

# Parents' survey: the findings

**Last year, we asked our parent members to tell us about their child's hemiplegia. An amazing 637 of you completed our family survey. That's almost a quarter of our family membership. Thank you! We believe this may be the biggest survey of hemiplegia in the world.**

We hope these findings help to improve life for families affected by hemiplegia, and provide a valuable insight for professionals too. It will take us a bit of time to go through all your helpful and fascinating comments, but here are the main results....

## **Diagnosis**

Right hemiplegia is more common, with 60% of parents telling us the condition affects their child's right side. Most parents reported their child's hemiplegia as mild (46%), while 44% said 'medium', and 10% said 'severe'. The vast majority of parents said their child had always had hemiplegia (84%) but 7% of parents told us that their child acquired it later in childhood, with the latest onset being fifteen years old. The majority of later childhood cases were caused by a stroke (44%), followed by an infection for 16% of children and by an accident for 7%. The most common infections seem to be meningitis and encephalitis. The majority of children were diagnosed in the first year of their life (45%) while 32% were diagnosed between the ages of one and two, and 12% were diagnosed between two and three years old. Only 11% of parents said their child was diagnosed over the age of three.

As one would expect, the rate of prematurity and multiple births was higher for families in our survey, compared to the general population. The national rate of prematurity currently stands at around 6-8%, whereas 33% of parents in our survey told us their children were premature. Likewise, the national rate of multiple births stood at 2% in 2006 yet, in our survey, 7% of children were either a twin or a triplet.

The answers to 'does your child have associated conditions?' were as individual as the children themselves. 'Yes' is the short answer, for 69% of parents. A majority of parents said that in addition to the visible physical effects of their hemiplegia, 67% of their children have learning difficulties, while 42% have epilepsy, 40% have visual impairments and 34% have speech impairments. Autistic Spectrum Disorder was also reported by a significant minority of parents (14%). Even more parents (86%) told us about other associated difficulties, with the main problem being irritability (61%). This is followed by attention span (59%), anxiety (55%), visio-spatial issues (50%), maths (49%), obsessiveness (44%) and reading (38%).

## **Therapy and treatment**

Most children (83%) receive some kind of therapy to help their hemiplegia. The majority (89%) receive physiotherapy. A large proportion (72%) receive occupational therapy, while 34% have speech and language therapy. At some point in their lives, most children (78%) have received other treatment for their hemiplegia. Ankle Foot Orthoses (AFOs - splints) is the most common, for 88% of children, followed by Botulinum Toxin injections (46%) and surgery (33%). Although the majority of parents said they were happy with the level of service and frequency of therapies their child receives (59%), 41% said they were not. Many parents commented that it was hard to access sufficient physiotherapy on the NHS or through schools. Some parents also report that the perceived mildness of their child's disability meant their child 'fell through the cracks' when it came to service provision.

### **Financial support**

Over half (69%) of families are in receipt of Disability Living Allowance. Of the 60% who receive the care component of DLA, most (63%) get the middle rate, while 23% get the higher rate. Out of the 38% of families who receive the mobility component of DLA, the majority (65%) receive the higher rate. For families who don't receive DLA, 23% had applied but their application was rejected. A significant number of parents commented that they had never heard of DLA, or did not think that they would be eligible. One parent wrote 'I am not aware of this benefit, but will now look into it'.

### **Education**

Most children with hemiplegia (80%) attend mainstream schools, while 9% go to a mainstream school with a specialist unit, and 10% go to specialist schools. The largest group of parents (52%) who filled out the survey have children at primary school. 23% have children in secondary school and for 9%, their children are currently in playgroups. Most parents (83%) said their children had been identified as needing extra support at school. The majority (72%) are happy with the support their children receive at school, although 28% feel their children are not getting the support they need.

Almost exactly half of the parents surveyed said their child had a statement of Special Educational Needs (SEN). A good number of children (61%) have been assessed by an educational psychologist, but unfortunately, 30% of parents didn't find this assessment useful. For the 69% of parents who told us their children experience difficulties at school, concentration seems to be the main problem (69%).

This is followed closely by difficulties with academic tasks (61%) anxiety (53%) and behavioural problems (30%). And sadly, 26% of parents told us their children are bullied. This is, however, a big reduction from the 63% of people who reported being bullied at school in our 'Over 16s' survey. We hope this suggests an improvement in inclusion and attitudes.

### **Life with hemiplegia**

Of the 509 families who told us their children participate in activities outside of school, the majority (63%) use mainstream facilities, while a good proportion (30%) use a bit of both. That's both mainstream and settings for children with disabilities. Activities cover a real range of interests from swimming, football and karate to chess, circus training and horse therapy. Sadly, over half of parents (51%) said that their children have some or great difficulty making and keeping friends. However 31% of parents told us it is 'fairly easy' for their children to form friendships and 18% said it is 'very easy'.

### **Support for families living with hemiplegia**

While most parents feel supported by their relatives (83%) friends (84%) and professionals (80%), 45% do not feel supported by their communities. On top of this, 47% told us they don't know any other families living with hemiplegia, and very few (19%) are involved with local disability groups.

### **The effects of hemiplegia on family life**

Hemiplegia does affect family life, according to 95% of parents. 66% reported positive effects, like 'It probably makes us closer,' 'Determination' and 'Appreciation of what we do have'. The biggest negative effect of hemiplegia seems to be its impact on siblings, for 75% of families. Feelings of resentment and neglect are common among brothers and sisters.

### **HemiHelp's services**

We are delighted to see that 98% of parents who completed our survey feel they have been helped by us. Most families found out about us from their physiotherapist or through our website. We are pleased that 25% were told about us immediately after their child was diagnosed or within a year of diagnosis (29%), but we are concerned that almost half of families (47%) had to wait longer, sometimes several years.

Our most popular resource seems to be our leaflets, which have been used by 84% of parents. A close second was our website which has been used by 76% of families, followed by our helpline, which 53% of families have contacted. However, 43% of parents aren't aware of all the information and support services we offer.

We are happy that 38% of families have attended a HemiHelp event such as a Fun day, a music workshop or a parents' conference – and we have noted that the main reason parents haven't yet been to an event is because of geographical location. Many parents gave useful suggestions on how we can improve our services. Thank you for these – we'll try to take them onboard.

### **Looking to the future... using our survey to support parents and carers**

The feedback we've received is invaluable. It will help families and professionals in a number of ways:

- HemiHelp trustee and parent, Liz Barnes, is now writing a user-friendly handbook on hemiplegia, in conjunction with Dr Charlie Fairhurst, which will reflect the findings of our parents' survey. This will be the first book of its kind – and a great resource for everyone living or working with hemiplegia. Watch this space for more details.
- To support those parents who don't yet know other families living with hemiplegia, we would like to improve and expand our local groups' network. See the facing page to find out how you can join a group – or even start one.
- For more personal, one-to-one support, we plan to recruit more Helpliners and Home Visitors. These are parents of children with hemiplegia. Go to page 16 to read a year in the life of a HemiHelp Home Visitor – and to find out how you can get involved. And go to page 23 to find out more about our helpline.
- We want to share the wealth of useful hints and tips that parents shared with us. There just isn't enough room to detail them all here – we received 10,000 comments in all. They cover treatments and therapies, special equipment, benefits and activities, just to name a few. Keep an eye on our website, where we'll post these priceless nuggets of information. We'll also use our survey findings to expand and update our range of leaflets.