

Psychological Issues After Pediatric Stroke

A supplemental interview with Dr. Mark Sandberg, Ph.D., ABPP for "Born to Survive," published in the January/February 2006 issue of Stroke Connection Magazine. (Science update October 2012) Dr. Sandberg is a Diplomate in Rehabilitation Psychology and a Clinical Associate Professor of Neuropsychology at Touro College. He is the Director of Psychology and Community Re-entry at St. Charles Hospital in Port Jefferson, New York.

Stroke Connection Magazine: *Psychologically, what happens after a diagnosis of pediatric stroke?*

Dr. Mark Sandberg: The first major hurdle involves the shock of learning a child has experienced a serious, life-threatening neurological injury, the simple recognition that children can have strokes. The initial reactions of the child and the family include feelings of shock and terror with the recruitment of emergency coping responses. There is a frantic search for answers on the part of the parents with sustained and targeted energy to get all the acute medical help available.

SCM: *After the child is stabilized, what happens next?*

MS: After a child's acute physiological needs are met and the child is medically stable, the family and healthcare staff turn their attention to the changes in moving, thinking and behaving that often result from a stroke. A picture of what has been lost, although perhaps blurry, begins to take shape. For the child and family, changes in physical capacity become the initial focus. How cognition and behavior have changed tend to be discovered over time.

When the child leaves the hospital and "re-enters" the community,

differences in functioning become more readily apparent. Abstract terms used by the hospital staff such as “visuospatial neglect” or “hemiplegia” become real in the home setting as the child attempts to resume old roles and routines, including basic activities of daily living. Images of how the child functioned before repeatedly well up and flood all concerned with strong feelings of sadness and apprehension about the future. Deficits in how the child thinks may be difficult to recognize and put into words early on.

It is particularly difficult to come to grips with losses of intellectual capacity, which are not uncommon after a stroke. Mental deficits are most difficult and stressful to handle. The term “denial” is often used at this early stage. While it refers to a refusal to deal with the truth, it is often a healthy response to prevent feelings of hopelessness. Other common feelings for both the child and family include depression, anger and fear.

It is critical to recognize that not only the child but also the family has gone through a trauma. The child neither exists nor can be cared for in isolation. The amount of emotional effort can't be overestimated. There are many facets of recovery, and dealing with them can seem insurmountable.

Surely the child wonders about what the future will bring. Of course, the parents will be painfully aware of the fact that their child is likely to have lost some capacities, some independence, some potential, etc. The uncertainty about the extent of these losses can persist for months and years, often leaving parents vacillating between hope and despair.

SCM: *What about other children in the family?*

MS: Siblings of the injured child can be seriously affected, a fact that has been well documented in the literature. School performance may decline. Symptomatic behavior can develop in the hope of gaining lost attention, and there may even be feelings of guilt that develop over remaining healthy. Conflicts between the injured child and siblings are common. New responsibilities are often assigned as the distribution of household chores

gets reallocated, and this may lead to feelings of resentment.

SCM: *What kinds of challenges does school present?*

MS: School is a critical period and much has been written about this phase of recovery. It's possible that some functions may have returned to normal while others remain impaired. Family exhaustion is likely to remain high as everyone struggles to deal with the reality of the child's new cognitive and behavioral style. It's at this point when the new set of cognitive strengths and weaknesses must be recognized and incorporated into educational approaches.

Depending upon the nature and location of the stroke, different cognitive deficits will emerge. It is imperative that the school understand these deficits so that approaches to learning can be individualized in a creative and flexible manner. Instruction should be delivered in the least-restrictive environment possible. Research has shown that cognitive and behavioral weaknesses often combine to create the most troubling barriers to educational and social success.

Perhaps most difficult is the social integration (or re-integration) that the child must learn to navigate. Friendships become challenged, old friends may drift away, and the child is faced with the task of sorting through a host of self-esteem issues. Language difficulties can make it hard to interpret social cues or emotion while attention deficits can present challenges to sustaining interest in discussions with peers. It is at this point that cognitive deficits can become mingled with emotional issues, and they are not easy to tease apart.

Of utmost importance is the development of accurate self-awareness. It is common for stroke survivors to misperceive their own strengths and weaknesses, and this misperception may lead the child to behave in ways that are inappropriate or even dangerous. A child may not understand certain restrictions or why certain responses are ineffective. Right hemisphere strokes present different emotional deficits than left hemisphere strokes. It

can be a delicate balancing act to guide a child through these deficits without dashing their hopes.

SCM: *Is there ever a time when parents can feel assured that they have seen everything their child's stroke can throw at them?*

MS: It is important for parents to recognize that difficulties in emotional functioning may not be seen for months or even years after the stroke. As academic and social complexities increase over time, the child's compromised learning and adaptive skills may not be able to handle age-appropriate developmental demands. In turn, the child may experience difficulties that are not evident at the beginning. In other words, deficits may be exposed over time as life's demands become increasingly complex and challenging.

Adolescence is a particularly demanding age period, as it is for any child, but it can be particularly so for a person who is faced with an altered set of behavioral and cognitive skills stemming from a stroke. The fact that there are delays in the development of deficits may be a difficult reality for parents and school personnel to cope with, but it is the reality for many survivors of pediatric stroke and so an important point to be aware of.

Because there is a high rate of emotional and behavioral difficulty following stroke, it is important to get professional assessment of these dimensions. Having accurate knowledge of a child's emotional and cognitive status following a stroke is a critical part of their recovery.

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