

# Disability - brothers and sisters

When your child has a disability it affects everyone in the family including brothers and sisters (siblings). How brothers and sisters react to having a sibling with a disability can depend on the kind of disability, their age, the age of the child with the disability and how it is managed in the family. Most importantly it will depend on how parents manage and the support all the children get from their parents. Brothers and sisters can have some of the same feelings of loss that parents have. It is important that their feelings are heard and understood. Brothers and sisters can also have a lot of joy from their relationships with their sibling with a disability, and learn a lot that will help them develop into caring, thoughtful young people.

## **Issues for brothers and sisters**

- Family life may need to be arranged differently to allow for the treatment and training needs of the child with a disability.
- Family outings and activities (where the family can go as a family) can be affected.
- Healthy children may miss out on time and attention from parents, and feel jealous of this; sometimes brothers and sisters fight between themselves because they know they cannot fight with the child with the disability.
- They may feel guilty if they complain because they are expected to be sympathetic or take extra care of their sibling; they may not want to be with them when they are with their own friends.
- They may be afraid of what the disability means to them; they may not understand that they cannot catch it.
- They may be embarrassed by their sibling's behaviour when their friends come around.
- They may be asked to act as carers to help parents out and might resent this.
- They may be worried and upset by their parents' reactions to the problem, especially if parents are grieving or fighting (which can happen under stress).
- They may feel a pressure to succeed to make up for the parents' disappointment.

## **What brothers and sisters say**

This section has some of the issues that have been raised by brothers and sisters, with some suggestions for what you might do to help them.

### **"People ask what it is like to have a sibling with autism"**

The brother or sister may learn to answer something simple but truthful.

- "Normal - I have never known anything different" or
- "It can be a pain sometimes, but so can my other brothers and sisters" or
- "She is my sister, not just someone with a disability".

### **"I am afraid that when my parents die, he will be my responsibility"**

- While parents hope that brothers and sisters will always care for each other, they need to make plans as far as you can for your child with the disability so there is not an unfair burden for the other children.

- Talk through this issue with your other children so you can hear their fears and talk about what can be done to plan ahead.

**"I hate asking my friends over to play because my brother always joins in and spoils the game"**

- Let the siblings know that they do not always have to include your child with the disability, just as they will not always want to include each other. This is especially important in the teenage years.
- Set up a place for your child with the disability with some special activities eg a video or TV, for when the other children have friends over.
- Some active children with a disability can be happily occupied on a swing so the other children can play together.

**"I always feel I have to explain to my friends that it is not genetic, it is not part of me and it is not catching"**

- Some conditions are genetic (run in the family) and some are not.
- Give children very clear information about the condition.
- Even genetic conditions do not affect everyone in a family and will not necessarily affect the children of the brothers and sisters.
- Get genetic counselling for the brothers and sisters if necessary, as they grow older and need this information.

**"I can never have my party anywhere I want to because she has severe asthma and these places would make her ill"**

- Children and young people should be able to have their special occasions with their friends.
- Some families have two birthday parties - one for the family where everyone can go and one just for friends.

**"My mum and dad could never watch my sport because they had to care for my sister and she would misbehave"**

- Try taking turns to watch the other children's sport.
- If it is a special match that both parents want to watch it may be possible to take your child with a disability and watch the match from the car.

**"My sister always gets the biggest part of mum's time and she gets away with everything because she's got problems"**

- It is important to try to make time for all the children, even if it sometimes means getting respite care or help with caring for your child with the disability.
- All children will test limits and it is not helpful for any child to have unfair allowances made for their behaviour. Children with a disability will fit in best and be more accepted if they are able to conform to the behaviour that is expected of other children. On the other hand, your other children need to know that you can only expect what each is capable of and that will differ between children.

**"My friends sometimes call people "a spastic" when they want to put them down. My brother is spastic"**

- Children may need help to cope with situations like this, where the friends may not be meaning to tease.
- They could reply by saying what spastic (or whatever word is used) means, and that it isn't fair to tease people who can't hold their own.
- If friends actually make fun of the child with a disability his brother might say something like "He does have some problems, but he is really good at...", or "Everyone has some problems. He is my brother and I feel sad when you tease him".
- Bullying is not OK and should not be tolerated. Sometimes a brother or sister can help, eg one sister used to say "My sister was born like that, what's your excuse?!" - which made the teaser stop and think.

**"I am not a person in my own right, I am just Sam's sister"**

- While parents you will need to give a lot of time to the child with the disability, and naturally want that child to feel special. It is important that all your children in your family feel special.
- Make regular special time with each of your other children.
- When you talk with friends make sure to talk about the achievements of all your children.
- If the care of one child is very demanding, try to get some respite care so you can spend time with your other children.
- Make sure that each of your children has your support in following their own special interests.

**"I have to care for my brother a lot when my mum is working because he has cystic fibrosis and is in a wheelchair, and I can't play with my friends"**

- Brothers and sisters of a child with a disability sometimes have to carry extra responsibility, especially in single parent households.
- This responsibility can help them to be more independent and have more skills and maturity than other children of their age.
- On the other hand all children need time to be children so it is important to make sure they get this. This might mean you have to get someone else to stand in some of the time.
- Some children do not say when they feel overburdened or may feel guilty if they complain. It is a good idea to check how they are feeling from time to time.

**"I often feel disappointed, because when my parents plan something for me, something goes wrong for my sister and we all have to go to the hospital"**

- If planning is a problem in your family because of the health needs of one of your children, try to work out an "in-case" plan...."in case" we can't go to the pageant, "in case" something goes wrong when it is your party.
- Plans made well ahead can include the support of a special relative or friend so that the celebration does not have to be missed.
- Otherwise another time for a special outing can be planned - work this out with your children if they are old enough.

## **"I am always expected to be the responsible one, to give in when there is an argument"**

- It is not good for children to always get their own way and children and young people with disabilities also need to learn to consider others as well as they can.
- Teaching your child who has a disability that she cannot always have her own way, and to behave in ways that fit in with the rest of the family, will make everyone's life easier, including her own in the long run.

### **What parents can do**

- Help brothers and sisters work out how to explain the disability to their friends.
- Explain how the disability was caused, because children may worry about it happening to them, or feel they caused the problem in some way.
- Give your other children permission to ask questions openly and give them answers so they understand what is happening.
- Listen to children's feelings. Try and find some special time for each child in the family.
- All children need time to be children. Helping to care for a brother or sister can be good for children but they also need plenty of time to play and be with their own friends.
- Allow siblings to be involved, eg let them help choose clothes for their brother or sister.
- Encourage brothers and sisters to be proud of their sibling's achievements and to realise the difficulties she may have had in getting there. Let them know that you are proud of their achievements as well.
- Make sure that your child with the disability does not destroy or damage your other children's work or belongings. Give them a safe place to keep them if this is a problem.
- Remember that your other children need to be able to live their own lives and not feel there is a burden placed on them. Make plans for the future of your child with a disability.

### **What one sister of a young adult with a disability said:**

"I love my sister dearly and I would not wish things to be any other way. If she was "normal" then she would no longer be the sister that I love and know."

### **Reminders**

- How parents manage a child with a disability will affect how brothers and sisters react.
- Brothers and sisters need time and opportunity to lead their own lives.
- Brothers and sisters can all have fun together and enjoy each other with support.
- Parents of children with a disability are often very busy; ask for help so you can make time for all your children.
- Every child in your family is important and needs to feel special and valued.

### **Resources**

Siblings Australia - services for siblings of children with special needs [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)

Source: SA Teen Health website