

Your loved one has a brain injury: Now What?

Imagine parents with a 7-year-old son. He plays baseball and enjoys riding his bike. One day while out riding, the son is hit by a car, and suddenly their lives are changed forever.

At the hospital, he is diagnosed with a traumatic brain injury (TBI). The boy will survive the accident, but the parents are unsure their son will ever walk again, ride his bike or play baseball. After he is released from the hospital, the boy begins to return to his life. It is quickly clear, though, that their son is developmentally falling behind his peers. He is more aggressive and has trouble remembering things. The parents are surrounded by therapists, physicians, staff and friends who are all offering advice and guidance on coping with the changes they are facing with their son, but no one knows their child the way they do.

Parents and guardians of individuals with a brain injury have a unique perspective on the results and treatment of a traumatic brain injury (TBI). Involved family members are able to see the child progress through the full continuum of care, from medical supervision in the hospital to therapy at a rehabilitation center. Parents have the best perspective when comparing what their child was like before and after the brain injury, and serve as the key link between teachers, therapists, case managers, friends and peers.

Brain injury is an unexpected, often catastrophic event. It affects the person with the brain injury and their family members for many years. Family members and guardians often have numerous additional responsibilities added to their lives, which require commitment, love and care.

Some people with brain injury may need supervision around the clock and assistance with basic activities of daily living, such as bathing, dressing or eating. This can put a great deal of responsibility on guardians as they try to navigate through the many different options of health care and support offered to their loved ones.

That is why assisted-living facilities and rehabilitation centers are available for those recovering from a TBI. Parents and guardians have a variety of options for living assistance for their loved ones. Whether a guardian chooses home care, outpatient therapy, apartment placement or community living, help is available.

Knowledge in several critical areas can help parents and guardians make the best choices for their loved one. This article provides information on those key items to begin the journey of learning and understanding what life will be like for families after a loved one has sustained a TBI. The story on the next page illustrates how a brain injury changed one family's life.



Nick and Bill Rakovalis

Educate yourself

We've all heard that knowledge is power and this is never truer than in the case of coping with chronic illness. Coping is difficult enough without adding the element of surprise. If families have some idea as to what they can expect from the injury, it is easier to prepare both psychologically and in practical ways.

Education about brain injury also allows families to learn that much of what their loved ones are experiencing is typical after this life-changing event. Knowing that they are not the only ones going through this experience offers many families a great deal of comfort.

There are many sources of information available to learn more about what to expect after a loved one sustains a traumatic brain injury. Some include:

- Treatment professionals including nurses, physicians and therapists
- Advocacy groups such as The Brain Injury Association of America and The Brain Injury Association of Michigan
- Books such as "Fighting for David" by Leone Nunley and "Ketchup on the Baseboard: Rebuilding Life After Brain Injury" by Carolyn Rocchio outline families' experiences in coping with brain injury

Education allows families to have realistic expectations, which makes coping with the changes their loved ones go through that much easier.

Coping with change

It is common for families to hold on for the day when their loved ones will once again be "like they were before." They continue to hope that their loved ones will behave the same as they did

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before their accident--before their injury. The reality is that even with mild brain injuries, the individual may not return to their pre-injury state. Even when the body and brain heal, those injured are changed by the experience. The family must often grieve the loss of the "old" daughter, son, mother or father before they begin to come to an acceptance of the "new" individual that their loved one has become. It is important to understand that this new person is neither better nor worse, but different.

Families need to allow themselves to go through the feelings associated with grief and loss to come to a level of acceptance. People often resist acceptance because they equate it with resignation, but they are two very different mental states. Resignation implies a loss of hope; with acceptance, people realize their loved ones have changed. Acceptance makes it possible to cope with a loved one whose life has turned out very differently from how the family and loved one once envisioned.

When an injury first occurs, it is common for families to put everything aside to deal with the needs of their injured family member. At some point, families must begin to return to a more normal life. It is often very challenging to find a balance that will work for the long-term. Family members must remember to make time for themselves and for relationships with others as well.

Eventually, it is important to re-engage in those things that were once a source of enjoyment for family members. Exercising, taking classes and going on vacation are all important facets to families' lives. Taking part in those activities allows for family members to be better prepared to support their injured loved one.

