

JOURNEY TOWARD RECOVERY

A Brain Injury Guide for Families



BY THE San Diego Brain Injury Foundation

Serving brain-injury survivors and their families since 1983

www.sdbif.org

DEDICATION

To courageous survivors, dedicated medical professionals, and generous caregivers.

JOURNEY TOWARD RECOVERY

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*“Recovery unfolds like the dawn, spreading glory on darkness,
teasing hope from despair.”*

- Charles Hansen, Brain-injury Survivor

INTRODUCTION

This guide has been written for anyone who has been touched by brain injury, whether mild or severe, family or friend. It is the goal of this guide to provide survivors, caregivers and loved ones with step-by-step tools they need to travel the incredible journey of recovery. This guide is not meant to be read at one sitting. We hope you will find the information you need at the time in which you need it.

People like you—including brain-injury survivors, their families, caregivers and medical experts—have provided useful information for someone taking the journey alongside a brain-injury survivor. The guide has been designed to assist you from the moment you hear the “news” through all the stages of recovery. We hope this guide can be your one source, freeing you from sifting through dozens of pamphlets, leaflets and books to get the information you need.

We also want to help you with issues that can arise after survivors are considered “recovered” by their doctors. The survivor may still struggle with a new way of life, a new sense of identity, changed relationships, job placement, daily tasks, and emotions. These issues can affect caregivers and loved ones as well.

One of the most significant factors contributing to a survivor’s recovery from brain injury is the involvement and support by the family. Though difficult, the journey can bring families together and help us appreciate what’s important in life. Survivors not only need to receive support from their caregivers and loved ones, but also *they* need to support others.

This reciprocal relationship will serve to strengthen the resolve of anyone touched by brain injury.

CHAPTER ONE: WHAT HAPPENED?

THE CRISIS BEGINS

It starts out as an average day. You are at home doing laundry, in the car running errands, or at work. The phone rings, you answer it, and the voice on the other end says something, but the words don't register. You ask the person to repeat it.

"There has been an accident," the voice says. "Are you the wife of Frank Smith?" You say yes. "Frank has been in a car accident and we need you to come to the hospital right away."

This statement takes your breath away. Is this real? You go on autopilot and get in the car, driving in a daze the whole way. Thoughts race through your head, "Is he alive?" "What condition will he be in?" "How am I going to handle this?"

After what seems like an eternity, you arrive at the waiting area at the hospital emergency room. No one can tell you anything except that there was a bad accident and Frank is in emergency surgery. After a while, the surgeon approaches you and says that it doesn't look good. "Frank has sustained a severe injury to the head. If he survives, he may not be able to speak or walk," the doctor says.

Your mind repeats that sentence again and again, but the meaning doesn't register.

WHAT YOU MAY BE FEELING

Perhaps at this point, you start to panic. You feel as if your whole world is collapsing around you. No one has prepared you for this! You have never been through something like this before and have no idea what to do. Your feelings go from panic to fear to anger to confusion and back again. The doctors are taking good care of Frank, but you feel so helpless. All you can do is wait and pray.

After a night of little sleep, you start to face reality.

You begin thinking of the possibilities:

Frank may not survive;

He survives but is in a coma;

He's not in a coma, but he is paralyzed and can't speak;

He is not paralyzed, but he can't function the way he used to.

The list goes on and on. You imagine how this situation will affect your family. Frank will no longer be able to support you financially or emotionally. In fact, you may have to support him. In addition to the emotions you felt yesterday, you now feel overwhelmed, stressed and devastated.

What you need to know is that these emotions are completely normal. You may even experience some that are not listed here.

Questions swirl about you:

Where can I go for help?

Who should I contact?

What steps do I follow to take care of Frank and myself?

The following chapters will try to answer these questions.

CHAPTER TWO: FIRST STEPS

As you struggle to understand your loved one's injury, three steps are especially important:

- 1. Designate a family spokesperson*
- 2. Identify medical team members and their roles*
- 3. Gather information*

DESIGNATE A FAMILY SPOKESPERSON

Being the spouse or closest kin of a brain-injury survivor does not necessarily mean you will be the best spokesperson for the family. The role of spokesperson is important because he or she is responsible for relaying information between the medical team and the family. He should be the main contact whenever information needs to be transferred. The information needs to be explained promptly and accurately. This may involve making several phone calls a day. Emotions, work

pressures, and other stresses may make it difficult for some family members to assume this role. Whether it is you or another family member, make sure that person has the motivation and availability to perform the task.

Identify Medical Team Members and Their Roles

You will meet several members of the survivor's medical team, all of whom have important roles. Be sure to write down the names and phone numbers of every member on the team. Your team may include some or all of the following (in order of usual appearance):

Emergency Physician—doctor responsible for providing immediate care when patient is brought to the emergency room; will coordinate subsequent care

Attending Physician—the doctor functioning in the primary role

Neurosurgeon—can also be responsible for coordinating medical treatment of the patient, deciding whether surgery is necessary and performing surgery when needed

Neurologist—doctor specializing in problems in the nervous system; may help coordinate neurological care, medications, and testing. Neurologists may also coordinate neurological rehabilitation and management of neurological issues over the near and long term.

Anesthesiologist—monitors the patient's anesthesia during surgery

Plastic Surgeon—responsible for reconstruction of damaged skin and supporting tissues.

Physiatrist—doctor specializing in physical medicine and rehabilitation, often responsible for coordinating medical treatment

Primary Nurse—provides and coordinates patient care, serves as a liaison to the medical team, and is often a patient advocate. Nurses are very knowledgeable and good resources for information.

Respiratory Therapist—ensures that the patient can breathe adequately

Physical Therapist—helps the patient regain movement

Occupational Therapist—helps with activities of daily living

Speech Therapist—helps the patient return to normal or alternate forms of communication, including cognitive and/or memory strategies

Social Worker—assists patients and families with social, emotional or financial problems resulting from the injury

Nutritionist—consults with the patient and family about eating habits that would most benefit the patient

Neuropsychologist—responsible for testing and tracking the patient's thinking abilities

Gather Information

With all of the commotion and confusion surrounding a brain injury, you will want to gather as much relevant information as possible and keep that information organized and accessible. A good person to keep this information is the designated family spokesperson. Some items to gather are anything related to the survivor's actual injury, medical history, medications, hospitalizations, insurance records, legal and financial information, and a journal of questions, answers, and concerns. By gathering information in an organized manner, you will begin to reclaim some feeling of control in your life.

