



A Registered Charity  
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## Information Sheet - Siblings

Sibling means a person who is a brother or sister of someone. Everyone with Down's syndrome is different and every family is different. Many of your experiences will be unique to you but many of your experiences will be exactly the same as those of anyone who has a brother or sister. Your brother or sister with Down's syndrome may be your good friend and sometimes, just like any brother or sister, you may argue and fall out. Most people say that they get on very well with their brother or sister who has Down's syndrome. We put some questions for siblings to answer on our website. We have used the information that siblings gave us to write this leaflet. You can find a list of the questions that we asked siblings and some of the answers that they gave us below.

Proud, happy, sad, jealous, annoyed, protective, guilty and embarrassed. These are some of the feelings that you may have at one time or another about your brother or sister with Down's syndrome. You may feel that you always have to explain to people about your sibling with Down's syndrome. Sometimes you may feel a bit lonely because it seems as if no-one else understands how you feel. These feelings are normal. Don't feel bad if you argue with your brother or sister or if they annoy you. Sometimes it helps to talk to your mum and dad or your friends about your feelings. If you don't feel like talking about how you feel to your family, you could join a group for siblings of people with disabilities. You can find information about sibling support groups from an organisation called 'Sibs' or you could join an online support group for siblings. You can find more information about 'Sibs' and online support groups at the end of this leaflet.

*'I am fourteen and I would not be the same person, had I not had my brother Gabe in my life. Having a sibling with Down's syndrome - or any disability for that matter - changes everything, and not necessarily in a bad way. I have a range of emotions about Gabe. Pride, when he says the name of his favourite muppet. Anger, when he gets into my room and cheerfully dismantles the contents of my closet. Even embarrassment sometimes when he yells or "does something weird" in public, although the embarrassment has steadily fallen away as I've got older. Through all these emotions, there is a happiness that is unique between siblings. My family is lucky to have Gabe in their lives'.*

Down's syndrome is a condition that some people are born with. Most babies who are born with Down's syndrome have it because they have an extra chromosome in each of the cells in their body. Chromosomes carry genes, which are the things that control the way our bodies grow and develop. People with Down's syndrome can look a little like each other, but your brother or sister will look more like you and the rest of your family.

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### DOWN'S SYNDROME ASSOCIATION

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e. [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)  
w. [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

information

Just as each one of us is different, each person who has Down's syndrome is different, but the condition always affects the way a person develops and learns in some way. People with Down's syndrome usually have some learning difficulties. This means they have trouble learning and remembering things in the same way as other people. For example, they usually take longer to learn how to walk and talk when they are little. Most children with Down's syndrome read and write, and many go to ordinary schools. Different people who have Down's syndrome will have different kinds of difficulties.

People with Down's syndrome sometimes have more coughs and colds, or other illnesses. They might have to see the doctor a little more often than other people.

Each person who has Down's syndrome is different and Down's syndrome is certainly not the most important thing about them. It is just a small part of who they are.

Siblings who call the Down's Syndrome Association tell us that they worry sometimes about what will happen to their brother or sister with Down's syndrome when they grow up.

In the past it was believed that there were many things that people with Down's syndrome could not do when in fact they had never been given the chance to try. Today people with Down's syndrome have more opportunities; many people with Down's syndrome now leave home and lots of them have jobs.

Here is what some siblings have told us about their lives with their brother or sister with Down's syndrome:

***What is your earliest memory of your sibling with Downs Syndrome?***

*I remember being jealous of the fact she was getting so much attention. I remember my mother telling me that she was not well and that I asked her if she had a cold. I didn't understand until later.*

*I was probably three or four and we had Easter egg hunts. My two other brothers and I would look in obvious places, but my brother Joe would look under magazines, or in the video and places where eggs couldn't have been.*

*Going to see her for the first time, I didn't see what was wrong because she was perfect. I think the doctors made it worse when they explained it in a really negative light. This made it harder for my parents to see the positive side.*

*Tom getting really frustrated that I could ride my bike without stabilisers and he couldn't even though he was two years older than me.*

*Going to see James in the special care baby unit after his birth and seeing him in an incubator. He was so tiny I could hold him in one hand, they were*

*not sure at first if he was going to live, but he did. It was quite scary seeing all the equipment that was keeping him alive.*

*Sharing a bedroom - me about five and she was about seven. We opened our Christmas Stockings together. Looking back, I now know this was a time when we were on a par in terms of understanding what was going on.*

