

This information sheet was written by Robert Goodman, Professor of Brain and Behaviour Medicine at King's College London.

What emotional and behavioural problems do children with hemiplegia face?

Many parents of children with hemiplegia have told us that their child's everyday life is less affected by the condition itself than by associated "invisible" problems affecting education, emotions, behaviour or relationships. The trouble with invisible difficulties is that people outside the family often don't take them seriously enough. A child who is unable to make friends or who has severe behavioural problems may be at least as badly off as a child in a wheelchair - but we all know that it is the child in the wheelchair who captures the public imagination, and attracts the most clinical care and research.

What was the London Hemiplegia Register Study?

How can we make schools, hospitals and the general public more aware of the invisible problems? The first step was to show that they really were as common and as important as parents say. This thought guided us when we began the London Hemiplegia Register study in 1987. Over the years, we studied many aspects of hemiplegia, but we devoted particular attention to possible difficulties with education, emotions, behaviour and friendships. All the families on the London Hemiplegia Register helped us with this by answering a long list of questions on the questionnaire that we sent out to them. Families of the 6 to 10-year-olds gave even more lavishly of their time and allowed us to interview them and their children at length. The same group were reassessed in detail about 6 years later when they were teenagers. This leaflet is about our findings on emotional and behavioural difficulties.

How do we define emotional and behavioural difficulties?

Defining emotional or behavioural difficulties is not a simple matter. Children may be little angels when they are fast asleep but most of them don't stay that way all day! Fears, worries, defiance, aggression and inattentiveness are all normal in some degree and at some times. If we had incredibly high standards – expecting saintly behaviour and a cheerful, confident mood at all times – no child would pass the test. In fact, researchers and clinicians take a more sensible approach and only consider that a child has significant emotional or behavioural difficulties if problems in these areas interfere substantially with the child's everyday life, or cause the child considerable distress, or result in marked disruption for others.

How many children with hemiplegia are affected?

Studies of representative groups of British children and teenagers show that around 10% have emotional and behavioural problems at any one time. By marked contrast, the London Hemiplegia Study showed that around half of the children with hemiplegia had significant emotional and behavioural difficulties.

This finding was so striking that we seriously wondered if our judgement was clouded by our particular interest in hemiplegia. Were we making mountains out of molehills? To test this possibility, we persuaded a doctor from a child and adolescent mental health service to check our results by reading a summary of what the parents and children had told us. Unlike us, this doctor was not specially interested in hemiplegia and she had never met any of the children or their families.

Her conclusions were remarkably similar to our own: we had diagnosed difficulties in 61% of the children and she diagnosed difficulties in 57% of the children. Many of the children had a level of problems that would have warranted referral to her child guidance clinic. She was struck, though, by one major difference between our group of children and the children she normally saw. The children in our study who had emotional or behavioural problems generally came from normal well-adjusted families – whereas most of the children she saw in her clinic came from deprived or disturbed or disrupted backgrounds. We suspect that this is because the problems seen in children with hemiplegia generally have more to do with brain factors than with family factors.

What causes these difficulties?

It is important for parents to realize the importance of brain factors because we live in a society that blames parents for their children's problems. If your son has tantrums or is frequently defiant, neighbours and friends may well think it is because you have brought him up badly. If your daughter has many worries or is afraid to stay overnight at her grandparents, your mother-in-law may think it is your fault that she is insecure. If your son has difficulty concentrating on his schoolwork, his teacher may blame it on family problems. Worst of all, you may be blaming yourself. Of course, no parent is perfect and there is always room for improvement – but in the case of children with hemiplegia, your child's constitution may well be more relevant than anything you have done or not done.

What kind of problems do children with hemiplegia face?

The emotional and behavioural difficulties of children with hemiplegia are very varied, but there are three common types of difficulties (sometimes occurring in combination).

- Roughly 25% of the children we saw posed major problems for their parents or teachers because of marked cheekiness, temper outbursts and refusal to do what they were told - the sorts of behaviour that are normal enough in the "terrible twos" but that become increasingly aggravating if the child remains a terrible six, a terrible ten or a terrible fifteen!
- About 25% of the children we saw had worries and fears that were marked enough to cause them considerable distress, restrict their activities, or interfere with their sleep or schoolwork.
- Hyperactivity was the third common problem. Roughly 10% of the children we saw were having marked problems with attention and overactivity both at home and at school, and even more were having milder problems of the same sort.

What can be done to prevent these problems developing?

The parents of younger children are often particularly keen to learn what they can do to prevent future problems arising. HemiHelp can be powerful preventative medicine because it provides support for parents as well as useful information about hemiplegia for schools and the general public. Beyond this, there is no single answer that applies to all families, for the good reason that all children with hemiplegia are different, just as their families are different.

One child with hemiplegia may be anxious, perfectionist and under-confident. By contrast, another child with hemiplegia may be impulsive, slapdash and too confident for his or her own good, e.g. jumping off ten-foot walls and bossing everyone else about. The first child may need a lot of encouragement from parents and teachers to take a few more risks, to feel more confident and to accept that not everything needs to be perfect. The second child certainly doesn't need any more encouragement to take risks, settle for second best, or feel even more self-confident.

Since each child is different, preventative advice needs to be tailor-made to the child. We are on the point of being able to offer HemiHelp families regular internet-based monitoring of child development from an early age so as to be able to detect as soon as possible those areas where the child could do with a bit of specific "rebalancing." Computerized feedback will provide links to appropriate leaflets, books and websites that suggest how to set about this rebalancing.

What treatments are there?

Until the day comes when all serious emotional and behavioural problems can be prevented, there will be a need for suitable treatments. Most of the children with hemiplegia who also have emotional or behavioural difficulties can be helped a lot. However, there is no one treatment that is helpful for all problems.

- For one child, the most important treatment may be advice to parents on how to handle difficult behaviour.
- For a second child, disruptive behaviour in school may be a response to unrecognised reading problems and the correct treatment may be extra help with reading.
- For a third child, with severe hyperactivity problems, a small dose of medication (not a tranquilliser) may result in a seemingly miraculous improvement in attention, learning and behaviour.
- For a fourth child, serious worries and fears may be relieved by some individual sessions with a psychologist or counselor.

What sources of help are there?

Though many appropriate treatments are already available, and new treatments are being developed all the time, it is still the case that many children with hemiplegia have emotional or behavioural problems that have not received the right sort or amount of help. Where should families look for help? HemiHelp is obviously a good place to start. Teachers, Health Visitors and GPs may all have useful advice.

Beyond this, specialist psychological assessment and treatment are most likely to be available from three sources.

- Firstly, some experts work within the educational system, including educational psychologists, school counselors, and members of BESTs (Behaviour & Education Support Teams).
- Secondly, pediatricians and psychologists with special expertise in emotional and behavioural problems may be found in Child Development Teams that exist for the diagnosis, assessment and ongoing management of children with disabilities or developmental problems. Many children with hemiplegia are already in touch with such teams.
- Thirdly, Child and Adolescent Mental Health Services (CAMHS) specialize in the assessment and treatment of emotional and behavioural problems – they employ a range of professionals, generally including clinical psychologists and child psychiatrists.

HemiHelp also has an information sheet on **Coping with Behaviour Problems**

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.

Helpline: 0845 123 2372 (Mon-Fri 10am-1pm)

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