

Emotional and Behavioural Difficulties

*This information sheet has been compiled from an article in HemiHelp Newsletter no. 7, Spring 1993. It was written by **Robert Goodman**, Professor of Brain and Behavioural medicine at the Maudsley Hospital, South London. Details of how referrals can be made are available from the address below.*

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 is, in my view, 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 is the London Hemiplegia Register Study?

How can we make schools, hospitals and the general public more aware of the invisible problems? The first step is to show that they really are as common and as important as parents say they are. This thought guided me when I first started the London Hemiplegia Register study. Over the last few years, we have studied many aspects of hemiplegia, but we have 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 6-10-year-olds gave even more lavishly of their time and allowed us to interview them and their children at length. This leaflet is about our first findings on emotional and behavioural difficulties in this 6-10-year-old group.

How do we define emotional and behavioural difficulties?

Defining what I mean by 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 I had incredibly high standards - expecting saintly behaviour and a cheerful, confident mood at all times - no child would pass the test. In fact, my standards are far from exacting. I 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?

As defined above, previous studies suggest that emotional and behavioural problems affect less than 10% of ordinary children. By marked contrast, our study showed that over 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 guidance clinic to check our results by reading a summary of what the parents and children had told us. Unlike us, this doctor had no particular interest 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 while 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 sees. For the most part, the children in our study who had emotional or behavioural problems came from normal well-adjusted families - whereas most of the children she saw in her clinic came from deprived or disturbed or disrupted backgrounds. I 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 realise this 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 as the child becomes a terrible six or a terrible ten! A similar proportion 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?

As we analyse our results further and carry out more studies, we should learn more about the factors that increase a child's risk of developing an emotional or behavioural problem. We obviously hope that this will teach us how to prevent such problems arising in the future. When I talked about our findings at the AGM of HemiHelp, parents of younger children were particularly (and understandably) concerned to learn what they could do to prevent future problems. I wish we had the answers, but I believe that Hemi-Help is powerful preventative medicine because it provides support for parents as well as useful information about hemiplegia for schools and the general public.

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 children with hemiplegia who have emotional or behavioural difficulties can be helped. 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 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 counsellor.

What sources of help are there?

Though many appropriate treatments are already available, and new treatments are being developed all the time, it is the sad truth that many needy children go untreated. Some parents have been helped by their local child guidance clinic, but many more have not had any help with their child's problems. Sometimes this is because the local professionals lack confidence in their ability to deal with a mixture of brain and behavioural problems. This is understandable enough but it should not prevent children with hemiplegia getting the help they need and deserve. In order to help meet this need, we now have a "Brain and Behaviour" clinic at the Maudsley Hospital - an NHS hospital in South London - where we are able to assess each child in detail and either offer treatment ourselves or provide advice to local services. Our aim is not only to help the children we see but also to develop new approaches that can benefit children with hemiplegia world-wide.

HemiHelp has a range of leaflets covering many of the areas touched on above, and also a Useful Names and Addresses List to help you contact other organisations.

HemiHelp

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