***What were your peers' reactions to your sibling? How did their reactions affect you?***

*Once when I told someone my brother had Down's syndrome, they replied with "I'm sorry to hear that". I was uneasy at their response because, to me, Joseph is just my brother and warrants no reason for anyone to feel sorry for him. I liken this reaction to funerals, no-one ever really knows what to say.*

*Most just accepted him. I was only three when he was born, so it wasn't really a big deal, we were just brother and sister.*

*As a teenager I was extremely aware of people's reactions to my sister. I've become extremely sensitive to the attitudes of others and tend to not have that much time for people who can't accept my sister for who she is.*

*My peers' reactions have generally been very good and they have been very understanding of idiosyncrasies and helpful when looking after her. When I was younger they often found it hard to communicate and understand her and I often had to translate what she wanted to say or do.*

*They think she is sweet but they also think she is annoying because she gets clingy when my friends come round. They get on with her and don't mind playing with her. They just think of her as my little sis.*

*Most of my friends were quite ignorant about Down's syndrome and in some ways that affected me. Some friends would sort of brush it under the carpet and get on with life, others asked questions and the rest just weren't interested. My closest friends just accepted him.*

*They were fine. I had the odd bad comment but most of my friends stuck up for James and many used to come to see him as well as me.*

*Generally my friends have been great. Sometimes they find it difficult to know how to act or what is the right way to communicate with my sister, but the more time they spend with her the more they see how fantastic she is and stop worrying! I am always really keen for people to meet her so that they understand more about Down's syndrome, and overcome their prejudices. It has shown me how to be more patient and caring.*

***How has having a sibling with Downs Syndrome changed your life?***

*I am much more caring to other people, but sometimes I have to look after her she can be a pain.*

*I felt that I never got my parents full attention and her needs had to come first. As I got older, I realised that this was how it had to be but as a child it was hard to accept at times.*

*I am more caring for others and understand other people's disabilities and will stick up for anyone who is getting bullied for whatever reason.*

*It's opened my eyes to how loving people can be, and how horrible. Tom is the most caring, up-front person I've ever met - he's totally non-judgemental and doesn't know the meaning of the word embarrassing. I wish I could be more like him!*

*It has made me consider a career in healthcare or education. It also means that things I may have done in the future (like move abroad or far away from my parents to work) I am less likely to do. My brother has changed my life in a very positive way, as our family is close and I have a very close relationship with my brother. He makes me really happy to be around him.*

***How do you think your life would have been different if your sibling had not been born, or had been born "normal"?***

*I took on more responsibility at a younger age than I would have done if Joe hadn't been born with Down's syndrome. I feel that we're a very close family, even now we're older and more independent, and this may be because of Joe. If he hadn't had Down's syndrome, we would all be doing our own thing, and not making as much time to be together.*

*I never think like that. My sister is my sister. I can talk to her about the same things I do with my other sisters. She's there for me just like I'm there for her.*

*I wouldn't have understood disability and would have stared if someone with Down's syndrome had passed me in the street.  
I don't think my life would have been that different. I do think my parents' lives would have been much different and ultimately a lot easier.*

*I would have been more ignorant about Down's Syndrome. If I could go back and change things, I wouldn't! Although, I do think it was hard on my parents because when she was younger he needed constant supervision and this really did limit their lives in terms of freedom.*

*I might not have ended up working with children with special educational needs. I might not have been so open-minded about people with disabilities*

***What effect did your sibling with DS have on your family (in your perspective)? Share some honest experiences you've had with your sibling, positive and negative.***

*My parents sometimes found it difficult to deal with the mixed reactions of other people when she was young, but this was in the 1950's.*

*The main effect to me is the one it has on my parents. They are in their sixties now and should be enjoying their retirement, but having my sister is a*

*tremendous strain on them both. I help out by having my sister over to stay, but it's only a small respite from the constant caring they do.*

*My brother has never really come to terms with the fact that he has a sister with a disability and I know he found it hard during his teens. I also think my dad struggles with my sister sometimes - he sometimes lacks the patience that is required or forgets that she is not as able as others - I have always found this very frustrating.*

*There have been times when I have felt that things would have been easier if my brother did not have Down's syndrome. I have a great appreciation for the things in my own life, but sometimes it's upsetting to think about the things that my brother will most likely miss out on.*

*It was very stressful for everyone at the beginning because he was constantly in and out of the hospital. In general, the whole family is a bit closer. Positive things are like when doctors told us to expect him to be slower than the average child it just made it more special when he did do things. Negative things are the fact he tends to be in and out of the hospital all the time. When he was first born me and my other siblings felt a bit left out because he got so much attention.*

