

One of the most revealing sections of the 2008 HemiHelp parents' survey was the response to the question of how their child's hemiplegia had affected any other children in the family. From the comments of the more than 500 parents who answered this question, it is clear that this is one of the trickiest aspects of having a child with hemiplegia in the family. Some comments were very positive:

Her big brother of 7 years is very supportive - also because he treats her like an equal she (aged 4) is more determined to do what he is doing.

My younger brother is supportive and is always searching new potential treatments for me.... My dad is amazing too - anything that can be done for me - he's done... It's definitely made my family stronger! (adult with hemiplegia).

We get along just fine with T in the family. We all look after him and we go camping, swimming and day tripping together. He is the centre of our family life but in a good way.

They are very tolerant of others. They are educators of their peers and very often defend other children against bullying/comments.

The 'special' child gets all the attention

Many more, however, mentioned negative effects. It is natural that the child with hemiplegia will always be 'the special one' to parents, and will always need more care and attention than other children in the family. This means that siblings get less of their parents' attention, and are forced to fit in with this child's needs. The comments below are typical of many:

We have numerous hospital appointments where the professionals always ignore M's sister or she is left with friends while we go to appointments. Physio at home takes time. Holidays are arranged around M's Botox injections.

As I am a lone parent my younger daughter is often left to amuse herself and has to wait until I am free.

Our time and attention for our other children has been minimised. Our son's condition has dominated our family life.

Seeing the other child's point of view

Sometimes parents try hard to do what seems best for a brother or sister, only to find out later that their efforts were not appreciated. One mother stressed that parents need to realise how different a child's view of life can be. She would try to leave her elder son at his friend's house while she took his younger brother to therapy appointments, believing that he would find playing with his mate much more enjoyable than hanging around the hospital.

But when he was older, he told her that he had felt his brother was going off with her to have fun, while he was left behind. And of course as children grow, their feelings about the child with hemiplegia become more obvious, which can lead to general stress in the family.

As a family T's disability affects their opportunities and as a family restricts many activities that we would like to have done. Her brother can get very resentful which is very difficult to manage.

We have 3 others who are quite resentful and embarrassed by their brother. We are not able to do things that other families enjoy - walks, shopping etc.

I permanently feel guilty that I could or should be doing more for both children. It puts an extra strain on the parents' relationship.

Assistant carers

It is not just a question of one child getting more attention. Siblings may be expected to help with exercises and therapeutic play, or to remind their brother or sister about using their weak hand, or later on in childhood to take him or her to school or to babysit. They become, in other words, assistant carers.

Some of this is of course true of all big brothers and sisters, but usually as the younger child grows up he or she becomes an independent and equal companion. Indeed it may be the child with hemiplegia who is the older one, and a younger brother or sister overtaking him or her physically and/or academically and becoming the 'responsible one'.

My daughter has had to learn to be very thoughtful about other people less able than herself because of her brother's hemiplegia.

Sibling has a lot of patience with O and enjoys helping him to walk (sometimes!)

In either case siblings have to deal with other children teasing or bullying their brother or sister, or the brother or sister's own difficult behaviour. Family outings are affected, and they may miss out on activities and friendships of their own.

We now avoid some children's play places/parks because he gets upset when other children push his little brother or stare.

Her brother and sister are very restricted in what they are able to do and also don't always want to have friends back home if L is being difficult.

Some of S's friends have said horrible things about J - she found this very hard.

It may seem obvious that families, whilst trying to do their best for their disabled child, should try not to leave out his or her siblings. However HemiHelp members' experience shows that this can be a difficult balancing act, and something that parents need to be very aware of.

What can parents do?

- Learn to recognise behaviour that expresses anger or frustration at the child with hemiplegia.
- Talk to them about their brother/sister's hemiplegia. Assure them that no one is to blame and stress that he/she is an individual with a personality with strengths and weaknesses like anyone else.
- Try to set aside time for each child individually, ideally at the same time each day/week. Arrange childcare for the child with hemiplegia so that you can do things with his/her sibling(s). Don't miss their important events (school play, sports day etc).
- Sometimes take the child with hemiplegia to these events: siblings supporting each other works both ways.
- Try to find activities that the family can enjoy together, but also other activities to enjoy separately, so that each child has something special. Praise them all equally when they achieve something or make a big effort.
- Don't expect siblings to always include their brother/sister in their play. Let them retreat to their bedroom(s) and when they get older let them lock the door.

- Acknowledge siblings' negative feelings about their brother/sister and talk about these feelings and about the guilt they may have about them. Explain that everyone gets angry with other family members sometimes.
- Discuss how they can talk to their friends about hemiplegia and how it affects their brother/sister.
- Don't let them feel too much responsibility for the child with hemiplegia. Discuss any anxiety they may feel about his/her future.
- As they grow up encourage their independence.

There may be a support group in your area where siblings can share their experiences and feelings. There are also several national organisations that support siblings and help them feel less alone:

Contact a Family www.cafamily.org.uk/families/familyissues is the CAF family section, with downloadable booklets for siblings, dads and grandparents.

Chip www.childreninthehighlands.com whose information is mostly for people in Scotland, has a leaflet on Brothers and Sisters in its Parent information pack which is useful no matter where you live.

<http://www.youngcarers.net> is part of Princess Royal Trust for Carers

<http://www.sibs.org.uk>

www.kids.org.uk

HemiHelp has a range of information sheets for both families where there is a child with hemiplegia and adults with the condition, as well as a Useful Names and Addresses List to help you contact other organisations.

***Hemiplegia** is a neurological condition that weakens one side of the body and affects one child in a thousand. It is sometimes described as a form of cerebral palsy and the effects are similar to those of a stroke. **HemiHelp** is a membership organisation offering information and support to children and adults affected by hemiplegia and their families.*

HemiHelp is happy for you to make photocopies of any part of this document.

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