



**BRAIN INJURY
ASSOCIATION
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Helpline: 1-800-669-4323

No Brain Injury is
Too Mild to Ignore,
or Too Severe to
Lose Hope

The Unvarnished Truth- There is No Cure for Brain Injury

By Carolyn Rocchio

The title of this article is not meant to be humorous or jar one's sensibilities, but it is a statement of fact. It concerns me greatly that as we near the millennium, we have made tremendous gains in the care and management of individuals with brain injury in the acute care setting and immediately post injury, but in many ways we are losing ground in preparing individuals and their families to manage life after brain injury.

I am increasingly dismayed with the trend to sugar-coat brain injury, and much of the blame is the result of the changes created by managed care. Ten-to-15 years ago, more individuals with brain injuries were able to access specialized rehabilitation through major medical insurance and more generous worker's compensation programs than exist today. It's ironic that at that time, when insurance carriers were paying for extended rehabilitation, there were only a handful of facilities with specialized brain injury programs and families usually had to travel long distances to use these limited facilities. Sadly, even when this option was available, many families -- unaware of the uniqueness of brain injury and its consequences -- chose not to exercise that option.

Now the situation is reversed, there are ample numbers of specialized rehabilitation facilities, but fewer have access to them due to insufficient or limited insurance resources and minimal state provided assistance. Managed care (HMOs, PPOs and the like) may provide hospital based services and some short-term therapies, but seldom do they fund extended post-acute cognitive and behavioral programs. Individuals with severe brain injuries, impacting on cognitive functioning, are routinely discharged from inpatient rehabilitation programs in a matter of two weeks in some cases, and three months of rehabilitation is now considered generous. Discharge planning is frequently nothing more than a list of medications and a measure of good luck. Family counseling and even family conferences have all but been eliminated.

Let's get one thing straight -- there is no cure for brain injury. Furthermore, there is no point at which one is pronounced "well." For 15 years I have managed the family help line for the Brain Injury Association of Florida, and I have handled as many as 2000 calls in a calendar year. I've often been asked, "when will he/she be well?," and it's hard to tell someone who is feeling overwhelmed that there is no ending point to brain injury, as it lasts a lifetime. However, the good news is that there is life after brain injury and although it may be a different life, life after brain injury is worth living. I also don't want to sound so redundant with my constant badgering about the issue of information, education and support, but families I speak with



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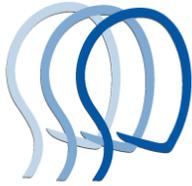
just aren't getting the information they need when they need it, and they call only when things get so far out of control that it is difficult to get back on track.

We've spent years trying to get brain injury recognized as a separate and unique disability, and this was necessary to create the awareness of the problem for the benefit of society and decision-makers. However, providers of specialized services now find themselves scrambling to find reimbursement for the services they know are vital to improving outcome for those with brain injuries. Many fine therapists are leaving brain injury rehabilitation for greater job security as a result of downsizing and managed care. Those dedicated providers struggling to find solutions to this dilemma now realize the need to reach out to other agencies and disability groups to share information and limited resources.

How can we achieve this "life of quality?" Everyone has a stake in this plan -- the person with brain injury, the family, the providers of services, community agencies and society at large. One thing I've discovered over the years is that brain injury recovery goes in stages. Families may be very accepting of the medical stage and subsequent relearning of basic skills and activities of daily life; however, very few recognize or are prepared for the changes affecting cognition. A typical scenario finds the individual returning to the family fold expecting life to go on as before.

Once individuals have mastered the more physical problems, expectations of resuming a pre-injury lifestyle are common but can be very disappointing. Although spontaneous recovery/progress should continue with appropriate support systems, improvement in cognition, e.g., increased awareness and insight, may contribute to new problems and unpleasant emotional reactions. For some, these changes may be delayed by the severity of the injury and become problematic as long as three-to-five years post-injury. Callers often describe their family member as "such a pleasant person who worked so hard in rehab to get better, now he/she's angry, abusive, depressed and destroying things around the house." The support system in place up to that time is gradually reduced, and the individual is possibly more in charge of his/her own destiny. This often coincides with the time the family members have begun to relax the ongoing support they've been providing and are hoping to refocus their lives in other areas. This is a crucial time in which family support can make the difference between progressing to a higher level or regressing.

Support/self-help groups play a vital role in the lives of persons with brain injuries and their families, and never more so than when the individual completes rehabilitation and finds that life is changed in ways that the individual and the family find puzzling or difficult to manage. Self-help groups enable the individual to identify with others with similar problems,



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and together solutions are often found. Additionally, as a result of group interaction, the individual feels less alone and a sense of "belonging" is very important to those whose lives have been dramatically changed. Many groups extend services into social areas sponsoring activities outside the regular meeting times, picnics, dinners out in the community, dances, volunteer opportunities and other ways members can be productive and fulfilled.

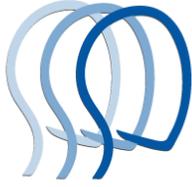
Families find groups very helpful in gaining insight into the long-term consequences of brain injury, ways to recognize problems in advance of their becoming difficult issues and sharing practical management strategies with other families. Former Surgeon General C. Everett Koop once said, "No prescription is as valuable as education," and this is very applicable to life after brain injury. It requires a lot of time and energy for families to maintain an appropriate level of support, but the dividends are well worth the investment.

During the rehabilitation process, be as involved as possible, ask questions, attend family conferences and learn all you can while your family member is in a structured setting. Make sure you are provided with a sound and realistic discharge plan. Once home, don't set back and assume everything will automatically fall into place. Establish a routine (structured environment), consistently enforce the discharge plan, and make sure that your family member has control over those aspects of his/her life that are safely manageable.

As difficult as it may sound, troubleshooting as you go can ease any burden you may assume in guiding your family member to the optimal level of functioning possible. Some who survive brain injury may never reach total independence, but all survivors of brain injury are entitled to a fulfilling life and that often is dependent on the willingness of the family to prepare to take on this responsibility.

Information, education and support, are the three most important aspects of rebuilding life after brain injury. Add to that an equal measure of love, and it can be a win-win situation.

Carolyn Rocchio is the parent of a son with a brain injury sustained in a 1982 automobile crash. She is the founder of the Brain Injury Association of Florida and a former member of BIA's Board of Directors. This article was originally published in "Family News and Views," Volume 5, Number 2 in February 1998. It is reprinted with permission from the Brain Injury Association of America.



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*Additional information can be found at: Helpline: 1.800.669.6443
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