every support group with resources for siblings here, but if you are a parent please contact our helpline on 0808 808 3555 to find out if there is a support group for your child's condition.

Alternatively you can search the Contact A-Z Directory to find support groups at

 www.contact.org.uk/medical-information

Financial help and grants


The Contact helpline has a list of charities which provide grants for families with disabled children.

 0808 808 3555 for a copy.

> Family Fund

Provides grants to families who are caring for a disabled child, which may ease the pressure on siblings by providing holidays, outings and recreational equipment that the whole family can enjoy together.


 01904 550 055

 www.familyfund.org.uk


For bereaved siblings

> The Compassionate Friends Sibling Support

Offers a support for bereaved siblings and parents.

 Helpline 0345 123 2304

NI Helpline 028 877 88 016

 www.tcfsiblingsupport.org.uk

> Winston's Wish

Charity for bereaved children. Also provide reading materials for children and parents on coping with serious illness and when someone has died.

 Helpline 08088 020 021

 www.winstonswish.org.uk

How Contact can help

Contact is a UK charity that provides support and information to families with disabled children, whatever the condition or disability.



Our helpline

Our freephone helpline can give advice about any aspect of raising a disabled child, including help with finances, education, emotional and practical support.

 **0808 808 3555**  **helpline@contact.org.uk**



Guides for parents

We have a range of free guides for parents, including:

- *Helping your child's sleep*
- *Relationships and caring for a disabled child*
- *Fathers*
- *Developmental delay* (explanation and developmental milestones)
- *Claiming Disability Living Allowance* (the main benefit for disabled children)

A full list of our guides is at the link below. All our guides are free to parents who call our helpline, and are free to download.



www.contact.org.uk/publicationslist

0808 808 3555

Updated by Lucy Pratt. With thanks to Monica McCaffrey of Sibs for her invaluable help.

contact *For families with disabled children*

Get in contact with us

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 info@contact.org.uk


 www.contact.org.uk


 www.facebook.com/contactfamilies

 www.twitter.com/contactfamilies

 www.youtube.com/contactfamilies

Free helpline for parents and families:

 **0808 808 3555** (Mon–Fri, 9.30am–5pm)

 helpline@contact.org.uk (Access to over 200 languages)



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