CHAPTER THREE: GETTING INFORMED

LEARNING ABOUT BRAIN INJURY

During this stressful time, family members and loved ones may feel confusion about what's going on. Learning as much as possible about all aspects of brain-injury

will help you feel more in control and help other family members to understand what is going on. By getting involved, you also create a support system for the brain-injured individual. Never be afraid to ask questions! The Internet is a wonderful resource, as are libraries, local colleges and universities, community centers, government offices, hospitals and medical team members.

Your community may have an organization like the San Diego Brain Injury Foundation to guide you toward helpful information and find others who are also struggling with brain-injury issues.

For those who want to know more about the occurrence and nature of brain injuries, this chapter will provide you with relevant data.

Types of Brain Injury

- Traumatic
- Non-traumatic

“My injuries were serious. My jaw was broken in three places, all my teeth were lying in my mouth and my nose was gone. I have had a total of four major surgeries to reconstruct my face, complete with 48 screws and six metal plates in my mouth and jaw. I lost a fifth of my brain in that incident and was in a coma for three and a half months. I am proud to say that I have gotten some gross movements back in my left side and I can walk on my own.”

- R. T., Brain-injury Survivor

Many people are confused about traumatic versus non-traumatic brain injury. Isn't all brain-injury “traumatic?” In medical terms, an injury that occurs from physical impact is traumatic; one with a biological origin, such as disease or heredity, is non-traumatic.

Traumatic brain-injury typically occurs as a result of an accident: motor vehicle, fall, bicycle, or sports-related. It also can occur as a result of intent: gunshot wound (self-inflicted or by others) or other physical assault. Non-traumatic brain

injury may result from stroke, aneurysm, tumors, degenerative neurological disorders, loss of oxygen, and other conditions.

Symptoms of Brain Injury

Whether traumatic or non-traumatic, brain injury can result in a variety of symptoms: some short-term, and others prolonged or permanent. It is important to remember that each individual will exhibit different symptoms (even some not mentioned below) and to varying degrees. We will describe three categories of symptoms:

- Physical
- Cognitive
- Emotional/Behavioral

Physical symptoms are often those that are most obvious to survivors and their loved ones. Treatment is typically straightforward. Common **physical symptoms** include:

- Fatigue
- Seizures
- Loss of motor control and coordination
- Sensory problems (e.g., noise sensitivity, visual misperceptions, blurred vision)
- Difficulty with speech
- Headaches
- Dizziness
- Bladder and bowel incontinence
- Nausea and vomiting
- Difficulty sleeping
- Balance difficulties
- Loss of smell/taste

Cognitive symptoms can be a source of great frustration both for the survivor and caregivers. These symptoms are related to intellect, language, memory, mental organization, and more. Some **cognitive symptoms** include:

- Loss of short-term or long-term memory
- Difficulty concentrating
- Confusion
- Slowed thinking
- Reduced organizational skills
- Difficulty completing tasks
- Impaired judgment
- Short attention span
- Lack of initiative

Emotional and behavioral symptoms also require a great deal of patience and understanding from the survivor's loved ones. These symptoms can be a direct consequence of the brain injury or develop as a result of the patient's emotional struggle dealing with his impairments. **Emotional/behavioral symptoms** include:

- Aggression
- Mood swings
- Depression or withdrawal
- Loss of interest in activities
- Impulsive behavior
- Lack of sexual inhibition
- Restlessness
- Increased frustration

Any of these symptoms can affect other symptoms. Even mild symptoms can interfere with a person's ability to function effectively at work, in personal relationships, and in daily life.

Incidence, prevalence, demographics

Brain injury strikes over 1.5 million people per year. That's one injury every 20 seconds. Approximately 500,000 of those injuries require hospitalization, and close to 75,000 injuries result in death. Between 70,000 and 90,000 survivors sustain injuries that are long-term or permanent. There are currently over 5 million Americans living with disabilities resulting from brain injury. Although these figures can be discouraging, they may also help caregivers realize that they are not alone.

Anyone can get a brain injury, although it is more common among males between the ages of 15-24, and adults over age 75. Motor vehicle accidents are the leading cause of brain injury, accounting for 44 percent of all cases. Falls are the second leading cause, accounting for 26 percent of all brain injuries. Falls are, however, the leading cause of injury in the elderly. Assaults with and without firearms account for 17 percent of injuries. (*Brain Injury Association of America, 2003*).

How the Brain Works

For many brain-injury survivors and their loved ones, it may be helpful to learn about the areas of the brain that have been damaged, and what can happen as a result of the damage. Although a great deal is known about brain function, there is still much more to be learned.

In healthy adults, the brain is composed of neurons (nerve cells), which are essentially communication fibers. Neurons carry messages throughout the brain and body, and the brain uses these messages to perform various functions, including moving, breathing, thinking, speaking, sensing, emotion, and most of the things our bodies can do. The brain is protected by cerebrospinal fluid, three linings (meninges) and the skull.

The brain itself is divided into left and right hemispheres. Within each hemisphere are four sections, or lobes: frontal, occipital, parietal, and temporal. Toward the base of the brain are the cerebellum and brain stem. Each section of the brain has certain functions associated with it, as described below.

Frontal lobe

- Planning
- Problem solving

- Initiative
- Judgment
- Self-awareness
- Organization
- Attention
- Personality

Occipital Lobe

- Vision

Parietal Lobe

- Visual perception
- Spatial perception
- Identification of shapes, sizes, and colors
- Sense of touch

Temporal Lobe

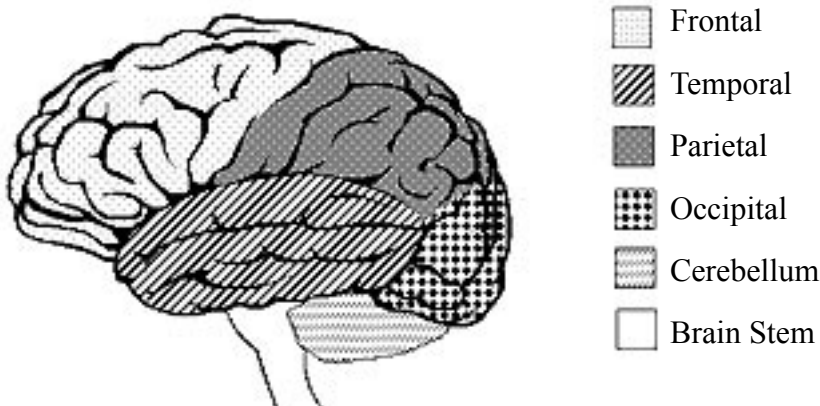
- Memory
- Language
- Organization
- Hearing