*When my sister came home from the clinic in Paris, I did feel pushed aside. For years my brother and myself had all the attention and suddenly there was someone else permanently in the family. It took me a while to overcome this.*

*I think that my sister has brought my family closer together because we all love and care about her so much. Of course, it can be difficult for us to be with her every second of the day, to keep her safe and out of trouble! If I am honest, this can be quite stressful for all members of my family. Having said that however, she is definitely worth the effort, and we wouldn't change her for the world!*

*My brother takes a lot of my mum's attention and is harder work for her. He's good fun to be with most days but he can also be difficult and stubborn.*

### ***Did you ever feel pressured because of your sibling?***

*I never feel pressured because of Joe, but I have felt I have felt a certain responsibility to take care of him. He would normally be at an age where he could look after himself without needing supervision, but I'm aware that he doesn't really like to be on his own. I feel that I am also responsible for looking after him when my parents go out for the evening. I know that they'd prefer to have me looking after him than anyone else. Having said that, my parents have never expected me to do this, and if Joe didn't have DS and was younger, I would still be happy to look after him.*

*No not really, I've had the normal telling off for calling him names, but don't all sisters do that? That has caused me to think more wisely what I say to my younger brother now, but it would be the same with anyone else.*

*I felt jealous of her and I think this has made me more ambitious in life generally. But not necessarily pressured.*

*No. However, I sometimes tend to put pressure on myself to constantly protect her and to keep her happy! She deserves all the attention though!*

*Many people ask if I lose anything (such as love or attention) from my parents because of Tom, but I can honestly say I don't and I certainly don't feel pressured.*

*Sometimes when I was a teenager I felt pressured to include my sibling when, as a teenager, you want to do your own thing. In general though I wouldn't say I've suffered any undue pressure.*

*I think because there are lots of brothers and sisters to help my parents out I have never felt pressured to take care of him.*

### **Notes for parents**

Most children respond well to being the brother or sister of a child with Down's syndrome. Research on siblings indicates that there are positive aspects in being the sibling of a brother or sister with a disability. Researchers have found that children in families where a sibling has a disability can become more mature, responsible, self-confident, independent and patient. These siblings can also become more charitable, more sensitive to humanitarian efforts and have a greater sense of closeness to family.

*"My brother has taught me more than he will ever know. He has taught me patience and how to be more accepting of others"*

Children who grow up together in the same family can form a unique bond, regardless of a brother or sister having a disability. In fact, the relationship between siblings and their brother or sister with a disability can be identical to the relationship between any brother or sister. They may be close and remain so into adulthood, or they may never develop a close relationship or grow apart as they get older. Family situations and circumstances, such as divorce or even cultural differences, and individual personalities can also affect the way a sibling relationship develops.

Throughout their lives, brothers and sisters will share most of the same concerns that parents of children with Down's syndrome experience, along with issues that are uniquely theirs. Naturally, siblings will spend a lot of time with their brother or sister with Down's syndrome. Sibling relationships are usually the longest lasting relationships in a family. Brothers and sisters are likely to be involved in the life of their sibling with Down's syndrome longer than anyone - including their parents.

It's important to remember that a lot of factors affect how siblings relate to each other, and not just the fact that one of them has a disability. However, sometimes having a brother or sister with a disability in the family creates challenges that other families may not experience. Some of these challenges can directly affect the siblings.

Having a baby with Down's syndrome in the family often requires a period of readjustment. Children take their cue from their parents - if parents feel positive about the new baby, they will too. If you are feeling distressed, talk to your other children about why you are feeling distressed. Tell them that it is not their fault and that you are just feeling sad at this time. Tell them that it will pass.

**Below are some of the issues that may come up for siblings:**

In any family, positive and negative feelings may develop between siblings or because of siblings. This is true in both families with and without a family member with a disability.

