



BRAIN INJURY ASSOCIATION OF NEW JERSEY

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No Brain Injury is
Too Mild to Ignore,
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Lose Hope

The Family: Its Crucial Role in Rehabilitation

By *Lauren L. Lerner, MD*

From the chilling moment that the unfamiliar voice on the telephone informs you “I’m sorry, but there’s been an accident,” the family becomes involved personally and completely in brain injury management and rehabilitation. Starting immediately after the injury, the trauma team will perform interventions requiring consent by the family.

Family members will seek and receive a great deal of information and data regarding the nature of the injury, treatment options and prognosis. At this point, the family may feel ill prepared to absorb all of the technical information. To combat these feelings, families should start compiling written information and reports—an activity that often proves beneficial later.

If the person with TBI is awake and conscious, the physical presence and support of the family is of immeasurable value, simply by providing familiarity and orientation in an otherwise foreign and frightening environment. Reassurances and affection can be calming, and family demonstration of support of treatments can reduce fears in the individual with TBI.

Ideally, rehabilitation interventions to prevent complications such as contractures and decubiti (i.e., pressure/bedsores due to prolonged pressure against an external object such as a bed, wheelchair, cast, splint) will be initiated on the first day. This also will serve to introduce the family to the concept and goals of the upcoming rehabilitation phase of injury management. The family will need to learn quickly the location of accredited, specialized brain injury rehabilitation programs. BIA and its chartered state affiliates can be invaluable sources of information regarding community resources.

Upon selection of and transfer to a comprehensive brain injury rehabilitation program, the family will be called upon to provide background information on everything from prior interests to favorite foods, from prior academic/vocational performance to personality traits. The rehabilitation team relies heavily on the family of the individual with TBI for a myriad of tasks such as the procurement of family photo albums during treatment of memory deficits. At all times, the family will be called upon to be supportive of the rehabilitation program and its methods.

Although at times overwhelmed by their own fears and frustrations, family members should bring their list of concerns to the appropriate hospital personnel or rehabilitation physician, as well as take advantage of the availability of psychological counseling services and family conferences.



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Seeking out assistance which can relieve their own concerns allows family members to assist the rehabilitation team and their loved one, rather than fuel the patient's frustrations with their own. To this effect, an important goal in any successful rehabilitation program is to help and support the family members as they adjust to major changes brought about by their loved one's TBI.

Depending upon the nature and severity of the injury, and as the individual progresses in the program, there will be opportunities for hands-on family instruction. This type of instruction may include techniques for performing tube feeding, passive range of motion and/or bowel and bladder management in the individual in coma. An individual with a severe TBI but who is conscious may utilize techniques for redirection and orientation, as well as physical assistance for transfers or gait. This hands-on education can help families better understand the care that is required and get them started planning for the return of the individual to the home and community environment.

Depending on the relationship—whether the person with TBI is a parent, spouse, child or a more distant relative—there will need to be accommodations for the person to resume his/her pre-injury family role as much as possible. A wide variety of issues, such as wheelchair accessibility, sexuality concerns and parenting challenges all will have to be addressed. Once again, this illustrates the importance of the family establishing good rapport and communication with the rehabilitation team who can provide guidance in these efforts.

Prior to discharge, key family members will have spent a great deal of time speaking with doctors, therapists and nurses, as well as reading TBI-related literature and other resources. Hopefully, the family members will have been introduced to support groups and the appropriate community resources. Additionally, many family members may be expected actually to perform basic medical procedures such as suctioning or tube feeding, thus assuming the new and critical role of “caregiver” or “care provider.”

Once the long-awaited discharge day arrives and the individual with TBI is allowed to return home, a new journey begins for the family. As the interaction increases from visiting hours to 24-hour care, family expectations may become more realistic. Not only is the family expected to fulfill caregiver functions, but they also must act as impartial observers and report any new progress, problem or change to the appropriate medical and rehabilitation personnel. After discharge, family members must coordinate outpatient services, schedule medical and therapeutic appointments, arrange for appropriate transportation and monitor medications. Now that the family member is home, it is very important the family remains current regarding the person's expanding abilities, so that appropriate balance is



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maintained between providing adequate supervision and assistance and allowing him/her to be as independent as possible. Additionally, the family should continue to maintain contact with support groups, psychological counseling and other community resources, all of which can help reduce feelings of isolation and provide practical information.

Throughout the next year or so, and as the person with TBI improves, issues of academic re-entry or vocational rehabilitation will need to be addressed. Eventually, the progress of the individual with TBI will slow down and even plateau. Hopefully by then, the family will have reorganized and/or established a new system to accommodate successfully the long-term needs of the individual, while still allowing maximal levels of independence in the least restrictive environment.

In summary, the family plays a major role in the management of a person who has sustained a TBI. Although these demands on the family can be frustrating and anxiety provoking, the family always should feel free to seek the assistance and support of the rehabilitation team to provide education and training at any point in the process. After all, the love, support and reassurance that a familiar family member provides to an individual with TBI are unique and irreplaceable adjuncts to therapy.

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