Cerebellum

- Motor skills
- Balance
- Coordination

Brain Stem

- Heart rate
- Breathing
- Arousal and consciousness
- Sleep and wake cycles
- Attention and concentration



Injury to any of these areas can interfere with the functions mentioned above. Symptoms can vary depending upon the individual, how severe the injury was, and even which hemisphere was involved. In general, injuries to the left side of the brain can affect movement of the right half of the body, language difficulties, depression, and impaired logic. Injury to the right hemisphere can result in difficulty moving the left side of the body, visual-spatial problems, changes in creativity, and decreased awareness of defects.

Classification and Levels of Brain-injury

Your medical team will use different measures to classify the severity of the brain injury. Two of the more common tests used to assess brain injury are the Glasgow Coma Scale and the Rancho Los Amigos Scale.

Glasgow Coma Scale

This scale is often used at the emergency scene or at the emergency room and measures three main responses: eye opening, best motor response, and best verbal response. These are graded using the numerical system below. The lower the score, the more severe the injury. However, this scale does not predict how well a person will recover or regain their functioning.

GLASGOW COMA SCALE

Response	Score
<i>Eye Opening</i>	
Spontaneous	1
To speech	3
To pain	2
None	1
<i>Best Motor Response</i>	
Obeys commands	6
Localized movements	5
Withdraws	4
Abnormal bending and flexing	3
Involuntary straightening and extending	2
None	1
<i>Best Verbal Response</i>	
Is oriented	5
Confused conversation	4
Inappropriate words	3
Incomprehensible sounds	2
None	1

Rancho Los Amigos Scale

This test is used to assess cognitive and behavioral functioning, and may be used repeatedly during the course of rehabilitation. The scale consists of three levels,

and is helpful for determining how a patient is progressing. Each level is briefly described below.

Level 1—*No Response.* The individual appears to be in a deep sleep or coma, does not respond to any stimulus, including voices, sounds, light or touch.

Level 2—*Generalized Response.* The individual remains primarily asleep, but may respond to certain stimuli such as pain. Movements do not seem to have any purpose. Eyes may open but do not focus on anything in particular.

Level 3—*Localized Response.* The individual remains alert for several minutes at a time and responds more consistently to general stimuli such as turning the head to noise, looking at people, or squeezing a hand when asked.

Level 4—*Confused and Agitated.* The individual is confused and agitated about where he or she is and what is happening around him or her. The slightest provocation can lead to aggression, restlessness, or verbal abuse. Conversations may be confused or coherent.

Level 5—*Confused, Inappropriate, Non-agitated.* The individual is confused and may not make sense in conversations. Agitation is no longer an issue, although the individual may experience some frustration as memory begins to return.

Level 6—*Confused, Appropriate.* The individual's speech makes sense and he or she can perform simple tasks such as getting dressed, eating, and brushing teeth. Knowing when to start and stop an activity may be difficult, as well as learning new things.

Level 7—*Automatic, Appropriate.* The individual is able to perform all self-care activities and is coherent. He or she may have trouble remembering recent events. Judgment and problem-solving abilities may be impaired, although the ability to learn new information is improved.

Level 8—*Purposeful, Appropriate.* The individual is independent and can process new information. Judgment and problem-solving abilities are restored. Some problems with short-term memory and judgment in unusual situations

may be evident, but typically don't interfere with daily life.

As patients improve after brain injury, they typically will move from one level to the next. However, it is common for an individual to exhibit symptoms in more than one level at one time. There is no set time period for remaining at one level or another—each individual will progress differently.

TREATMENT AND REHABILITATION

Depending upon the severity and location of the brain injury, the patient may spend time in any of several types of care units, undergo several forms of diagnosis and treatment, and receive various kinds of long-term or follow-up care. Following the initial visit to the emergency room, most patients will undergo extensive care in the hospital, followed by treatment in a skilled nursing facility, nursing home, or in the patient's own home. Many types of equipment and procedures will be used at each stage of recovery, and the length of recovery will vary.

The Hospital Stay

A patient with moderate to severe brain injury can expect to spend several weeks or even months in the hospital. There are two main units in the hospital that provide comprehensive care for the brain-injury patient: the intensive care unit and acute care. The medical team in each unit will use several tests to evaluate, monitor and treat the patient.

Types of Care

Intensive Care Unit (ICU). This is an inpatient unit where patients with moderate to severe injuries are taken following the emergency room. The goals of the ICU are to stabilize the patient, manage his care, and prevent medical crises.

Acute Hospital Care. Once a patient is stabilized, he may be transferred to a regular hospital unit. Acute care is also inpatient and still provides essential care for the patient's well-being. The patient may receive care and treatment

from members of the medical team such as the physiatrist, various therapists, rehabilitation nurses, neuropsychologists, and social workers.

Rehabilitation

“During the surgery that followed, complications set in resulting in aphasia, which essentially erased Don’s prior ability to speak, read, write and do math. He knew what he wanted to say, but any words other than ‘yes’ and ‘no’ came out as gibberish. Even something as simple as the alphabet was no longer recognizable and had to be relearned during hours of intensive rehabilitation.”

- Family Member

Following acute hospital care, patients will likely undergo extensive rehabilitation to regain everyday functioning. The types of rehabilitation required will depend upon the location and extent of the injury as well as on the individual patient’s needs. Length of rehabilitation will also vary, from several weeks to several months, possibly even years.

Types of Rehabilitation

Patients may undergo one or more of several types of therapies:

Physical therapy—Help regain physical movement and function

Occupational therapy— Help regain fine motor skills

Speech therapy— Help regain normal or alternate forms of communication, may include assistance with memory and thinking process

Cognitive rehabilitation—Address difficulties with memory, attention, planning, problem-solving, organization, behavior, and social communication

Each of these types of therapies is performed or managed by the

corresponding therapist, as described in Chapter Two.

Rehabilitation Settings

The types of rehabilitation described above may be performed in a variety of settings. The location will depend upon the needs of the patient, the recommendations of the medical team, and, possibly, insurance coverage.

