Caring for Spastics

CARING FOR SPASTICS

Perfect balance, control, coordination. The grace of champions.

We start practising very early, long before we can remember. And although a few of us become champions, most of us develop an extraordinary degree of control over our bodies.

All movements originate here, in the brain, so complex that researchers are still unravelling the ways in which it controls countless physical movements and thought processes. We do know that the main surface areas are here, and that the most important regions inside the brain are the basal ganglia, the cerebellum and the reticular substance. Through these three regions pass a complicated system of related messages that eventually reach the part of the body that is being moved.

In fact, by the time we're two years old, we become capable of quite complicated eye and hand coordination. But if these control mechanisms are damaged, this coordination can be seriously affected.

Spastic is the popular term for what doctors call cerebral palsy. It's caused by damage to one or other of these main areas of the brain. Once brain cells are damaged, the control of various parts of the body is affected. When the damage is mainly here, messages no longer run smoothly to the different parts of the body. They become rather like electric shocks, involuntary movements occur that can cause a person's limbs to jerk violently. It makes ordered control of movement very difficult. This type of cerebral palsy is called athetosis.

When the damage is mainly in these areas, the messages become distorted, broken, unclear, as if the limbs was being pulled in different directions at the same time. The muscles seem to be stiff and the limbs move in a slow, ponderous fashion. This type of cerebral palsy is called spasticity.
The degree of damage varies in cerebral palsy and can affect more than one main area. Speech and hearing can be affected if this area is damaged, and the damage may extend to here, which may mean the person has a mental handicap, as well as a physical one.

Cerebral palsy is a major problem in Britain, a very rough estimate puts the number of people suffering from the disorder at around a hundred thousand, and it's a problem that concerns all of us, particularly as a child with cerebral palsy can be born to any family. Its exact causes are largely a mystery.

"It's, it's the emotional strain that's the greatest, I mean the slow dawning that here is a child that is different from […] that's got one just the same age and is making your child as... You know how mothers compare babies and how it was always not doing the things other children of her age were doing.
If someone can write down a table of things that are going to happen, then most people can face that but it is the kind of unknown quantity aspect of, of the condition. It is very hard to take."

Anxieties like these that all parents with handicapped children share, prompted a group to form the Spastics Society, to fight for a brighter future for their children and the many thousands of families who have to face the enormous problems of bringing up a handicapped child.

Now, over 20 years later, it's become the leading organisation in the world for the care, welfare and training of people suffering from cerebral palsy. With a hundred and eighty local groups in England and Wales, it's established through their efforts over a hundred and sixty residential homes, training centres, hospitals, industrial units and schools.

Research is also an important part of the Spastics Society's activities, and it's financed a unit at Guy's Hospital. Here, an intensive program of research is being organised into the causes of cerebral palsy.
But the answer to the problem doesn't only lie at the end of the microscope. That's just one approach. The care of newborn babies, particularly those born prematurely, and trying to discover mothers who may be at risk during pregnancy. are as important as any scientific breakthrough. It's a long haul, attacking on a number of fronts, but reducing the incidence of cerebral palsy by perhaps 1 or 2% a year.

For the child with cerebral palsy, one of the first contacts with the Spastics Society may well be here. If he's to gain benefice fully from the range of services the Society offers, he needs to be assessed to find out just what he can and cannot do.

Assessment mainly involves trying to overcome communication difficulties and map out a picture of what lies behind those difficulties, in terms of his potential.

"If we provide the, the pointing and the questions, the speech, and give him a chance to simply think about how to solve problems."

John is a severe athetoid. His speech and coordination are very limited, so there's little point trying to use ordinary communication methods to get through to him.

"OK, let me do some pointing, John. You're ready? We're looking for the one that's different. Is it that one? Is it that one? Yes, it is that one.
Which one is different? There we have to look at them all, and one of them is not the same as the others. Yeah. Is it this one? Is it this one? Good boy!"

Although John has hardly any means of expressing himself, beyond nodding his head, by the time these various tests were completed, his IQ was assessed at a 120.

A generation ago, his future would have been bleak. He'd had been classified as impossible to educate, and would probably have spent most of his life in an institution for the mentally handicapped.

But now John will join the thousands of children with cerebral palsy who benefited from the many special schools the Spastics Society has built, schools like Ingfield Manor, where the Society has pioneered new techniques for the teaching of the severely physically handicapped child. At Ingfield, education of mind and body are seen as inseparable. The teacher of reading and writing also teaches walking, sitting and hand control.

