

Bringing up any child is a voyage into the unknown. When a child or young person has additional needs the stresses and uncertainties are magnified, and the support of family and friends are more important than ever. However, both parents and young people themselves often find a lack of understanding even amongst people closest to them, as you will see from comments below, taken from recent HemiHelp membership surveys.

They don't understand his problems, they seem to avoid the issue. Frightened to ask? They don't understand his difficulties, mostly because they never ask. Maybe they don't know what to say? Embarrassed?

I don't have many friends - don't want to burden them - worry they won't cope and will refuse.

We feel very isolated from our community and what those without "special needs" are able to easily do.

People living with hemiplegia often put a brave face on things and don't ask for help when they need it. As a result, their lives can turn into a constant struggle, both physically and psychologically, and they can also feel very alone and marginalised in the wider family and community. But your help could make a big difference, and we hope that reading this leaflet will give you the confidence to offer it.

What is hemiplegia?

Childhood hemiplegia affects about one child in a thousand. It is most often caused by a stroke which happens before or around the time of birth, or less commonly by an accident or illness later in childhood. As with any stroke, the most obvious result is weakness or stiffness and lack of control down one side of the body. It is uncertain why. A few factors, for example premature birth, are known to play a part. It is not caused by anything the mother does or does not do during pregnancy. Hemiplegia is a permanent condition, so it will not go away and it cannot be cured. But it is also non-progressive, which means it will not get any worse, and with help its effects may be reduced.

What difficulties can be associated with hemiplegia?

Specific learning difficulties such as dyslexia, visual perceptual and concentration problems are common, as are emotional and behavioural problems. And hemiplegia can also cause medical problems such as visual impairment, speech difficulties and epilepsy. People with hemiplegia may also have difficulty with school subjects such as maths.

Children and young people with hemiplegia usually live in a 'mainstream' world, and life can be a constant struggle to keep up with their peers. These 'invisible' problems can be more frustrating and disabling than the hemiplegia itself. Hemiplegia acquired later in childhood after an accident or illness can be especially frustrating, since the child has to struggle to do things that were easy before. The process of recovery may go on for years; the child will need patience and constant encouragement.

How can you help the parents of a child with hemiplegia?

Listen to them. A sympathetic ear can be a lifesaver in difficult moments.

Because J's hemi is quite mild, friends and family prefer to act as though he is fine (plus we are not good at asking for help).

Family, who'd have them...? As we do, perhaps, they ignore greater significance and only focus on positive and ignore downsides, whereas friends allow you to "vent" and try to understand.

Believe what they tell you about their child. Parents feel guilty enough without being blamed for aspects of their child's behaviour which they are working hard to change.

My parents have been supportive, my husband's parents very unsupportive. I suspect that somewhere they blame me for her disability.

They don't realise all the hidden work that's involved on a daily basis e.g. dressing, tying laces, making a sandwich etc etc.

Relatives kept saying "I'm sure everything will be fine" when the paediatrician had clearly said there was a high possibility that it wouldn't be. I found that very unhelpful.

Praise and encourage, and not just when things are going well. It is when life is difficult that a reminder of what has been achieved is particularly welcome.

As J is mildly affected people don't see the hidden issues. He joins in with everything in a mainstream setting but it takes far more effort for him to progress and achieve his goals. Grandparents only see the good points and ignore what it takes to get there. This can be a good and bad attitude as the positive should be highlighted, but sometimes I would like all our efforts acknowledged.

Give them a break. Offer to look after the child for a few hours to allow the parents time alone or with their other children. Alternatively, offer to look after brothers and sisters to give parents more time alone with the child with hemiplegia. And don't forget to include the family on social occasions.

I do not have time to keep up friendships of my own.

Relatives: support not offered but given when requested.

Friends: I need to ask for help.

I think, even though they are educated people, they are not comfortable around our child, and so we are seldom included in social activities.

Help with therapy. You might feel more confident about this if you can drop in on a therapy session, so you can help with the sorts of things the parents do with the child at home.

Care for the child. If the child has epilepsy find out what to do if he or she has a seizure. Contact the National Epilepsy Society. HemiHelp also has an information sheet on the condition.

Our daughter has complex epilepsy which means that friends and relatives do not feel confident enough to offer much help.