Acute Inpatient Rehabilitation—Follows acute hospital care, focuses on intensive cognitive and physical therapies in the early months after injury. May be based in the hospital or in specialized skilled facilities.

Subacute Rehabilitation—Often performed in a skilled nursing facility or nursing home, and focuses on less intensive rehabilitation over a longer period of time.

Day Rehabilitation (Day Hospital, Day Treatment)—Takes place in the hospital as a structured program, but the patient returns home at night.

Outpatient Therapy—Typically for patients who do not require inpatient treatment. May include those who have progressed but need assistance with more complex tasks or those whose impairments are not severe enough to require inpatient treatment. May take place in the hospital, skilled nursing facility, or other settings.

Home Treatment—Some hospitals and rehabilitation centers will provide rehabilitation within the home.

Community Re-entry Programs—Designed to assist the patient regain skills needed to return to independent living and work. Therapies focus on higher level motor, cognitive, and social skills, and can take place in the home or in a rehabilitation center.

Independent Living Programs—Provide housing for brain-injury survivors, with the goal of helping individuals attain independent living. Programs may vary in levels of assistance, depending upon the needs of the individual.

“I had two good words. I could finally say ‘cat’ and ‘dog’.”

- D. S., Brain-injury Survivor

Selecting a Rehabilitation Program

As with any form of treatment, it is essential that family members research different hospitals, rehabilitation programs, treatment centers, and personnel. A facility or program that helps one survivor may not be as helpful to another individual. In addition, once a program or facility has been selected, family members should continually monitor treatment and progress to ensure that the appropriate treatment is being received. Many communities offer assistance in providing care, as well as helping family members locate qualified specialists.

Some of the questions family members should ask when selecting a rehabilitation program are:

- Does the program specialize in brain injury?
- Does the program address the patient’s and family’s needs?
- Does the program offer a continuum of rehab programs/services to address the needs of the brain injured over time?
- Can they give you good references or referrals from patients who have gone through the program?
- What does the program cost? Is it covered by insurance?
- Can family members observe the program?
- How are family, friends, and caregivers involved with the program?
- Are there support groups for the family?
- Are the facility and staff members licensed, and if so, by whom?
- Is the program accredited by an internationally recognized organization?
- What other accreditation does the program have?
- What is the staff turnover rate? (If the staff is continually changing, that

may indicate problems with the facility.)

- ❑ Can changes to the program be made if requested by a family member and if it is in the interest of the patient?
- ❑ Is the facility clean and pleasant?
- ❑ Is the staff professional and friendly? Do they seem to care about the patients?
- ❑ What is the procedure for discharging the patient?

There are clearly many questions family members can and should be asking when considering a rehabilitation facility, and the list above should not be considered comprehensive. Your local hospital and community health centers should be able to provide you with a list of rehabilitation providers. Information can also be obtained on the Internet or through national health organizations.

How to Make Things Easier for Everyone

There are some things caregivers and family members can do to minimize stress on everyone: the patient, other family members, the medical team, and yourself.

If the patient is in the confused and agitated state, minimize his stimulation. This includes limiting flowers, television, visitors, phone calls, and even physical contact. In fact, a gentle touch can be extremely agitating to a patient in this state. Speak in a calm, slow manner and in simple sentences. However, do not talk down to the patient. Limit visits to the morning hours, when the patient may have the most energy. This applies to after the patient returns home, as well. Encourage visitors to briefly ask the patient how he or she is doing, then to move onto other topics of conversation. If the patient wants to talk about the injury, she will.

Let the medical team do their job. You may know the patient, but they know brain injury. You can do your research, make suggestions, and ask questions. Actually, we encourage that you do so. Just realize that your medical team is doing their best for the patient. Follow their recommendations and adhere to hospital rules. Ask each member of the medical team how and when she prefers to be contacted should you have a question. Ask who to contact in an emergency or if you have a question that

can't wait. Write down all of your questions and the answers you are given. Try to realize that members of your medical team are human and have their own pressures and concerns. A little morale booster goes a long way—send flowers, write a thank-you note, or just smile and tell them you appreciate what they are doing.

Take care of yourself! See Chapter Five for ideas on coping. If people offer to help, let them. It will not only relieve some of the burden on you, but it also will let others feel useful. Feel free to ask others to help, as well. Talk to friends, family, social workers, and other professionals about what you are going through. Join support groups and keep yourself occupied.

CHAPTER FOUR: THE PATIENT'S EMOTIONAL JOURNEY

"We act sweet, we pick up after ourselves, we get to [survivor group] class on time...you'd think everything is wonderful and good! But it's NOT! I can't do what I used to do—I can't even be how I used to be. The one thing I've been scared of is that this new life would be empty, hard and meaningless. The one thing I don't want to say—and I'm scared I'll mean it someday— is that I'm sorry or mad that they saved me."

- Charles Hansen, Brain-injury Survivor

WHAT THE SURVIVOR MAY BE FEELING

Perhaps the most disturbing to survivors who have sustained a brain injury is the loss of identity. Many of us take for granted the things with which we identify ourselves: our job, our hobbies, our relationships and roles. Imagine all of a sudden not being able to go to work, drive a car, cook a meal, play a game of basketball, help your children with their homework, console a friend, go for a walk, or even hug your family. Not only that, but you require assistance from others for even the most basic skills. Brain-injury survivors must come to terms with their new limitations, new roles, new sense of who they are, and where they fit in. The person she (and you)

knew before the injury has been replaced by someone who is, in essence, a stranger. This can be more difficult to deal with than the physical limitations.

Many times, an individual who has suffered a brain injury will experience feelings that others would consider natural, such as **frustration**, **disappointment** and **depression**. However, injured individuals may also experience feelings that come as a surprise for family members and loved ones. Along with the brain injury comes a whole new set of circumstances. Without the ability to care for himself, the patient may begin to feel **useless** and **helpless**. Having to rely on someone else to take care of one's basic needs can make the patient feel like a **burden**, no matter how good the caregiver is at assuring the patient he isn't.

One of the issues that brain-injury survivors frequently encounter is that they do not appear physically disabled. In fact, their disability may be solely cognitive in nature. Without the physical reminders, others may not be aware of the patient's limitations and can act intolerant, causing the patient further **embarrassment** and frustration.

