



"Massive Minds, Huge Hearts, Guided by God"

Disability – Brothers and Sisters

When there is a child in the family living with disability or chronic illness it affects everyone in the family, including brothers and sisters. Sometimes the needs of brothers and sisters can be overlooked.

Brothers and sisters have the chance to learn a lot that will help them become caring, thoughtful young people. It is important their feelings are heard and understood and they have the support they need to manage any challenges.

Issues for brothers and sisters

The impact on brothers and sisters can depend on:

- the nature of the disability or illness
- their age, and the age of their sibling
- how the child with the condition behaves
- the support that parents provide for each child in the family.

Research shows that many brothers and sisters face challenges but grow to be more compassionate, tolerant and mature and to have a better understanding of difference. Others can be negatively affected by stress in the family, taking on too much responsibility or not having as much nurturing as they need.

Brothers and sisters may feel love and be protective of their sibling but also feel grief, sadness, embarrassment or anger. They may feel they can't express negative feelings and keep these to themselves. They can feel alone and that their needs don't matter.

Some impacts on brothers and sisters include:

- family life needing to change to allow for any treatment or other needs of their sibling
- family outings and activities being affected, for example, where the whole family can go
- missing out on time with parents and feeling jealous
- fighting between themselves because they know they cannot fight with their sibling
- feeling guilty about their own abilities when they see their sibling struggling. They may feel they cannot express their own difficulties
- being confused about the condition and worrying they may have caused it or will 'catch it'
- feeling embarrassed by their sibling's behaviour when their friends visit or when they go out

- being asked to act as carers to help parents out and resenting this. They may feel they can't complain
- being worried and upset by their parents' reactions, especially if parents are grieving or fighting, which can happen under stress
- feeling pressure to succeed to make up for any limitations their sibling may have.

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Brothers and sisters and their sibling with a disability or illness can have fun and enjoy being together. Brothers and sisters are often the people who have the longest relationship with their sibling.

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What parents can do

You might not be able to remove all the stresses for brothers and sisters but you could:

- help them understand the disability or illness and say it is OK to ask questions. Work out how they can talk about it with others
- listen to their feelings and show you understand
- spend special time with each child. All children need to feel loved and valued
- let them have time to be children. Helping to care for a sibling can be good for children but they also need plenty of time to play and be with their own friends
- allow them to be involved in caring for their sibling in ways they choose. Show you appreciate what they do
- celebrate the achievements of all your children, no matter how small. Say that everyone in the family has their own strengths
- make sure that your child with a disability doesn't damage other children's belongings. Give them a safe place to keep things if this is a problem
- watch for signs of stress in brothers and sisters, for example, problems with sleeping or eating, being withdrawn, headaches or tummy aches.
- encourage them to link with other children and young people in a similar situation. They can learn they are not alone and share information and ideas
- make sure they have a network of supportive family and friends to talk to
- make plans for the future of your child with the condition. Brothers and sisters need to live their own lives and not feel over-burdened.

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It is important that brothers and sisters feel listened to and understood.

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What brothers and sisters say

'People ask what it is like to have a sibling with autism.'

Work out with your child how they could answer these kind of questions. They could say something simple and truthful, for example:

- 'It's just normal for me I have never known anything different'
- 'It can be a pain sometimes but so can my other brothers and sisters'
- 'She is my sister, not just someone with a disability'.

'I am afraid that when my parents die, s/he will be my responsibility'

- While parents hope that brothers and sisters will always care for each other, they need to make plans so that all children can work towards a good life in adulthood.
- Talk this through with your children so you can hear their thoughts and any fears. Talk about what can be done to plan ahead.

'I hate asking my friends over to play because my brother/sister always joins in and spoils the game.'

- Let brothers and sisters know that they do not always have to include their sibling, just as they will not always want to include each other. This is more so in the teenage years when friends are extremely important to young people.
- The child with the condition may be able to join in with games if they have some help. It can be good for children to learn to be flexible with different abilities.
- You could set up a place for your child with the condition to do some special activities when your other children have friends over, for example, video, TV, playing on a swing, or something else they enjoy.

