What is hemiplegia and how many does it affect?

Hemiplegia is a neurological condition caused by damage to the brain. In 80% of cases it happens before or around the time of birth and is known as congenital hemiplegia. Parents will usually only become aware of their child’s hemiplegia gradually during his or her infancy as they display developmental delays or ‘one-sidedness.’ Some children acquire the condition (acquired hemiplegia) later in childhood following a stroke, a virus or infection such as meningitis or head trauma. Every day in the UK between one and two babies are born with hemiplegia which means that one child in 1,000 is affected by this lifelong, incurable condition. Although comparatively unknown, it actually has the same statistical incidence as Down’s Syndrome. Given the statistics and the fact that most children with hemiplegia attend mainstream schools, this implies that most teachers will experience at least one child with hemiplegia in their educational careers.

Effects and treatment of the condition

Dr Charlie Fairhurst, (Paediatric Neurodisability Chair for the UK, author of the Hemiplegia Handbook and Consultant at the Evelina London Children’s Hospital) explains that “the effects are similar to a stroke and it results in a varying degree of weakness and lack of control on one side of the body. In one child this may be very obvious; he or she may have little or no use of one hand, may limp severely and have poor balance. In another child it will be slight and only shows when attempting specific physical activities.”

Since hemiplegia is caused by damage to the brain, it is not just motor development that may be affected. Over half the children have additional diagnoses. Some of these are medical in nature, such as epilepsy, visual impairment or speech difficulties. Many children have less obvious additional challenges, such as perceptual problems, specific learning difficulties or emotional and behavioural problems.

Treatment is based on a multidisciplinary approach and almost always involves physiotherapy and occupational therapy. Speech therapy may be required or treatment for epilepsy as this affects 1 in 5 children with hemiplegia. There are a number of therapies to aid movement ranging from botulinum toxin (botox) injections to reduce muscle stiffness to orthopaedic surgery. Most children will wear orthoses (splints) on the arm and/or leg. Furthermore, the child may receive behavioural support at school and psychological support to deal with behavioural and emotional issues.

Supporting children with hemiplegia in schools

It is important for teachers and learning support assistants to be aware of the therapies the child is receiving and to liaise with the treatment team. Best practice would see the child’s teaching assistant or other staff member incorporating the interventions advised by the therapists into daily activities with the child. A ‘holistic,’ integrated approach will undoubtedly provide an optimal learning environment for the child.

Sharing information before the child starts school is crucial because hemiplegia affects each child differently. One child may have quite severe physical impairment but no problems with learning. Another may be less physically affected, but have considerable cognitive difficulties. Obviously, the earlier the issues are identified and addressed, the better the chances of successful intervention. Some whose disability is fairly mild do well with informal help with practical tasks from staff and peers whilst others will need a formal Statement.

Physical support

There are different forms of support that children with hemiplegia require at school, the most obvious deriving from the physical impairment. The child may need help within the classroom with using a ruler, scissors and artwork. At lunchtimes, the child may need support eating, for example cutting up food or pouring a drink. PE lessons can pose a number of challenges starting with just getting changed to actually using equipment, especially activities relating to balance. There may be mobility issues between classes with the child taking longer to contend with stairs or longer distances. This may make the
child late for a lesson so there needs to be some allowance for this or some assistance provided. However, Dr. Fairhurst says “teachers should encourage the child to take part as much as physically possible.” The aim is to support the child but at the same time encourage the child to use the weaker side to make them as ‘two-sided’ as possible.

Learning and behavioural support
As well as physical support, children with hemiplegia will need support to help them access the curriculum. However, hemiplegia is sometimes perceived as a mild physical disability and teachers are not always aware of the less obvious aspects of the condition. Robert Goodman, Professor of Brain and Behaviour Medicine at King’s College London, reports that “often the 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.”

Issues common in children with hemiplegia include dyslexia and/or dyscalculia, visual impairment and visual perceptual problems. They often also have other difficulties that will impact on their learning; for example, with short-term memory or attention span. They will also tire more quickly than their classmates. Furthermore, studies have shown that over half of children with hemiplegia will experience emotional and behavioural problems. These can include: excessive shyness, difficulties making and keeping friends, excessive anxiety, irritability, a tendency to be easily distracted, aggressiveness, immature behaviour, fear of failure resulting in unwillingness to do tasks, obsessive-compulsive traits, difficulty coping with change, concentration problems.

Understandably then, the school day can be really exhausting for a child with hemiplegia. Schools need to recognise these issues and work to minimise them. The book ‘Hands Up for Andie’ by Brenda Palmer highlights a number of these issues and is a useful starting tool for teachers to help children in the class understand how it feels to have hemiplegia.

HemiHelp – support for schools
HemiHelp is the national charity that provides information, support and events for children and young people with hemiplegia, their families and the professionals who support them. A key part of what they do is to work with schools to raise awareness of hemiplegia and help teachers support pupils with the condition. In order to assist schools, the charity provides training in schools and has put together a primary schools pack ‘The child with hemiplegia in primary schools.’ They are currently working on a secondary schools pack. To request training or a primary schools pack, please call 0207 609 8507 or visit www.hemihelp.org.uk. To see the information sheets, please visit www.hemihelp.org.uk/professionals/education.

Whilst school may pose more challenges for a child with a disability, with the correct support infrastructure, these can be overcome. To end this report as we began, with a famous Mandela quote, “It always seems impossible until it’s done.”

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