The patient may or may not express these feelings. Putting yourself in her shoes, and putting aside your own issues and wants, will help you really understand what the patient needs.

WHAT THE PATIENT NEEDS FROM FAMILY AND FRIENDS

Every brain-injured individual is different. It may take some trial-and-error to figure out what the patient needs. This may take some time and cause temporary uneasiness when mistakes are made, but by learning what the patient needs, you can help speed up recovery. Based on comments from other brain-injury survivors, we have compiled a list of some of the qualities patients found most helpful from their caregivers and loved ones.

Patience—It will likely be difficult for patients to re-learn tasks, be able to hear what you are saying, remember the simplest things and follow the proper way to behave. Muster all of your strength to avoid pushing them, getting annoyed, or doing things for them that they can do for themselves.

Respect—Keep in mind that a person with a brain injury is still a

human being and deserves respect. For example, if a person is unable to communicate, we may assume that he does not understand what is going on around him. Someone who cannot speak may be perfectly able to hear and understand language. Speak to the adult patient as an adult and treat her as an adult. In the presence of others, show respect for the patient. Share in her joy and accomplishments, no matter how small they may seem to you.

Understanding—in order to practice patience and respect, caregivers and loved ones need to adopt a well-informed perspective. This means not only learning about brain-injury and its consequences, but also being able to show the patient and others that you are aware of and empathize with her situation. Patients do not want your pity but rather an acceptance of who they are, even with their limitations and abilities.

Knowing When and When Not to Push—This can be very tricky. Different patients will respond to different types of encouragement to recover their abilities. Use the patient as your guide. Begin by gradually encouraging the patient. At each step of the way, either ask the patient how he is doing or observe his behavior and facial expressions to determine if you need to back off. The goal is to help him try to the best of his ability while minimizing the frustration that accompanies the effort. You can acknowledge how difficult this process is and give him positive feedback.

Flexibility—You have figured out the right way to encourage the patient. Even if one day you unwittingly upset her, you may have done nothing different than before. Brain-injury survivors can experience mood changes. What worked once may not work another time. The range of emotions and challenges the patient experiences changes throughout the recovery process. You may need to change your routine or how you behave.

Sense of Humor—Many people in the company of a brain-injury survivor are so afraid to offend the survivor that they clam up or act stiff and distant. Remember that brain-injury survivors spend much of their time “surrounded” by their injury. Sometimes, lighten the seriousness of the moment by saying or doing something to make the patient laugh. Naturally, you won’t make

jokes about her limitations. Bring a joke book, a cassette or video of her favorite comedian. You may still offend someone, but that's the chance many comedians take! Feel free to laugh if the patient makes a joke!

Love—This goes without saying. If you are having trouble expressing your love for the patient, try visualizing the times in your life where you felt the most love for him and try to regain that moment. Think of things about the person that you used to love and that you love now. Imagine how good it will feel for the patient to feel loved. Along with laughter, love can do wonders for helping the patient heal.

CHAPTER FIVE: COPING

“Whenever someone would ask how I was holding up, I would politely smile and say ‘fine.’ They knew, as well as I, that I wasn’t fine. In fact, I was exhausted and felt like a raging volcano ready to erupt. It was when my 12-year-old daughter almost cowered at my asking her if she finished her homework that I realized I had been snapping at her relentlessly. Now I take better care of myself. I talk to a psychologist. I started bike riding with my daughter, and I feel I can now be a better mother.”

- J. P., Caregiver

Just as important as the patient's well-being is the well-being of his or her support group. This includes family, friends and caregivers. It is easy for the loved ones of a brain-injury survivor to get engrossed in caring for that individual and putting their own needs and wants aside. What many people *don't* realize is that by not taking care of themselves, they are also hurting others. If a person burns herself out to the point that she can no longer function, then how good a caregiver can she be? Think about what would happen if you burned yourself out and weren't available for your injured loved one when you were really needed? And as human beings, we have the need and the right to live our own lives and take care of ourselves to a

reasonable extent.

The first step in learning to take care of yourself is learning how to cope with your feelings. Acknowledge that you have them, that there is a reason why you have them, and that you need to do something positive to manage them. We will suggest ways for you to do this.

The next step in taking care of yourself is knowing what to expect from yourself and from others. If you expect someone with a broken leg to go for a run with you, you will only set yourself up for disappointment and frustration. Similarly, you cannot expect someone with a brain injury to function the way he used to, or even the way you think he ought to now. Part of knowing what to expect is learning not to expect anything other than one's best efforts. If a brain-injury survivor is taking months to utter one word, then perhaps that is the best he can do. If you are disappointed in yourself for not being with the patient seven days per week, give yourself a break—you are probably doing your best as well. When you don't have high expectations, you learn to appreciate and be happy with the little things.

The third step is learning to strike a balance between encouraging progress and accepting limitations. Look for support groups and other resources to help you create this balance.

ACCEPTING AND MANAGING YOUR FEELINGS

Many of the emotions you felt during the first few days may last for days, weeks, or even months. You may still have moments of panic, fear, anger, confusion, frustration, stress, and feeling overwhelmed. What is helpful to know is that, with time, most of these feelings will subside. It is important *not* to suppress your feelings or blame yourself for having them, or even wonder why it's taking so long for the feelings to go away! There is a reason you are having them, and they will lessen when they are ready.

One common emotion that family members experience is **denial**. They refuse to acknowledge that things are as bad as they are. They believe that they are handling things just fine, and that everything will be back to normal soon. Although this does not represent reality, it can be a healthy, short-term way for some people to cope. In a sense, denial gives those experiencing it a “vacation” from the constant turmoil they

are feeling. In the same way an actual vacation can renew and refresh an individual, this sort of mental vacation can also prepare individuals for handling upcoming issues. Denial can be a problem, however, if the family member has unrealistic expectations about recovery and/or interferes with the medical team.

As a family member, you may experience tremendous feelings of **guilt**, and may either blame yourself or others for allowing the patient to do something that contributed to her injury. A certain amount of guilt is normal, but extreme guilt and/or blaming others can be damaging. Families need to keep things in perspective: don't dwell on the past but try to focus on the present.

There are things you can do to deal with your feelings appropriately. Instead of taking your anger out on yourself or someone else, utilize the many stress-reducing strategies as described later in this chapter.

What to Expect During the Recovery Process

"I was unable to drive for several years. After finally getting my license reinstated, my difficulties with direction and short-term memory made driving alone extremely difficult and frightening."

