



# Siblings and understanding disability

by Mary Lloyd

*Having a good understanding of their sibling's disability, and being prepared with a simple explanation can be very helpful when children ask the unexpected question.*

*"Before I learned about autism, it was confusing and hard to understand why my brother seemed different from me and from most other kids I knew. I didn't really know why he talked out loud to himself, or copied what I said and repeated it right back to me, or flapped his hands in the air when he got excited."*

It is very common for siblings to feel unsure about their brother or sister's disability. A lack of understanding can leave children feeling scared, embarrassed, guilty and confused. Taking the time to explain the disability in language that is easy for them to understand will help to offset these feelings. Explaining disability or illness can be difficult. You need to take into account the child's stage of development and their ability to comprehend the information. Take the time to plan your explanation and use simple language.

It is important to explain disability to children of all ages. Very young children are easily confused and they can make the wrong connections between things or events. For example young children will often mistakenly believe that they can catch a disability. The fear of something being contagious is common for young children. You only have to think of the number of times you've heard a young child say something like, "I'm not touching that, that's got Girl germs!"

Very young children also have a tendency to link things or events to themselves. For example when a young child is told that their parents are not going to live together any more, it is common to hear a child say something like, "Please mum I promise I'll be good, I won't be naughty any more, I promise!" In this case the young child has linked the fact that the parents are separating to their behaviour. In the case of siblings who have a brother or sister with a disability, it is not uncommon for a young child to think that they may have done something to cause their sibling's disability.

It is often difficult for adults to imagine how children can make these connections. You can find many examples of these errors in the sibling literature. In the following example a young girl believes that playing with her hat has caused her brother's epilepsy.

*"He was playing with my hat and then went very quiet under the dinner table. There was such a panic in the house, it was Christmas lunch. I never let my brother play with anything of mine after that — it was an obsession — in case it caused another seizure."*

When children reach primary school they begin to notice differences between each other. It can often be confusing when other children make comments or ask questions about their

information provided by  
Down Syndrome Victoria  
219 Napier Street  
Fitzroy Victoria 3065  
T: 1300 658 873  
F: (03) 9486 9601  
E: [info@dsav.asn.au](mailto:info@dsav.asn.au)

[www.downsyndromevictoria.org.au](http://www.downsyndromevictoria.org.au)

sibling's disability. These questions and comments may be the first time that siblings begin to understand that there is something different about their brother or sister, and that other kids don't have siblings with the same differences like theirs.

*"I had grown to understand that Em was 'special', but it wasn't until I was in primary school that I began to notice real differences between Emily and myself. Comments such as "Your sister's a retard", "spastic" and "mental" became common to me around the school yard. Finally, the penny dropped. My sister's disability wasn't just something that meant she couldn't learn as fast, didn't always behave as well as other people her age, and had to wear glasses. In the school yard it wasn't looked on as such a simple matter. This was a bigger deal than I thought."*

*Finding the right words to explain a child's disability can be a challenge for parents. The trick is to keep it simple, but to give enough information that helps to explain the differences whilst trying to throw in some positives as well.*



*Mary with her children Matt, Abbey and Jess*

Questions about a sibling's difference aren't always meant to be unkind. Children learn about their environment by asking questions. Having a good understanding of their sibling's disability, and being prepared with a simple explanation can be very helpful when other children ask those unexpected questions.

For example when my daughter was in prep her friend asked her why her brother jumps up and down and flaps his hands. She responded "that's cause he's got Fragile X." My daughter's response at age five was simple and reflected her level of understanding of her brothers' unusual behaviour. The problem arose when her friend had a follow-up question, "What's that?" To which she answered "Um, I think it's a disability thing". Not satisfied with this they decided to ask her friend's older brother who was in my son's class. He answered their questions by saying "he's got brain damage". The result was one confused little girl who didn't really know what to make of this information, except that it didn't sound good.

Giving children simple explanations using language that is familiar to them can help to offset feelings of confusion or embarrassment.

Examples of this may be:

*"He's got a disability. It's called Fragile X. It means that he does different stuff like flapping his hands when he gets excited, or when he's happy. He's a really good reader! He reads the TV guide every week. It's cool."*

*"She's got cerebral palsy. It means her legs don't work properly. She can't stand up so she has to use a wheel chair. Sometimes mum lets me ride in the chair."*

*She can't speak, but she can tell me stuff anyway."*

*"He's got autism. He does different things to me. He can talk a bit. He's learning slowly. He says words over and over. Sometimes he gets mad because he doesn't understand. Like if I play with his stuff he doesn't like it. But he loves computers and he can climb better than any kid ever."*

*"It's called epilepsy. It means that sometimes she has fits. That's when she falls down and her body shakes a bit. Sometimes she just stops and stares for a little while. When she has a fit she can feel really tired and she needs to have a sleep. But when she wakes up she's okay."*

*If you are unsure of the answer to a question, be honest, tell them you need time to think about it first and that you'll get back to them.*

Finding the right words to explain a child's disability can be a challenge for parents. The trick is to keep it simple, but to give enough information to explain the differences whilst trying to throw in some positives as well. As children get older they may ask more questions in order to get a better understanding. Just keep giving them little bits of information and check if they understand you.

When children enter the teenage years they tend to ask questions that help them understand what the future might look like for their sibling with the disability. At this age they are trying to build a realistic understanding of what is possible.

Adolescents may ask questions about whether or not their brother or sister will ever have a boy/girlfriend, will they get married, or drive a car, or live away from home.

As they get older they may start to wonder what role they will play in the ongoing care of the brother or sister. It is not uncommon for adolescent siblings to ask "Who's going to look after John when you're gone"? Clarifying their own, and their sibling's, future is an important issue for adolescent siblings.

If you try to ignore the questions or redirect the conversation because you're unsure of what to say, it can give the wrong impression to children. If you are unsure of the answer to a question, be honest, tell them you need time to think about it first and that you'll get back to them. Discuss the question with your partner, or a friend, get advice on the best way to answer. But always follow up with them to make sure that you have answered their question.

Having good open communication in the family contributes significantly to sibling well-being and adjustment. When you take the time to answer your child's questions, you are letting them know that disability is not a taboo subject and if they are confused or unsure they can ask and feel reassured.

*Mary Lloyd is a psychologist and presenter of the ACD's Sibling Workshops for parents*

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