

Disability – brothers and sisters

Parent easy guide 61



Parenting SA

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's managed in the family. It will also depend on how parents support all the children in the family.

Brothers and sisters can have some of the same feelings of loss that parents have. It's important that their feelings are heard and understood.

Brothers and sisters can also have a lot of joy from their sibling with a disability, and learn a lot that will help them be caring, thoughtful young people.

*This PEG uses 'he' and 'she' in turn.
Change to suit your child's or young person's sex.*

Issues for brothers and sisters

- > Family life may need to change to allow for any treatment or other needs of the child with a disability.
- > Family outings and activities can be affected (e.g. where the whole family can go).
- > They may miss out on time with parents, and feel jealous of this; they may 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 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 realise that they can't catch it.
- > They may be embarrassed by their sibling's behaviour when their friends visit.
- > 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 any limitations their sibling may have.

What brothers and sisters say

The following are issues raised by brothers and sisters, with some ideas about what parents might do to help.

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

A 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 for their child with a disability so there isn't an unfair burden on 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.



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'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 more so in the teenage years.
- > Set up a place for your child with the disability with some special activities e.g. a video or TV, for when your 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 and some are not.
- > Give children very clear information about the condition.
- > Even genetic conditions do not affect everyone in a family, including the brothers and sisters.
- > Get genetic counselling for brothers and sisters if needed as they grow older.

'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 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.'

- > Try taking turns to watch the other children's sport.
- > If it's 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's important to make time for all your children, even if it means getting respite care or help with caring for your child with the disability.
- > 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 with 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'.'

- > Children may need help to cope with situations where their friends may not mean 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.
- > Bullying is not okay and should not be tolerated. If friends make fun of a 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 don't like it when you tease him.'*

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

- > As parents you will need to give a lot of time to your child with the disability, and naturally want that child to feel special. It's important that all 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 cerebral palsy 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, and more so 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.
- > All children need time to be children so it's important to make sure they get this time. This might mean you have to get someone else to stand in sometimes.
- > 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.

'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's your party.
- > Plans for a special outing can include the help of a special relative or friend so that 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 disabilities also need to learn to consider others as well as they can.
- > Teaching your child who has a disability that she can't 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.

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, e.g. let them help choose clothes for their brother or sister.
- > Encourage your other children to be proud of their sister's achievements and to realise the difficulties she may have had in getting there. Let them know you are proud of their achievements as well.
- > Make sure that your child with the disability doesn't 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 live their own lives and not feel burdened. Make plans for the future of your child with a disability.

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.

Contacts

Parent Helpline: Tel 1300 364 100

24 hours a day, 7 days a week for advice on child health and parenting

Child and Family Health Centres: Tel 1300 733 606

9am – 4.30pm, Monday to Friday to make an appointment at your local Centre

Kids Helpline: Tel 1800 551 800

Youth Healthline: Tel 1300 131 719

Disability SA: Tel 1300 786 117

Novita Children's Services: Tel (08) 8243 8243

Disability Information and Resource Centre:

Tel (08) 8236 0555

TTY (08) 8223 7579

Country callers (SA only) 1300 305 558

Websites

www.parenting.sa.gov.au

For other Parent Easy Guides including:

Developmental delay, Children with a disability, Child abuse, Protecting your child from sexual abuse

www.cyh.com

For parenting and child health information

www.siblingsaustralia.org.au

For directory of sibling support services and relevant books for different ages

www.acd.org.au/siblings/index.htm

Association for Children with a Disability, information and support for siblings

www.dircsa.org.au

Disability Information and Resource Centre

www.novita.org.au

Novita Children's Services

www.raisingchildren.net.au

For information on raising children

www.juliafarr.org.au/youth/

Julia Farr Association Youth Group for young people living with disability

www.carersaustralia.com.au

Carers Australia (SA)

www.wchfoundation.org.au

'There's no such thing as a silly question: A practical guide for families living with a child with chronic illness, disability, mental illness or a life threatening condition.'

www.shinesa.org.au

Resources for teenagers with an intellectual disability

For more information

Parent Helpline 1300 364 100

Parenting SA

Children, Youth and Women's Health Service

Telephone (08) 8303 1660

Internet: www.parenting.sa.gov.au

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Parent Easy Guides are free in South Australia

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