- D. S., Brain-injury Survivor

From the patient

The patient is understandably going through a lot, both physically and emotionally. Each injury is different and each patient is different. The patient can be a trooper and roll with the punches, or she can be devastated. There may be times when the patient is in denial, is depressed, and is not motivated to try to recover. There may be other times when the patient is so anxious to get better that she will put in all of her effort to attain the goal of recovery. There may be times when the patient needs a shoulder to cry on, a coach to push her to recover, or merely to be left alone. Family and caregivers may at times serve as emotional "punching bags" for the patient. In fact, the patient may feel so loved and reassured by certain family members that she feels safe enough to express feelings this way. On the other hand, many patients will be surprisingly cheerful.

No matter how the patient acts and reacts, he will need to know that family and friends are available for support. This includes encouraging him when appropriate, leaving him alone when asked, and making a joke or two to cheer him up. If a patient does take some anger out on family or friends, it is important that everyone not take it personally.

From yourself

Most family members and caregivers will expect themselves to be superheroes. You may expect yourself to be available at the drop of a hat, to be encouraging, understanding, patient, supportive, and all of the other qualities the patient needs. And you will have to accomplish all of this while maintaining a life of your own.

While these qualities would be ideal, it is not realistic for caregivers to expect themselves to be all of these things all of the time. Caregivers can expect to experience the joys of seeing someone accomplish something they never thought they would accomplish. However, caregivers can also expect to lose their cool, to get impatient, to want to give up, to leave, and to break down. We are human—these things are going to happen. That is why it is so important for caregivers and those closely involved in the recovery process to take regular breaks.

Learning to Strike a Balance

“I was by his side 24 hours a day for two months. I got little sleep, ate poorly, and practically cut myself off from the rest of the world...It finally hit me when I suddenly panicked and had to get out of the hospital, right away. I drove for two hours, collected my thoughts, and found that for the past two months I had lost my identity, just as he had...I had become just one of the pieces of equipment in the hospital. During that drive I made the difficult decision that I had to limit my visits and make time for myself.”

- C.R., Caregiver

There is an art to maintaining a balance between fulfilling your obligations to others while being true to yourself.

Taking care of yourself

Each person needs different things in order to feel taken care of. Some may need weekly massages, some may need a round of golf, some may need a shoulder to cry on, and some may want to go shopping. Whatever brings you the greatest sense of comfort (as long as it is not destructive), should be done on a regular basis. Turn off the ringer on your phone and have someone else (the family spokesperson) update family members on the patient's condition. Assign different family members to different tasks and hospital shifts.

Strategies such as deep breathing, leaving the room, going for a walk, and squeezing a "stress" ball can help you deal with your emotions at that moment. Helping others should make you feel energized. If not, you need to take more breaks and do more for yourself.

It is often very helpful for family members to share their feelings with each other, with friends, other family members, or professionals. The important thing is to get them out! Speak with others who have gone through something similar. Join support groups. Encourage others to ask questions and to express their feelings as well. At minimum, keep a journal (written or on tape) to express everything you are feeling.

Your local hospitals and community centers can provide you with information on caregiving, and the Internet has several sites for caregiver support. We strongly suggest you contact these or other agencies and get involved in a support group.

Empower Yourself

The suggestions in this section can apply for both the caregiver and the patient. During stressful times such as this, many people feel a loss of control. Although it is not possible to control the person's brain injury, recovery, treatment, behavior, emotions, etc., it is possible to regain a sense of control simply by taking initiative for the things that *are* in your control. This may include doing things to improve your health and well-being, helping others, and making life simpler for yourself.

Exercise

There are few health experts, if any, who would argue that an otherwise healthy individual shouldn't exercise. Under a physician's guidance, exercise can alleviate stress, improve your health, help your self-esteem, and give you a sense that you are accomplishing something positive. The latter benefit may be most relevant for caregivers who are feeling helpless.

Volunteer Your Time

There is probably nothing more valuable than helping others without expecting anything in return. If for whatever reason you cannot help your loved one to the extent that you desire, you can volunteer your time to do something on a more philanthropic level. This helps others lets you feel useful and needed. You may also help the patient indirectly by volunteering for a brain injury-related cause.

Use Lists, Computers, Timers and Post-it Notes

Brain-injured or not, when people are stressed, memory often suffers. Instead of trying to force yourself to remember something. Write everything down. This way you can help clear your head. Take advantage of computer technology for creating journals, to-do lists, and electronic reminders. You will be amazed at how relieved you will be that you do not have to remember a dozen or more items. Your mind will be more available for more important things, like being mentally and emotionally available for yourself and others.

CHAPTER SIX: FINANCIAL ISSUES

“We used up all our savings and had to sell our house because we could no longer pay the monthly mortgage. My wife could not work full-time because she was my caregiver. It was when we contacted an attorney and learned about our options that things turned around.”

- T.G., Brain-injury Survivor

Families going through this crisis know too well the financial burden involved in treating and rehabilitating the patient. What many families don't always consider is how the patient and his family will be taken care of financially for the long term. Insurance typically covers costs associated with treatment and rehabilitation, but families are often at a loss when it comes to planning income sources for future household and well-being costs. Some of the sources for both categories of financial assistance are outlined below.

Funding for Rehabilitation

Private Insurance

Medical costs associated with illness or an accident are covered by private health insurance, either with an individual or group plan. The patient *must already have insurance in place*, because most carriers will not insure a patient after an injury. The amount of coverage, doctors and hospitals covered, and services covered will vary among different policies, so it is important to contact the patient's health insurance carrier to find out specific benefits.

Medicare

Medicare is available to individuals over age 65, or who have a disability, or who have chronic kidney disease. It is administered by the federal government, and applied for through the Social Security Administration. Medicare coverage has two parts. Part A covers hospital services including inpatient hospital services, skilled nursing facility care, and home health care. It does not usually require payment. Part B covers physician services, laboratory services, and outpatient hospital care.

Medicaid

This is a jointly-funded project between the federal and state governments to assist states in providing medical care to eligible needy individuals. Within broad national guidelines, each state establishes its own set of eligibility criteria, type, duration, amount, and scope of services, and rate of payment. Check with the Medicaid program in your state for details about coverage.