'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.'

- Give children very clear information about the disability or illness. Start with simple explanations and give more details as they get older.
- Some brothers and sisters can benefit from genetic counselling when they are older, to help answer their questions. Genetic conditions do not always affect everyone in the family.

'I can never have my party anywhere I want to because s/he has severe asthma and these places would make them ill.'

- Children and young people should be able to have their special occasions with their friends.
- Some children have two birthday parties – one for the whole family 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.'

- You could try taking turns to watch children's sport or make other arrangements for the child with the condition.

'My sister/brother always gets the biggest part of mum's time and they get away with everything because they've got problems.'

- It's important to make time for all your children, even if it means getting help with caring for your child with the disability or illness. You could look into getting respite care from services.
- All children will test limits. It's not helpful for any child to have unfair exceptions 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's expected of other children. 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'.'

- Dealing with teasing, name calling or bullying is not easy. These things are never OK and should not be tolerated. It may be directed at your child with the condition or at brothers or sisters. It may be intentional or not.
- Talk with your child about how they could respond.
- Encourage them to seek help from adults if they need it.
- If it happens at school, you could talk to teachers about the school's bullying policy and actions that could be taken.
- Some children may feel able to respond by:
 - explaining what 'spastic' (or whatever word is used) means and saying it is never OK to call people names
 - saying things like 'He does have some problems, but he is really good at...', or 'Everyone has some problems. He is my brother and I don't like it when you tease him'.

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

- You will need to give a lot of time to your child with the disability or illness, and naturally want that child to feel special. It's important that all children in your family feel special.
- When you talk with friends make sure to talk about the achievements of all your children.
- Make sure that each child has your support to follow their own special interests.

'I have to care for my brother a lot when my mum is working because he has cerebral palsy and is in a wheelchair, and I can't play with my friends.'

- Brothers and sisters can be expected to take on extra responsibility – more so in single parent households. This can help them develop skills and be more independent, but needs to be kept in balance.
- Some children do not say when they feel overburdened or may feel guilty if they complain. It's a good idea to check how they're feeling from time to time.

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Brothers and sisters can benefit from learning skills to help their sibling but it is important they are not overburdened. They need time just to be children.
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'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 this is a problem in your family, try to work out an 'in case' plan... 'in case' we can't go to the pageant, 'in case' something goes wrong when it's your party.
- Plans could include the help of a relative or friend so the celebration doesn't have to be missed.

'I am always expected to be the responsible one, to give in when there is an argument.'

- It's not good for children to always get their own way and children and young people with a disability or illness also need to learn to consider others as well as they can.
- Teaching children that they can't always have their own way, and to behave in ways that fit in with the rest of the family, will make everyone's life easier, including theirs.

Getting help

Parents

Parents of children with a disability or chronic illness are often very busy and there can be many sources of stress. It is important to make as much time as you can to look after your own needs and do things you enjoy. There are services for carers that may be able to provide support or networks of others you can talk to.

Brothers and sisters

Connecting with others in a similar situation can help children and young people feel they are not alone. Siblings Australia can be a good place to start. You could also talk with your doctor, school or other health professionals if you have any concerns about brothers and sisters, and seek any help and support they need.

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Being connected with others can make a big difference to how brothers and sisters cope.
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You can get further advice and information from:

- School
- Your GP
- School Nurse
- Suffolk Young Carers - <https://suffolkfamilycarers.org/young-carers/>
- Activities Unlimited - <https://www.access-unlimited.co.uk/activitiesunlimited/>

- TOPCATS Support for young people with additional needs -
<https://infolink.suffolk.gov.uk/kb5/suffolk/infolink/service.page?id=K0L88NFstcs>
- <https://www.sibs.org.uk/>
- <https://www.scope.org.uk/advice-and-support/balancing-care-for-siblings/>
- <https://carers.org/about-caring/about-young-carers>

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<https://parenting.sa.gov.au/easy-guides>