



Siblings

Information for families

UK

Incorporating **The Lady Hoare Trust**

Introduction

This guide is about 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. Relationships with our siblings are likely to be the longest we have and can be important throughout our adult lives too.

In previous times, children with a disability or long-term illness may have spent long periods in hospital or have lived there permanently. Today nearly all children, whatever their disability, spend most of their time with their family. This means that their contact with their brothers and sisters is more continuous. 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 a Family in recent years.

"It's the same as in any brother or sister relationship, only the feelings are exaggerated."

Sibling

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Web: **www.cafamily.org.uk**

Research about siblings

Studies about siblings of disabled people have tended to report a mixed experience. It is often 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 adult 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.”

In a study, 29 siblings aged between 8 and 16 were interviewed¹. All said that they helped to care for their brother or sister, about whom they spoke with love and affection. The difficulties they experienced were:

- being teased or bullied at school
- feeling jealous at the amount of attention their brother or sister received

- feeling resentful because family outings were limited and infrequent
- having their sleep disturbed and feeling tired at school
- finding it hard to complete homework
- being embarrassed about their brother or sister’s behaviour in public, usually because of the reaction of others.

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

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Growing up together

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 go a long way to help them deal with worries and difficulties that are bound to arise from time to time.

Below we highlight some of the issues that often crop up for siblings of a disabled child, and some examples of the ways parents have found of responding to these:

Limited time and attention from parents

- protect certain times to spend with siblings e.g. 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?

- 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

- 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.

Stressful situations at home

- 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.

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Restrictions on family activities

- try to find family activities that everyone can enjoy, e.g. swimming, picnics
- 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

- 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

- realise that non-disabled relatives can be embarrassing, especially parents
- find social situations where the disabled child is accepted
- if old enough, split up for a while when out together.

Teasing or bullying about a brother or sister

- 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.

Protectiveness about a very dependent or ill brother or sister

- 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

- 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.

Working together for siblings

Parents are already short of time and energy and mustn't feel that they have to handle everything alone. Those who belong to support groups may be able to swap ideas with other parents or they could suggest a discussion about siblings at one of their meetings. 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.



"It helped to know that I'm not alone with a disabled brother or sister."

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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.

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An adult sister remembers

"I am one of five girls. I am the eldest and was 11 years old when Helen was born. She was a beautiful baby and I fell in love with her instantly. However, as time went by, I gathered from various overheard conversations that something was seriously amiss. Helen has profound physical and mental disabilities and I remember there were a lot of disagreements between my parents on the best thing to do. There were loads of visitors and phone calls but no-one ever really explained what was going on.

Eventually my parents joined the local Mencap group. They found this very helpful but I was not keen on having to join them in attending the social activities when I preferred to see my own friends. One of the difficult things

for me was not having enough of my parents' attention.

As the eldest, I was often the 'little mother'. I felt obliged to be supportive to my parents and felt guilty about resenting this. It was not acceptable to complain about Helen's behaviour even though she often bit or attacked us. I was told how lucky I was to have a sister like Helen – a view I did not always share! It was not until I became an adult that my sisters and I actually talked together about our experiences of growing up with Helen.

As a parent myself, I now understand how tough it was for my parents. I realise, too, that I would have had to compete for attention anyway with four sisters, even if one had not had special needs. These days one of my greatest pleasures is the delighted smile on Helen's face when she sees me."

How one family planned for the future

"Ever since I was a teenager, I've been anxious about who would care for my brother when both my parents die. I have three brothers, of whom John is the youngest. He is 25 and has learning difficulties. He has always lived at home with my parents. I used to feel concerned that my parents had made assumptions about who John's main carer would be and they seemed unwilling to consider any alternatives.

Three years ago, I encouraged them to hold a meeting with all the key family members, including John, to talk about his long-term care arrangements. We had a fairly formal meeting, which my husband chaired. We began by acknowledging that Mum and Dad would not be around forever to look after John and that we should get some sort of plan down in writing which we could review at a later date. Then we each took it in turn to say what we felt would be the most positive arrangement for John and what level of involvement we wanted to have in his care.

It was great having someone chair the meeting so that we were not

interrupted even if we said something that others disagreed with. I was actually surprised at how much in common our views were, and how each of us wanted to contribute to John's care.

The main areas where we felt differently were about how much money my parents should put into a trust, and about what rights John had as an adult. I certainly felt for the first time that I had a chance to say what I felt about these things.