The day-to-day routine consists of a series of tasks broken down into simple movements repeated time and time again.

"I kick. I kick.
1, 2. 1, 2. 1, 2. 1, 2. 1, 2.
I go over, over, over, over, over, over."

It looks a bit like brain washing, and in a way it is because what the teacher is trying to do by constant repetition is recondition the child's movements, so that this simple gripping exercise develops into this, then to using the fingers like this, to using a pencil. And when that is impossible, the child can be taught to use a typewriter. Or if that it is impossible, technology can simplify the task.

"[…] Good."

"*Clean the first one, give it a good clean and keep singing… One… clean the second one…*
- Push right, step left and stretch.
Push right, step left and stretch."

For the children at Ingfield, the aim is physical independence, but not all spastic children are that lucky. This child is physically handicapped, mentally handicapped and deaf. He's a pupil at Meldreth Manor, a school designed by the Spastics Society to provide a stimulating environment and the most up-to-date teaching techniques for 120 children who are mentally, as well as physically handicapped.

One of the main characteristics of mental handicap is that the concentration span is often limited to a matter of seconds, so learning by ordinary teaching methods often produces poor results. In this classroom, the children have a teacher, paints and toys, the usual classroom materials, but the progress of each child is carefully monitored through a one-way mirror and recorded on videotape. Progress can be compared with earlier results and then the increase in the child's concentration span quickly recognised and built upon.

Mechanical aids to teaching are also widely used, particularly with children suffering from the athetoid form of cerebral palsy who have difficulty using their hands.

Some of the children at Meldreth are also deaf, which particularly complicates the teaching of the mentally handicapped, and to overcome this, a special signing system has been introduced.

"Good! What little boy doing? Good, good boy!"

The Paget Gorman System has a number of advantages over other types of sign language. Each word has a separate sign; you can indicate tenses and various suffixes and affixes, in fact, all the detail of the spoken world. This means that for the deaf child, language and understanding can be developed to a far greater degree that what would be possible with traditional sign language.

"You are very clever."

These children are no different in terms of their potential from the child who lives in a hospital for the mentally handicapped. The difference is that these children have a unique chance to develop, thanks to the resources and expertise at Meldreth. As they develop they become more alert and responsive, and so they appear less handicapped and start to develop personalities of their own.

"What are we going to sing?
- *Polly Wolly Doodle all the day*
- Polly Wolly Doodle all the day? O*h, I went down South for to see my Sal Singing…*
- *…Polly Wolly Doodle all the day*
- *My Sal she is a really nice gal. Singing…*

- *…Polly Wolly Doodle all the day*
- *Fare thee well, fare thee well Fare thee well my fairy fay. For I'm goin' to Louisiana for to see my Susi-anna Sing…*
- *…Polly Wolly Doodle all the day.”*

“*John!*
- *Nice shot.”*

The Thomas Delarue School has an atmosphere very different from the quiet, protectiveness many people associate with schools for the handicapped. Here, great emphasis is placed on competitiveness and on being as physically independent as possible.

For school leavers, coming to terms with the outside world is just as important as passing O or A levels. A survey in the local town of access facilities in shops for a wheelchair, illustrates the simple point that the outside world doesn’t make that many allowances for the handicapped.

This film has looked at the school years and the work the Spastics Society does with the help of its many local groups to provide opportunities for these children to develop their full potential. But spastics don’t suddenly disappear at 16 or 18, and the Spastics Society aims to help them through their adult life. Every year, for instance, their social workers and career advisory officers pay over 20,000 visits to the parents of handicapped children and to adult spastic people. And now, over three thousand spastics, once considered unemployable, are holding down jobs in commerce and industry.
But the problems that the adult spastic faces are daunting, problems of further education and housing, problems of mobility, and employment. And the Spastics Society, with its own money or in partnership with local authorities, tries to provide solutions. Any progress made is all too often an uphill struggle against apathy or attitude, which though polite and well-meaning, appear prejudiced.

What can it be like to be stared at every day of your life when you walk down the street or go into a room? To have to fight to be accepted as the person you know yourself to be and not as someone people feeling embarrassed by or sorry for? These are questions most of us are lucky enough not to have to answer. It would be nice to think that when this girl grows up and takes her first steps into the outside world, she won’t have to answer them either.

“*Push the left step right and stretch.*
- Push the left step right and stretch.”

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