Brain Injury Rehabilitation Road Map

People have written me asking for some insight to what happens when a loved one is admitted to the hospital after sustaining a brain injury. With that in mind, I have written a brief overview of the rehabilitation path and the personnel involved.

The Statistics

The brain injury patient club is a nondiscriminating association that "welcomes" 1.4 million new members and bids good bye to over 50 thousand annually in the United States alone. There are two types of brain injury:

- Traumatic brain injury (TBI)–the result of an outside blunt force such as a vehicle accident, fall, violence, or military warfare
- Acquired brain injury (ABI), also referred to as non-traumatic brain injury–the result of an internal condition such as infection, lack of oxygen, drug overdose, or the leading cause, stroke

Whatever the cause and clinical definition, the road to recovery is fraught with potholes and detours that requires, among many attributes, perseverance and patience.

The Blow

The initial shock of learning of a loved one's injury can seem like a nightmare from which you will eventually awake. Then reality sets in as the routine of ordinary life is drastically altered. The patient and family members must grapple with what has happened, while simultaneously trying to set a course for treatment. As if the injury to the brain were not enough to digest, then comes the realization that other body parts are affected—messages aren't getting through to the limbs. Some effects of brain injury may not be immediately apparent, such as the impact on executive functioning skills. It's like a one-two punch: first the physical devastation, then the cognitive deficits. As your loved one faces the prospect of an extended hospital stay, you try to interpret reams of medical jargon and navigate the medical system maze.

The patient remains in the acute care facility until medically stabilized. It is then time to transport the patient to another facility for the next stage of recovery, usually a rehabilitation hospital. The patient and family members are responsible for choosing where the patient will continue recovery.

Choosing a rehabilitation facility is an important decision that requires research and a lot of legwork. My neurologist likened it to purchasing a home. It is that big a deal, as the patient's prospects for recovery and quality of life are at stake. Consider the following criteria in making this decision. Does the facility specialize in brain injury rehabilitation? Is it accessible to family and friends, the patient's support system? Do the personnel and the culture of the facility exude a sense of caring? This last element is particularly important, as you want to feel the staff's genuine commitment to the well-being of your loved one.

It Takes a Team

As part of the admitting process to the rehab facility, the patient is assigned a physiatrist. Do not confuse physiatrist with psychiatrist: the former is the doctor responsible for the patient's overall rehabilitation; the latter is responsible for the patient's mental health. With head injury, it is not uncommon to have both assigned. The physiatrist determines what type of therapies are necessary overall for recovery and also provides medical treatment, for example, pain medicine, other prescriptions, and tests.

Think of the physiatrist as the head coach who assembles a team of assistant coaches (therapists) who together come up with a game plan for the best possible outcome in the patient's recovery. The physiatrist is responsible for coordinating all of a patient's care through to discharge, and sometimes extending to outpatient care. It should be obvious (a "no brainer" if you will), but it is extremely important that the patient have a high level of confidence in the physiatrist. If a different doctor is in charge of outpatient care, the transition from one to the other must be, of necessity, a smooth one.

Just as "it takes a village" to raise a child, it takes a team to rehabilitate a patient after a significant brain injury. The physiatrist, as the head coach, oversees the members of the coaching staff who are professional caregivers assigned to assist in recovery of specific functions. Initially, these specialists within each therapy discipline evaluate the patient to establish a baseline to measure progress. Subsequently, they are responsible for examining, testing strength, range of motion, and creating a rehabilitation plan within their discipline. While there is a common goal of getting the patient well, there are specific concentrated areas of therapy:

- Physical Therapist (PT)–assists with coordination, balance, posture, and walking, either re-training muscles or with the help of prosthetics. Think of the PT role as rehabilitating below the waist.
- Occupational Therapist (OT)–assists in regaining functions that allow daily activities and tasks such as personal grooming and to promote independence. Think of the OT role as helping to regain fine motor control of hands and rehabilitating above the waist.
- Speech Therapist (officially called Speech Pathologist)–assists in regaining language skills and in rehabilitating swallowing difficulties, as well as cognitive executive functioning skills. Think of the speech therapist role as rehabilitating above the neck.

Another key player in patient care is the case manager, a hospital administrator responsible for working with the patient and the health insurance provider. The case manager manages the transition from critical care hospital to rehabilitation hospital, to home. As part of the transition to home, the case manager arranges the initial outpatient services such as visiting nurses, home health aides, and transportation services.

Support Network

As members of the support team, family and friends must learn to cope with their own suffering while helping the patient deal with the unknown. They have their own diagnosis: fear and helplessness. The patient's support network plays an essential role in the overall treatment.

The road to rehabilitation can seem endless. In the beginning, everyone is on-board and at full attention. As time passes, the attentiveness can wane. Some may drift away entirely. Tending to a loved one through extended recovery can be exhausting. To avoid burnout, set up a schedule for visitors to take shifts so that the burden doesn't fall on a few individuals. Use social media to involve others who can't be physically present to send cards, photos, and messages of encouragement.

When visiting, be positive and upbeat. Laughter and humor can be the best medicine, but let the patient dictate the pace of interaction. Bring items such as games, a deck of cards, books on tape, music. Engaging in activities not only shapes your visit, but also provides stimulation for the patient. Sparing the patient hospital cafeteria food always wins points. Understand, however, that despite your best efforts, the patient is likely to suffer bouts of depression, justifiably so, given the circumstances. With a brain injury, the depression can be organic, stemming from the brain damage itself and treatable only with medication.

The key thing to remember is to be patient with the patient. You may notice behavioral changes. People with brain injuries often become outspoken and unfiltered. Let the patient process all the emotional stages, denial, grief, anger and ultimately acceptance. Other suggestions:

- Strive to be nonjudgmental.
- Make concrete offers of help (laundry, childcare, errands).
- Listen attentively to what the patient says.

Resources:

Listed below are organizations that offer assistance, guidance and services. In addition, each state has its own brain injury association, all of which fall under the umbrella of the National Brain Injury Association of America. Be wary of Internet search results on brain injury, as many of the listed sites are law offices looking for potential clients.

http://www.biausa.org/
http://www.traumaticbraininjury.com/
http://www.headinjury.com/
http://www.ninds.nih.gov/disorders/tbi/tbi.htm