We came to a joint agreement about what should happen and about what financial support would be available. We recognised that there were some issues that we still felt differently about. We agreed to review our plans in five years' time, or in the event of changing circumstances.

At the end of the meeting, I felt very relieved that at last there would be something on paper, and that the responsibility for John's care was being shared by us all. Since then my father has died and I'm so glad he had the chance to say what he wanted for John."

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Siblings groups

Many siblings have found it useful to join a local siblings group or young carers project.

Many groups are started by local professionals working together with the support of parents. Individual groups and projects vary but tend to be run on a similar format:

- a small group of children or young people take part, within a narrow age range e.g. 9-11 or 12-14 years old
- the group meets weekly for a few hours, perhaps longer if they go on a trip
- the adults running the group come from several different agencies and professional backgrounds, e.g. teaching, childcare, psychology, youth work
- groups offer a mixture of recreation, socialising, discussion and activities such as games and role play; the emphasis is on self expression and enjoyment
- transport is often provided and can offer an extra opportunity for talking
- confidentiality within the group is emphasised
- the group is encouraged to feel the group is theirs, deciding on rules and activities.

Those who work with groups of siblings often comment that they learn a great deal from the youngsters taking part. Some of the benefits to siblings include meeting others in a similar position, sharing ideas about coping with difficult situations and having a good time.

Contact a Family is interested in hearing about local developments in work with siblings, so that it can pass on information to interested people in that area.

"I like the trip we had - I'd never been on a train before."

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Siblings and the law

The Children Act 1989 is the framework for the support offered to children "in need", including those with disabilities. The approach of this legislation is to emphasise the child as part of their family. As well as one or two parents, this might include brothers and sisters, grandparents or other relatives, who are often important figures in any child's life. The guidance and regulations of the Children Act which refers to children with disabilities² states that "the needs of brothers and sisters should not be overlooked and they should be provided for as part of a package of services for the child with a disability".

Local authorities have a duty to provide services to children who have been assessed as being "in need" under the Children Act or "affected by disability" under the Children (Scotland) Act. So siblings should be on the agenda of agencies who aim to support families with a disabled child.

Sometimes brothers and sisters who provide a substantial amount of care are described as young carers. This may mean they are entitled to an assessment of their needs in their caring capacity.

Other support

Not all siblings will want to join a group or have the chance to do so, and 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.

The Princess Royal Trust for Carers

Unit 14, Bourne Court, Southend Road
Woodford Green, Essex IG8 8HD
Tel: 0844 800 4361
Web: <http://www.youngcarers.net>

The Princess Royal Trust for Carers has a website dedicated to siblings and young carers including discussion boards and chat rooms (moderated by adults who have been police-checked). It has an 'Agony Aunt' page for young people's questions plus information on young carers projects around the UK.

The Children's Society

Edward Rudolf House, Margery Street
London WC1X 0JL
Tel: 0845 300 1128
Web: <http://www.youngcarer.com>

The Children's Society has a website for young carers, their families and those who work to support them. The site includes links to useful organisations, and information on local young carers projects around the UK.

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

CarersNet

Web: <http://www.carers.net>

Website for the Coalition of Carers in Scotland. It has information on young carers projects in Scotland.

Sibs

Meadowfield, Oxenhope,
Keighley, BD22 9JD
Tel: 01535 645 453
Web: <http://www.sibs.org.uk>

Sibs runs workshops, training and conferences on siblings issues around the UK. It gives support, advice and information for siblings, their parents and professionals, including factsheets for younger siblings.

Siblinks

Web: <http://www.siblinks.org>

Website for teenage siblings of children with cancer, including a moderated website forum for young people.

Sibling Support Project

6512 23rd Ave NW, 213
Seattle WA 98117 USA
Web: <http://www.siblingsupport.org>

Sibling Support Project is an American based siblings information website with the opportunity for siblings to make contact with each other. It has useful books and resources for professionals and siblings applicable to the UK.

Further help

Specific disability support groups often have information and booklets for affected children and siblings. The organisations listed below produce literature specifically for siblings.

The Society for Mucopolysaccharide Diseases

MPS House, Repton Place,
White Lion Road, Amersham,
Buckinghamshire, HP7 9LP
Tel: 0845 389 9901
Web: <http://www.mpssociety.co.uk>

National Autistic Society

393 City Road, London EC1V 1NG
Tel: 0845 070 4004
Web: <http://www.nas.org.uk>

Other support groups

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 Family Directory - The essential guide to medical conditions, disabilities and support*' online via our website.