Workers Compensation

If a patient is injured while at work, her employer's workers compensation policy can cover much of the services required for treatment. Each policy is different and maintains strict eligibility requirements. These need to be verified with the patient's employer and appropriate state offices. Be sure to find out about pay due to vacation time, sick leave, long-term disability income. Check the possibility of an extended leave of absence being granted, and eligibility for pension benefits. Some insurance policies provide for supplemental income following accidents. Workers' compensation may also provide income in some cases.

Crime Survivor's Compensation

If the brain-injury resulted from an assault or violent crime, the survivor may be eligible for benefits through this program. Approval for benefits is through an application process initiated by contacting the local justice administrative office. Benefits will vary with crime survivor's compensation as well.

Long-Term Sources of Income

Supplemental Security Income (SSI)

SSI is available to disabled individuals (defined according to the Social Security Administration) who have never been employed, have a low income, few assets, or were disabled prior to having contributed to the Social Security fund. Eligibility is based on financial need. SSI benefits are considered a supplement, and the amount paid can vary from state to state. Application is through the Social Security Administration.

Social Security Disability Income (SSDI)

SSDI is available to individuals whose disability occurred within five years of their last employment, and have been employed a specified length of time. Spouses over age 62 may receive benefits, as well as a spouse of any age who is caring for a child who is disabled or under age 16. Widows and widowers over age 50 who become disabled are eligible for this benefit provided their deceased spouse would have met the requisite employment criteria. Unmarried children may also receive

benefits, as long as certain criteria are met. There are no financial requirements for this benefit, and benefits can be received until age 65. After age 65, SSDI benefits automatically convert to Social Security retirement benefits. Application is through the Social Security Administration.

Aid to Families with Dependent Children (AFDC)

This aid is available to families with children under age 18 at home in which one parent is disabled. Certain financial requirements must be met. Application is through the local Department of Social Services.

Other Sources

According to an article on the website for the National Association of State Head Injury Administrators (*NASHIA, 2003*), many states have passed legislation creating programs and services for brain-injured individuals and their families. These programs are typically designed to provide services not available from other state and federal programs. Contact your state legislative office to see if a program like this exists in your state.

CHAPTER SEVEN: LEGAL ISSUES

A brain-injury survivor may have several legal issues to consider, whether or not the injury is the responsibility of another party. It will be helpful for family members to become familiar with some of the laws and acts listed below, as well as others that are not mentioned here.

LAWS RELATING TO BRAIN INJURY

Personal Injury Law

If an individual has sustained a brain injury as a result of the action or inaction of another person or entity, he or she may file a personal injury lawsuit against the person or entity responsible to recover monetary damages. Each personal injury case involves establishing liability and damages. Liability refers to demonstrating that the person or entity being charged is legally responsible for the injury. Damages refer to

the amount of monetary damages, which in turn depends upon the extent or amount of injury suffered. There are certain time limits (statute of limitations) for filing a legal action and failure to meet the deadline permanently prevents recovery in a court proceeding. In addition, the longer the delay in hiring a lawyer, the more stale the evidence becomes, making effective legal action more difficult.

Medical Malpractice

This often results in personal injury and may be handled by a personal injury attorney, but it bears separate discussion. Medical malpractice typically, but not always, results from negligence on the part of the physician or other health care provider. This can take the form of surgical error, improper diagnosis, failure to diagnose, medication errors, lack of informed consent, among other matters.

Signing a physician's consent form does not give the physician the right to perform at substandard levels.

To claim medical malpractice, the brain injury survivor (victim) must establish the health care provider's (defendant) legal duty, that he or she failed to meet the standard of reasonable care relating to that duty, resulting in injury to the survivor.

Before consulting with an attorney, become familiar with the survivor's medical records. The patient has a legal right to view his own records, so this should not be a problem. It is essential to file a claim as soon as possible, so as to avoid the statute of limitations expiring and causing the case to be dismissed as untimely. Each state has a different statute of limitations, so check with a local personal injury or medical malpractice attorney.

Olmstead Act

On June 22, 1999 the United States Supreme Court ruled in *L.C. and E.W. v. Olmstead* that it is a violation of the Americans with Disabilities Act (ADA) to require disabled individuals to be treated in an institution versus in a community-based setting. What this means for the brain-injured patient is that if she wants to receive treatment and/or services in the community rather than in a nursing home, for example, she is legally entitled to do so. If the state refuses, then the state is violating the ADA unless it can provide sufficient reason. The Olmstead decision does not, however, give an individual the right to remain in an institution if the state determines

that individual should be placed back into the community (*NASHIA, 2003*).

Other Legislative Acts

Over the past several decades, Congress has passed a number of acts to protect the rights of disabled citizens. If at any time you feel your loved one is being treated unfairly, be sure to contact a governmental agency, attorney, or go online to find out more about his rights. Listed below are brief descriptions of some relevant acts, along with the year they were passed or amended.

The Fair Housing Act (1968)—prohibits discrimination in the sale, rental and financing of dwellings based on race, color, religion, sex or national origin. Title VIII was amended in 1988 to include individuals with disabilities.

The Rehabilitation Act (1973) —requires vocational rehabilitation agencies to develop an “individualized written rehabilitation program” for each individual receiving services. Section 504 of the Act protects disabled individuals from discrimination in federally assisted programs and activities. Sections 501 and 503 protect the disabled from employment discrimination by federal agencies or federal contractors.

The Employment Opportunities for Disabled Americans Act (1986)—ensures SSI benefits and Medicaid coverage for disabled individuals whose income exceeds “substantial gainful activity” levels.

The Americans with Disabilities Act (ADA) (1990)—prohibits discrimination in employment (for employers of 15 employees or more), public services, public accommodations and services that are operated by private entities, and telecommunications. State and local governments are covered regardless of size.

The Rehabilitation Act Amendments (1992)—recognizes that disabled individuals are capable of making informed decisions, are competent, have many abilities, and want to participate in normal routines. Title I presumes that individuals with disabilities, including those with severe disabilities, are capable of engaging in gainful employment. Title VII establishes standards for independent living.

The Ticket to Work and Work Incentives Improvement Act (1999) — ensures health care coverage, employment preparation, placement services, Medicaid coverage (even while the disabled individual is employed, if desired), and “tickets to work,” which provide access to services needed to maintain employment (*NASHIA*, 2003).