Coping aids

Families often find help in coping through:

- Support groups of those who are going through a similar experience
- Faith and religion
- Other family members and friends
- Meditation
- Yoga
- Exercise
- Hobbies and leisure activities

Purposefully taking time to relax and participate in things they enjoy or find meaningful is crucial. It is important to make time for personal things for the entire family.

Cognitive changes and concerns

There are some changes and concerns that are common with people with a brain injury. Some may have difficulty with memory retention, aggression or behavioral issues. For others, temper

may improve. Family members need to look for a change in themselves, not a change in their injured loved ones, so that they accept that this is who they are now. Talk to professionals and look for compensatory strategies to overcome their new deficits and challenges. For example, if a person with a brain injury has difficulty remembering things, keep a planner. Write down subjects they repeatedly want to talk about, such as why he or she has to go to therapy. Then, rather than becoming frustrated when the same conversations are recurring every day, the person understands what is expected without having to be told repeatedly.

Dealing with anxiety and depression

Often, a person with a brain injury may have a lot of anxiety and depression. They may be worried about getting back into a vehicle or going out in public because they look different or ambulate differently. They want to know why this happened to them, and are grieving the loss of the old self. They are upset they are not who they used to be. Remind the person of the things about him that may be better than his old self and encourage the person to build on his strengths.

Empathetic listening

One of the best ways to help with anxiety and depression is to listen. Continue to try to listen and understand. One of the most important things to learn to help a person with a brain injury is empathetic listening.

Let them talk and say what they want to say, then gently be positive with them without being "over the top." Maybe it is a miracle to be a survivor of a car accident. Focus on the opportunity for a second chance at life, and decide what can be done with it. Give them hope for the future, so that they will develop goals and accomplish them. Maybe what a person with a brain injury can do with his or her life is not what was originally planned or hoped for, but life can still be experienced. If people believe the experience has meaning, they can endure anything. Learning to understand the new needs of loved ones, while being aware of what they can and cannot achieve, is a fine balance and difficult to achieve. Take advantage of all of the resources to be had, such as family, friends, health care professionals and research materials. Remember, help is available. ❖

See Page 3 to learn how Nick Rakovalis' family copes with his injury.

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Nick Rakovalis' Story

Nick Rakovalis is a Rainbow client at the NeuroRehab Campus. When Nick sustained a traumatic brain injury in December 1996, his father Bill was working at General Motors and Nick's mother had recently died from leukemia. At the time, Nick, the oldest of four children, was married and working full-time at an airport. When the accident occurred, Bill was swept up in the many concerns of the time. While coping with the loss of his wife, Bill juggled a full-time job, cared for his injured son, stayed involved with his other children and worked to maintain his house and his health. Bill realized how overwhelming it was all becoming when he fell asleep at the wheel while driving home from work and had an automobile accident of his own. He realized something had to change.

Bill made a difficult but critical decision. Within a year of Nick's accident, Bill retired early from his job at General Motors. "It was important," he explained. "I love my son. He needed me more than ever, so I retired a few years earlier than I would have liked. You do what you have to do, you know. Family involvement is much easier once retired."

Nearly 13 years after his accident, Nick lives at the NeuroRehab Campus where Bill visits him three times a week. Nick also goes home to his father's house at least once a week, where he visits for the day with his family.

The hardest part in dealing with Nick's injury, Bill said, is that he cannot help his son retrieve what he lost. "Nick was very hard working and loved his job. He was married. He misses all of that stuff, and there is no way to help him with that. So, I just try to be here for him as best as I can," Bill explained.

Bill said family visits are very regular. Nick has a very high-level of cognitive ability, but has other medical complications that must be cared for. Bill makes sure to have other family members at the home to visit with Nick. Bill cooks his son breakfast when he arrives and they spend the day together, having lunch, watching television and visiting with siblings and extended family. Maintaining a support system and relationship with family and friends allows the Rakovalis' to support each other and maintain a healthy lifestyle.

Interview by Nicole Bonomini, Rainbow Visions Assitant Editor;
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