

SIBLINGS

The relationship between brothers and sisters is likely to be the most long standing one that any sibling will experience, which is why many parents express concern about the likely effects on a family when one child is diagnosed with a chromosome disorder. Parents know how difficult it can be to manage all the needs of any family. If a family has a child with special needs there are extra emotional and practical demands on your time and energy. The whole family will need support to adjust to this change in circumstances. Most siblings cope very well and sometimes gain strength from their childhood experiences. Parents' reactions and attitudes to their child's disability are important. It can influence the way siblings accept and learn to value their brother's or sister's individuality.

All children want to grow up in a strong, secure and loving environment. It will help if families are able to discuss openly and frankly what has happened and why. There are various support groups for siblings (details below) who have made suggestions about ways to reassure siblings. These are some of the most common difficulties that siblings have experienced and some helpful

tips: -

- **They don't know what is wrong** – children fear the unknown and imagine the worst. If they are old enough to understand, try to explain to them what a rare chromosome disorder is (use the Unique Comic Tales). When other children ask questions, they will be able to explain why their brother or sister is disabled. As they get older you can give more detail. If that is difficult, ask the paediatrician or another professional to talk to them. Keep them informed about what happens during hospital appointments or treatments.

- **Feeling left out** - a child with special needs takes up a lot of time and it can mean that there is less available for the rest of the family. Siblings may realise their parents are busy and not want to bother them. Make sure they get a chance for some time on their own with you. Perhaps you can get respite care. (Don't forget that any assessment for services must take into account the needs of all the family, particularly siblings.) Include them in discussions about any changes to family routines, care needs or therapy treatments.

- **Embarrassment** – their brother or sister looks different or behaves differently to other children and attracts attention when out in public. This is hard to deal with, especially if one of the siblings is at a sensitive age. Some parents opt for the 'glass bubble' approach; nothing of any importance exists outside their bubble and they ignore any stares or comments. Other parents stare right back or explain that their child has a rare disability. If you stay calm and not allow

other people to upset you, the rest of the family will learn from your example. Look for social outings with other disabled children. Arrange the occasional separate outing. Joining a young carer's group or sibling support group can help them to feel more confident and less isolated.

- **Negative feelings** – it is only natural that siblings will sometimes feel angry, sad, or fearful about their brother or sister.

But if you can encourage them to talk about their feelings, even share your own, it will help them to understand that these negative thoughts do happen from time to time. It does not mean that their brother or sister is not loved or cared for. It might help if they can talk to some one outside the family like a school counsellor or family friend.

- **Limited social life** – Siblings may find it difficult to invite friends over or there are few opportunities for family activities. Are there holiday schemes for disabled children, which would offer siblings a chance to have friends over? A lock fitted to the bedroom door would offer some privacy and prevent annoying interruptions. It has the added benefit of protecting toys and precious possessions.

Siblings may not experience any difficulties at all. Or they can hide their feelings away. Give them opportunities to share their thoughts and feelings. Let them know that they are special too and an equally important part of the family.

RESOURCES

Young Carers Initiative is part of The Children's Society and provides a support network, newsletter, and runs projects.

www.childrenssociety.org.uk/youngcarers or www.youngcarer.com

SIBS – has a number of fact sheets on issues for siblings, parents and professionals, runs

a support network and workshops for parents and siblings. Phone advice line 01535 645453 www.sibs.org.uk

Carers National Association - for information, advice and support for carers, including young carers www.carersonline.org.uk

Kidscape – for support and advice on dealing with bullying and teasing
www.kidscape.org.uk

Princess Royal Trust for carers www.Youngcarers.net

Contact a Family website have a useful factsheet www.cafamily.org.uk/pdfs/siblings.pdf

The Sibling Project – Australian support group www.siblingsaustralia.org.au

The Sibling Support Project – Based in Seattle, USA. www.siblingsupport.org

Books

Unique Tales comic in English or Italian
<http://www.rarechromo.org/html/Siblings.asp>

<http://www.theotherkid.com/book.html>

<http://www.e-bility.com/books/siblings.php>

The following titles are some of the many available from www.Amazon.co.uk or www.amazon.com

- **Don't Call Me Special: A First Look at Disability** (First Look at Books) (Paperback) by Pat Thomas
- **Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs** (Paperback) by Donald J. Meyer
- **Living with a Brother or Sister with Special Needs: A Book for Sibs** (Paperback) by Donald J. Meyer and Patricia F. Vadasy
- **Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs** (Paperback) by Donald J. Meyer
- **Sibling Stories: Reflections on Life with a Brother or Sister on the Autism Spectrum** (Paperback) by Lynne Feiges and Mary Jane Weiss
- **Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs** (Paperback) by Kate Strohm
- **Everybody is Different: A Book for Young People Who Have Brothers or Sisters with Autism** (Paperback) by Fiona Bleach
- **Special Brothers and Sisters: Stories and Tips for Siblings of Children with Special Needs, Disability or Serious Illness: Stories and Tips for ... Children with a Disability or Serious Illness (Paperback)** by Annette Hames and Monica McCaffrey
- **Oh, Brother!: Growing up with a Special Needs Sibling (Paperback)** by Natalie Hale

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