If she had a seizure in public the reaction was "poor disabled child" - I don't think they knew how to react.

Find out about hemiplegia for yourself. HemiHelp has a wide range of information sheets which can be downloaded from our website or ordered through the office.

Help the child by:

Treating him or her as an individual. A child with additional needs has the same need for acceptance, love and attention as any other child.

Trying not to make comparisons. A child may not be picked for the school football team or reach Grade 7 piano, but might be putting in as much effort for more modest gains, and will gain immeasurably from praise and encouragement.

Developing a unique relationship. It might be going out to a café or reading together, or it might be teaching (or re-teaching) a skill - swimming, riding a bike or even shoelace tying. A child with hemiplegia may have low self-esteem, and such attention can give them a real boost

Don't forget **brothers and sisters**; they need attention too

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.

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

My disability has had a significant effect upon my brothers as I have often needed more attention. My stress and anxiety levels have tended to have a knock-on effect upon everybody in the household.

As the child grows up

I think that the time when a young person's difficulties and worries may become more obvious to him or herself, may be the very time when they are more reluctant to draw attention to themselves, therefore problems are often overlooked, causing even more anxiety for the young person.

Children with hemiplegia become young people and then adults with hemiplegia; they don't grow out of the condition, in fact you could say that they grow into it. The challenges they face not only don't go away; they in fact become more complex. At first glance they may appear to be fine, but they still need continued support and understanding.

My uncles/aunts forget I have hemiplegia and I don't like staying with them as I'm more aware of it when around them because they forget I have a disability.

Because my physical and learning difficulties are slight I am not seen as disabled by everyone or they forget and expect me to be the same as everyone else. This leads to difficulties at work and home / social life.

As physical appearance becomes more important looking different, wearing special shoes or a splint, or appearing clumsy, can all affect the young person's sense of confidence. For girls in particular growing up brings new challenges (at this age girls develop earlier than boys). Finding suitable shoes that are also fashionable, putting on makeup and jewellery, doing their hair in the latest styles – these are all issues to be faced.

During the summer months I find I get a little down because I get jealous of people and all the strappy shoes/sandals they can wear.

Sounds daft but I want to be like my friends and wear dresses and high heels, but I can't, I have to wear frumpy flat boots (even in summer) and usually trousers to hide the scars from the operations I've had.

At this age keeping up with classmates in sport and other activities becomes more difficult. Young people who have until now lived in a completely mainstream world may have to adjust the way they think about themselves.

From a teenager's point of view, there is NO positive effect of having a disability and being different.

My hemiplegia marked me as different - in my teenage years I became very conscious of this and it was a contributing factor to the anxiety and depression I suffered from.

Because of their physical impairment gaining independence is not as easy for young people with hemiplegia as for other young people of the same age.

People are reluctant to give me a Saturday job when they know I am disabled.

My parents mollycoddle me and my siblings go places without me.

My mum is extremely protective of me - she still feels responsible for me and I guess I do need her - painting my nails, doing up buttons and cutting up things to name a few.

And it is not just a matter of physical differences. Other, invisible, difficulties often associated with hemiplegia now become more disabling than obvious physical ones. Social difficulties, emotional problems, lack of confidence can all have a significant impact on young peoples' lives

I have a difficult time making friends - many people know me but I'm reluctant to open up to people.

I have a boyfriend now but I do not have many other friends and do still have some social communication difficulties.

Emotionally I feel I can get more stressed out and worked up about little things that aren't significant.

All this means that you as a family member or friend can still have a very valuable role to play, whether it be taking the young person out (a show, a football match, a shopping expedition, a new activity or just a pizza or coffee), offering to help with any schoolwork that might be causing difficulties or just being a good listener. Teenagers and young adults don't always find it easy to be open about their difficulties, but may be very happy to find someone they can talk to who isn't a parent or teacher.

And don't forget that parents also still need a break or a sympathetic ear – it can be hard constantly hearing about other young people's exploits and achievements when your son or daughter is finding growing up a frustrating process.

See also **HemiHelp** Information Sheets **Brothers and Sisters, Emotional and Behavioural Problems** and **Coping with Behavioural Problems** and **Contact a Family's** downloadable booklets for siblings, dads and grandparents at www.cafamily.org.uk/families/familyissues

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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