Books for siblings

Gilley the Giraffe who Changed

Nimmi Channa (2006)
Published by the Encephalitis Society
ISBN 10: 0955218012
ISBN 13: 9780955218019

Living with a Brother or Sister with Special Needs – A book for sibs

Donald Meyer and Patricia Vadasy (1996)
Published by University of Washington Press
ISBN 10: 0295975474
ISBN 13: 9780295975474

The Other Kid - A draw it out guidebook for kids dealing with a special needs sibling

Lorraine Donlon (2007)
Published by Llumina Press
ISBN: 9781595267801

Siblings: Coming unstuck and putting back the pieces – Stories of everyday life with children who are different

Kate Strohm (2004)
Published by David Fulton Publishers
ISBN 10: 1843122324
ISBN 13: 9781843122326

The Sibling Slam Book – What it is really like to have a brother or sister with special needs

Edited by Donald Meyer (2005)
Published by Woodbine House
ISBN 10: 1890627526
ISBN 13: 9781890627522

Special Brothers and Sisters – Stories and tips for siblings of children with special needs, disability or serious illness

Edited by Annette Hames and Monica McCaffrey (2005)
Published by Jessica Kingsley
ISBN 10: 1843103834
ISBN 13: 9781843103837

Views from our Shoes: Growing up with a brother or sister with special needs

Edited by Donald Meyer (1997)
Published by Woodbine House
ISBN 10: 0933149980
ISBN 13: 9780933149984

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For parents and professionals

Brothers and Sisters – A special part of exceptional families

Peggy A. Gallagher, Thomas H. Powell, Cherly A. Rhodes (2006) (Third edition)

Published by Brookes Publishing Company

ISBN 10: 1557667195

ISBN 13: 9781557667199

Brothers and Sisters – How to help the siblings of very sick and disabled children

Sarah Barrell (2002)

Published by Sarah Barrell

ISBN 10: 095428710X

ISBN 13: 9780954287108

Brothers and Sisters of Disabled Children

By Peter Burke (2003)

Published by Jessica Kingsley

ISBN 10: 1843100436

ISBN 13: 9781843100430

Brothers, Sisters, and Special Needs – Information and activities for helping young siblings of children with chronic illnesses and developmental disorders

Debra J. Lobato (1990)

Published by Brookes Publishing Company

ISBN 10: 1557660433

ISBN 13: 9871557660435

Listening to Siblings – The experiences of children and young people who have a brother or sister with a severe disability

Janet Ratcliffe (2003)

Published by The Hansel Trust

ISBN 10: 1903745055

ISBN 13: 9781903745052

Sibshops – Workshops for siblings of children with special needs

Donald Meyer & Patricia Vadasy (2007)

Published by Brookes Publishing Company

Company

ISBN: 1557667830

The Views and Experiences of Disabled Children and Their Siblings – A positive outlook

Clare Connors and Kirsten Stalker (2002)

Published by Jessica Kingsley

ISBN 10: 1843101270

ISBN 13: 9781843101277

Winston's Wish

Web: <http://www.winstonswish.org.uk>

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

References

¹ All in the Family – Siblings and Disability (1995) NCH Action for Children

² The Children Act Guidance and Regulations, Vol. 6 (1991) London: HMSO

Contact a Family is on Facebook, MySpace, Bebo and YouTube. We also have an office in Second Life.

Join us at:

MySpace

www.myspace.com/contactafamily

Bebo

www.bebo.com/contactafamily

Facebook

www.facebook.com

and search for 'Contact a Family'

YouTube

www.youtube.com/user/cafamily

Second Life

You can find our Contact a Family virtual advice office in Second Life on Aloft Island 19.40.22 (PG) or visit <http://tiny.cc/P9A5l> to teleport there directly.

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

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Mon–Fri, 10am–4pm;

Mon, 5.30–7.30pm

Access to over 170 languages

www.cafamily.org.uk

www.makingcontact.org

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Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

- Relationships ^(UK)
- Fathers ^(UK)
- Grandparents ^(UK)
- Working ^(UK)
- Concerned about your child? ^(UK)
- Understanding your child's behaviour ^(UK)
- The tax credits guide ^(UK)
- Disabled children's services in England and Wales ^(England & Wales)
- Benefits, tax credits and other financial help ^(UK)

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