



BROTHERS AND SISTERS: BRAIN INJURY IS A FAMILY AFFAIR

By Carolyn Rocchio

Time and again we talk about the many ways brain injury affects every member of the family; however, often overlooked in the process of "getting through the catastrophe are the brothers and sisters (siblings) of the person who has been injured. Although articles and book chapters provide some personal glimpses into the wide range of emotional and physical upheaval experienced by siblings, many families suffer needlessly for lack of this information when it is most needed. As a basis for this article, a number of families were contacted and asked to share their experiences. The siblings in question were at various ages and in various life stages at the time their sibling was injured, therefore, reactions discussed are those of youngsters still living in the family home as well as adult siblings living independently.

Almost universally families reported major problems of which they were unaware at the time the injury occurred, due to their pre-occupation with the medical crisis. The injury naturally occurs suddenly and unlike anything the family may have ever discussed or planned for, such as a plan for an escape route in the event of a house fire, they are immersed in a life and death situation over which they have little or no control and no preparation.

In the immediate aftermath of notification of the injury, young children in need of care may be quickly deposited with neighbors and relatives, older children may be told to stay put in school or jobs until further information is available. There is no perfect plan but siblings experience an emotional roller coaster that is often influenced by non-verbal cues they receive from their parents or caregivers, e.g. relieved voices versus weeping or sad facial expressions, conversations that cease when a sibling enters the room, sudden over-protection, or the onset of financial austerity/sacrifice, which is often perceived as unjust punishment to siblings. Seldom do any two siblings within a family react similarly and their response to the injury undergoes periodic changes over time and with maturity.

Some common reactions are:

- the young sibling who reverts to bed wetting and previously outgrown babyish mannerisms.
- the sibling whose school performance drops off dramatically.
- the younger brother who surpasses the athletic skills of his pre-injury role model brother with brain injury and never lets him forget it.
- the sibling whose shared bedroom no longer resembles the safe haven it once represented, as it is now cluttered with a wheelchair, splints, medications, and other necessary items.
- the sibling who no longer feels comfortable bringing his friends home for several reasons, e.g., rules governing noise or loud music, the sibling with the brain injury looks and acts differently, the house is cluttered with therapeutic devices, and "home just isn't home anymore!"
- siblings that harbor resentment for the time, energy, and financial resources directed toward the sibling with brain injury.
- older kids often resent the emotional and physical drain on aging parents who must provide care for their sibling, thus, robbing the parents of their "golden years" and time to enjoy the grandchildren.
- siblings worry about added responsibilities for caring for their sibling not only while the parents are still living, but their expectation of increased responsibility after the parents are gone.
- siblings often express their embarrassment when a sibling with cognitive deficits says or does something inappropriate in public.
- many express the feeling of general neglect because friends and family are always inquiring about the person who is injured but never ask about the other siblings.
- children also experience a form of double standard discipline when the sibling who has been injured is permitted to "get away with" more than the others and allowed to circumvent family rules that once were strictly enforced for all.
- siblings express feeling guilty about their changed feelings for their sibling who has been injured.
- many siblings felt that they were never included in discussions or provided information about the extent of the injury and, as a result, conjured up false ideas that often were even more devastating than reality.
- the structured environment, so necessary to the well being of the sibling with brain injury, often imposes unfair restrictions and hardship on siblings with active schedules.
- some siblings are unable to accept and unwilling to learn more about the long lasting consequences of the injury and frequently accuse the parents of over-protection and genuinely feel that if left to his/her own devices the sibling with the injury will be "just fine!"
- unfortunately some siblings cannot deal with the injury, won't read any literature or watch any videos to become better educated. When they are of an age to leave the family home, they exit, often under very poor terms.

- Do the aforementioned issues exist? You bet they do and this is just the tip of the iceberg. It is apparent that history cannot be rewritten but there are some strategies that when employed can lessen the impact of brain injury on other siblings in the family.

Former Surgeon General, C. Everett Koop, once stated, "No prescription is as valuable as education." Naturally education about the nature and consequences of brain injury better prepares the entire family for dealing with brain injury. Some suggestions from other families with long term experience in managing life after brain injury includes:

- be honest, no one knows the extent of recovery, particularly in the early weeks or months following brain injury, but keep your options open and hope alive. Things have a way of working out and there are many wonderful and inspirational stories about triumph over disability occurring over long periods of time.
 - give the other children the tools to work with, e.g., literature, open and frank discussions on an appropriate age level, opportunities to visit the sibling while hospitalized, but most importantly allow the siblings to deal with the situation in the way they are most comfortable.
 - include the children in the rehabilitation setting, when possible.
 - encourage children to talk about and write about their siblings injury and their own feelings about the event.
 - understand the differences in reactions and validate those differences. For example: One sibling adamantly refuses to visit the hospital, read literature, and/or discuss the injury, while another sibling is the opposite and participates extensively during and after the crisis stage of recovery. Reassure the "disinterested" sibling that it's okay to feel as they do and to not feel pressured to participate in things that make them uncomfortable or frightened.
 - try to minimize the disruption in the home that has a negative affect on the other children.
 - invite children to support groups to expose them to others families with similar problems, thus, making them feel less "different" and alone.
 - help young children prepare "show and tell" or school reports about brain injury to increase the awareness of their peer group. This can be a self-esteem booster for a child that has been on the sidelines while the sibling with brain injury appears in the spotlight.
 - most families report that, with the passage of time, children who may have been reluctant to acknowledge the injury initially most often come around and frequently become central figures in the life of the sibling with brain injury.
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- time management becomes a critical area for parents who must juggle home responsibilities, jobs, the child who has been injured and still have quality time for the siblings. This is the perfect time to call upon your friends and

family, most of whom are willing to help but don't know how. Ask them to provide respite for the child with brain injury while the parents enjoy some special event with the other children or have a quiet dinner out together.

- arrange for activities, games, sports, outings that were previously enjoyed by the whole family. Most survivors of brain injury are not "fragile and can participate in many wholesome and fun activities that encourage the reemergence of healthy competition.
- some siblings may respond well to counseling when and if their reactions to the injury appear to have lasting implications and/or appear to be affecting their emotional health adversely. Although brain injury changes everyone within the family unit, siblings have long been relegated to a bystander role when in reality they are major players in the ongoing process of recovery, rehabilitation, and quality of life issues. Their emotional health is of primary importance and families can minimize the negative effects by establishing a plan for inclusion from the onset.

References: Spanbock, Paul. "Children and Siblings of Head Injury Survivors", *The Journal of Cognitive Rehabilitation*, July/August, 1992, pgs. 8-9. Sachs, Paul R., *Treating Families of Brain Injury Survivors*, Springer Publishing, New York, 1991.