- Guilt about not having a disability, while the brother or sister does have one. Some siblings may even feel they are to blame for their brother's or sister's disability. If you are upset about the diagnosis of your child's disability or you are having difficulties with your child who has a disability, try and explain the way you are feeling to your other children. If your other children see that you are upset but are not given an explanation, they may think that they are somehow to blame for the way you feel.
- Embarrassment of the sibling's behavior or appearance. At some time in their lives the sibling who does not have a disability may avoid contact with the brother or sister, not invite friends to the home, etc.
- Fear that they might develop the disability. Children (and sometimes even adults) may think that disabilities such as Down's syndrome are contagious.
- Anger or jealousy over the amount of attention the brother or sister with a disability receives, especially if the child's disability requires additional care.
- Isolation or feeling like no one else has the same feelings or experiences about having a sibling with a disability.
- Pressure to achieve in order to "make up for" a brother or sister's inabilities. The sibling who does not have a disability may feel that achieving highly at school, in sports or other ways will compensate for the fact that a brother or sister with a disability is not able to do as well. Parents may sometimes subconsciously transfer expectations of high achievement from their child with a disability to their child or children who do not have a disability
- Caregiving, especially if it conflicts with plans with friends or the responsibility becomes overly burdensome.
- Information needed about a brother or sister's disability. Siblings often are not given clear information about why a sibling has a disability, how it affects him or her and what the family can do to help this family member.

Many of these feelings affect children as they are growing up, but siblings often continue to have concerns even as adults. For example, siblings who do not have a disability may be concerned about the future of their sibling with a

disability after the parents die, especially if this brother or sister still lives at home.

**Parents of children with disabilities often worry about how to meet the needs of the other children.**

### **Some Tips:**

- Treat the child who does not have a disability as a child, not just as another adult carer. Do not demand or expect a child to take on responsibilities for which he or she is unprepared.
- Remember that children have feelings too. Take time to ask them how they feel about having a sibling with a disability. Encourage them to express their feelings openly even if you don't like what you hear.
- Provide siblings with choices and include them in decision-making. Discuss family matters with your children, especially if it affects them personally. Ask for and consider their opinions and advice.
- Give them information about their brother or sister's disability. Answer their questions and respond to their concerns in a simple but precise manner. Emphasise that no-one is to blame for their brother's or sister's disability. Come to terms yourself with your child's disability. Encourage siblings to see their brother or sister as an individual with similarities and differences to themselves. Meet other families who have a son or daughter with Down's syndrome, perhaps through a local support group.
- Spend regular time with your child - have a special time for him or her each day
- Celebrate your child's achievements, even the small ones

### **Resources - Siblings**

### **UK Support Organisations**

**Sibs** - for brothers and sisters of people with special needs

Meadowfield  
Oxenhope  
West Yorkshire  
BD22 9JD

Helpline No - 01535 645453  
Email - [info@sibs.org.uk](mailto:info@sibs.org.uk)  
Website - [www.sibs.org.uk](http://www.sibs.org.uk)

Sibs provide support, advice and information on sibling issues via email and via their helpline service.

**Contact A Family**

209-211 City Road  
London  
EC1V 1JN

Helpline No - 0808 808 3555  
Email - [info@cafamily.org.uk](mailto:info@cafamily.org.uk)  
Website - [www.cafamily.org.uk](http://www.cafamily.org.uk)

Contact a Family is the only UK charity providing support and advice to parents whatever the medical condition of their child.

**Online Support and Email Lists**

**Sibs Encounter** - online support group for brothers and sisters of people with disabilities.

Website - [www.sibspace.org](http://www.sibspace.org)

**SibKids** - Yahoo email list for the siblings of children with special needs worldwide (managed by 'The Sibling Support Project')

Website - <http://groups.yahoo.com/group/SibKids/>

**SibNet** - Yahoo email list for and about adult siblings of people with special needs worldwide (managed by 'The Sibling Support Project')

Website: <http://groups.yahoo.com/group/SibNet/>

**Useful Websites****The Siblings Support Project (USA)**

Website - <http://thearc.org/siblingsupport/index.htm>

**Literature**

Living with a Brother or Sister with Special Needs: A Book For Sibs  
Second Edition, Revised and Expanded (1996) by Donald Meyer and Patricia Vadasy  
University Of Washington Press  
ISBN - 0295975474

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs

Edited by Donald J. Meyer

Woodbine House (1997)

ISBN - 0933149980

Brother, Sisters and Learning Disability. A Guide for Parents

by Rosemary Tozer

BILD Publications

ISBN - 1873791879

Sisters, Brothers And Disability - A Family Album

by Lydia Gans

Fairview Press (1997)

ISBN - 1577490444

Think About - Having a Learning Disability

by Margaret and Peter Flynn

Belitha Press Ltd

ISBN - 1855618079

**The Down's Syndrome Association does not sell these books. However, all these titles can be ordered through any large book retailer or via the internet (e.g. [www.amazon.co.uk](http://www.amazon.co.uk) ). Book prices may vary according to the individual retailer and availability.**

**Stuart Mills & Will Creed, DSA 2005**