

# Quality

## Enhancing quality of life for people affected by traumatic brain injury

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### ***Head Injuries Happen to Families***

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Perhaps it was a phone call that changed your life so dramatically. Although you didn't know it then, many strangers would soon enter your life; most of them would be speaking "medicalese" and offering confusing and conflicting messages. One of the first things these strangers might have told you was that a person very close to you had sustained a head injury, was in a coma, and might never awaken.

Raised with the belief that medical skill and technology could repair damaged bodies, you assume that the injured individual will recover and resume life with few, if any impairments. Maybe there will be a limp or some scars, but the person will be the same person you always new. After all, doctors cure people, don't they?

While the injured person appears to sleep, untroubled by the social, emotional and financial problems which the head injury has caused, you make decisions, meet obligations, and survive the acute crisis. Ready or not, willing or not, able or not, you assume new roles and responsibilities. Nothing can prepare you for any of this, but you know it's only temporary. Soon things will be back to normal.

Unfortunately, head injury is unlike other illnesses and injuries. You discover that little is known about recovery and that the few available treatment programs are incredibly expensive and located hundreds of miles away. Physicians providing treatment may simultaneously relay prognoses which range from total recovery to little hope. Or may relay information you neither understand or accept. You don't even know what questions to ask so you don't get answers. You know that the person who existed before the injury has changed but you're not sure how or for how long.

Somehow, you survive the acute period and follow your loved one to a rehabilitation setting staffed by three shifts of professionals, none of whom are related to or knew the patients before they were injured. Compliance with "orders" from white cloaked professionals is usually expected and given by both patients and family members. Everyone sees (or imagines) daily progress in walking, speaking, eating, dressing – all the activities which used to be routine and taken for granted. It all looks easy, even though garbed in words like apraxia, ataxia, and hemiparesis. Everything will soon be OK.

Eventually the discharge date arrives, although far too often discharge is primarily a financial decision and/or results from a lack of appropriate rehabilitation or long term care facilities. No matter how much progress has been made, you may not feel ready to provide the care, support, and rehabilitation which is needed. But somehow you will. You must. No acceptable alternatives are offered.

Usually, you receive limited guidance about what to expect and what you should and can do to facilitate recovery. The information which you are able to acquire focuses on what is best for the individual. Which frequently does not coincide with what is best for you and other family members. Nevertheless, you duck into the nearest telephone booth, don your red cape, wave your magic wand, and become an instant rehabilitation professional. At the same time you remain the spouse or parent of a person who continues to behave in unfamiliar and confusing ways. From now on you will be expected to fill both roles competently and confidently.

The family is often more anxious than the injured individual, who is frequently unaware of significant disabling deficits. Even family members who visit the hospital or rehabilitation setting daily usually do not fully understand how drastically their loved one has changed or the impact these changes will have upon the daily life of every family member. Family members who attempt to follow through on recommended therapy programs in the home setting are rapidly perceived as “bad guys with black hats”. What appeared so easy in the hospital becomes a disaster at home. Your husband refuses to bathe, your son becomes increasingly angry and strikes out at everything, your house is full of barriers which make everything difficult. Within days, you are exhausted by trying to do everything you have been told to do, everything that is expected of you.

You persevere because there is no alternative. It’s all you can do to get through the day without collapsing. You fight back tears. You control your anger. You cry yourself to sleep. Most of what you have to do is less than enjoyable and you don’t have time for any activities you enjoy. Friends stop visiting because they feel uncomfortable. You become more and more isolated. Although you feel guilty, you may find yourself wishing the injured individual had not survived. In fact, the person you knew before the injury did not survive. And, unless something drastic is done, it feels like your family will not survive either.

The recommendations which follow may ease your way somewhat but they are only recommendations; they are not engraved on stone tablets:

As soon as possible (and before signing any legal documents), consult with an attorney experienced in representing individuals who have sustained head injuries. A skilled attorney can determine whether financial recovery from a third party is possible and can help you obtain federal, state and local benefits to which you are entitled (Social Security, DSHS, VA, DVR, public school system, etc.). An attorney can relieve much of the stress and paperwork which accompanies and complicates recovery from a head injury, allowing you to focus on more personal matters.

Become knowledgeable about appropriate management of specific medical problems related to the injury. While neurologists, neurosurgeons or physiatrists frequently supervise medical care following a head injury, the nursing staff is most likely to have the time to teach you specific procedures and to answer your unasked questions.

Cognitive (thinking, memory, reasoning, judgment, etc.) and behavioral problems following head injury are usually more disabling than medical or physical problems. Therefore, you must ensure that the injured individual receives a detailed neuropsychological evaluation and that the results of that evaluation are discussed with you in terms which you can understand. If you

know what abilities are impaired you are less likely to make unreasonable demands upon your loved one (and on yourself) and you are more likely to be able to anticipate problems.

Contact and join those organizations which focus their efforts on prevention, treatment and research into head injury: the National Brain Injury Foundation, state head injury associations, and local support groups. Read newsgroups dedicated to brain injury on the Internet, AOL and CompuServe. These organizations can provide you with detailed information about community resources and facilities, put you in touch with other individuals who have surmounted the problems you are currently facing, and help you get your needs met.

Be assertive (not passive, not aggressive) about getting your needs met. Educate yourself about the rights of disabled individuals and make certain you obtain all benefits to which you are entitled. Continue asking questions until you get answers, even though the answer will frequently be that there is no answer. Remember, you are the expert on the injured individual; you interact intimately on a daily basis. Although you may not fully understand the medical situation, you know the strengths, weaknesses and personality which existed prior to the injury.

Avoid attempts to be Superman, Mighty Mouse and Wonder Woman. Maybe you don't need to dust every day (or even every week). Maybe the injured individual can do some things you are doing, albeit not quite as quickly or as well. Most injured individuals have too much time on their hands anyway; let them try. Living with a person who has sustained a head injury is frustrating, exhausting, and stressful. If you maintain your perspective, your sense of humor, and your ability to call upon others for assistance and support, it can also be a rewarding experience for the entire family.

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