PATIENT AUTONOMY ISSUES

Along with legal and financial considerations that should be attended to are issues related to the patient’s autonomy. Decisions must be made relating to medical treatment, management and use of funds and property, and even designating caregivers for the injured individual’s dependent children. Some of these decisions will need to be made immediately, and some over time. We strongly urge you to seek the advice of attorneys specializing in legal, financial, and long-term issues specific to brain-injured individuals and their families.

Guardianship

A guardianship is a legal relationship between the disabled individual (ward) and a court-appointed individual (guardian). The guardianship is established once a judge determines that the disabled individual is “incompetent,” based on medical documentation. The guardian is given the duty and right to act on behalf of the injured person to make personal, legal, and financial decisions that may affect all aspects of the injured person’s life.

Although appointing a guardian can be difficult and emotional for families, it should be determined as soon as possible whether this is the best option. Family members should consult with their attorney, physician, social worker, and proposed guardian for help in making this determination.

Power of Attorney

This is a written legal agreement by which one person (principal) appoints another person (agent) to act on his or her behalf. The agent is given either restricted or broad authority to make decisions ranging from medical treatment to financial decisions. A power of attorney is similar to a guardianship, except that it typically

requires little, if any, court supervision, and is selected by the brain-injured person. The brain-injured individual must be competent enough to select a valid power of attorney, and that selection must be made very carefully, as the court is not closely monitoring the agent.

Conservatorship

This is similar to a guardianship with the exception that the brain-injured individual does not need to be declared incompetent by a judge. The relationship is still established in the court, however. Conservators are primarily responsible for managing the brain-injured person's financial affairs, but may also extend to issues of personal well-being.

Trusts

The use of a trust can be an additional method for managing the property of an individual incapable of managing it on his or her own. The "trustee" handles the investment and distribution of funds in such a way as to benefit the brain-injured person, and the trustee's conduct is enforceable by law. If trust property requires expert management, a bank or other institution can be named as trustee. Trusts can be designed to be rigid or flexible in how funds are invested and distributed, depending upon the needs of the injured individual.

Estate Planning

Estate planning involves arranging for the management and disposition of an individual's estate following his or her death. This may include the use of wills, trusts, insurance policies, and other devices. Trusts may be created to ensure adequate financial resources for the injured individual after the death of a family member or caregiver.

CHAPTER EIGHT: BEYOND RECOVERY

Many people believe that once a brain-injured person has regained basic functioning that he or she is "recovered" and no longer needs assistance. While that may be true in the sense of physical or occupational rehabilitation, there are still

issues for which the person will need guidance. Even if a brain-injury survivor is capable of living independently, he still has to adjust to a new way of life, a new sense of identity, new relationships, and changes in his job skills or work relationships. This may sound trivial compared to what the patient previously went through, but these can be huge issues for the survivor.

Practical Issues for the Patient

Here are some typical challenges patients face.

Adjusting to New Realities in Daily Life

Imagine you are a brain-injury survivor and have just been labeled as “recovered” by your physician. You still have problems with your memory, attention span, organization skills, depression and planning. You can’t hear very well, and you can’t walk without a cane. On a typical day, your alarm goes off, but you don’t hear it, so you wake up late. Not only that, but you allotted yourself the same amount of time it used to take you to get ready in the morning, except that now it takes you over twice as long. You can’t remember where your socks are. You forgot how to use the toaster, and you forgot to take your medication.

You can no longer drive yourself to work or to run errands so you have to take a bus, but you forgot how to get to the bus stop and even which bus to take. You’re getting tired from walking around the neighborhood with a cane looking for the bus stop, and once you get there, people are staring at you because you walk “funny.” You forget the name of the people you work with. Perhaps you have been “demoted” to a simpler job. Now it’s time to go home and cook dinner, but you can’t get yourself organized enough to put a meal together, so you eat some crackers. You have trouble getting your pajamas on, forget to set the alarm, and you can’t fall asleep.

For some, this may sound extreme, and for others, this sounds like a “good” day. A brain-injury survivor may have to contend with scenarios just like these, and even though the scenarios will get easier, it may take some time. There may also be some things that will never be the same, such as his memory, organizational skills, and the ability to walk unaided. There will be stares and even comments from strangers, and awkward comments from friends, acquaintances, and family members.

The brain-injury survivor will be seen in a different light by almost everyone around him. Some people may feel pity; others will feel admiration. If the person appears normal physically but has cognitive difficulties, people may even feel annoyed and impatient with his limitations. Hopefully, though, most people will treat the brain-injury survivor as the individual he has always been and is now.

Regaining a Sense of Identity

“My life as a husband, a father to my 9-year-old son, an industrial consultant, and fiction writer changed forever. Some aspects for the worse, but some for the better.”

- D.M., Brain-injury Survivor

As mentioned in Chapter Four, one of the major issues brain-injury survivors often find they can no longer define themselves by their jobs, hobbies, relationships, social status, or possessions. They must find a way of redefining themselves. They learn to focus on what they are able to do now. A father may not be able to help his kids with their homework, but he can now spend more time with them and laugh. He may not be the shrewd businessman he once was, but he has discovered his compassionate side and wants to help others. He can still joke and make people laugh, and this comforts those who remember him for his humor. He cannot dance without a cane, but he tries, and has learned to be more loving with his wife.

The process of regaining a sense of identity will be different for everyone. Some people may want time to figure it out on their own, and others will want plenty of support and guidance from their families. Whatever the method, families should respect the needs and wishes of the survivor.

Reforming Relationships

A woman may identify herself as a wife, mother, sister and supervisor. With the injury comes a change in identity, a change in roles, and a subsequent change in relationships. The relationships may not change for the worse or even end. In fact, many relationships can become stronger and more satisfying.

One of the crucial elements in reforming relationships is **forgiveness**. If a brain-injury survivor was once cruel and mean-spirited, the injury may have turned him or her around into a caring and responsible individual. Family members and friends need to be able to forgive the past. There may also be the scenario in which a kind and gentle person has turned into an angry and pessimistic person. Try to forgive that as well. If you know it is not in their “nature,” perhaps there is a biological reason for the new behavior that they cannot control. Forgiveness may even need to come without an apology from the injured person, because he may not be aware of any prior or current offensive behaviors.

If a survivor has children, the issue of reforming relationships can be very complicated. Parents have their traditional roles, and children know this. When those roles change, such as when the parent is no longer able to serve as an authority figure, the children may rebel, retreat, or exhibit other harmful behaviors. If this is an issue in your family, we strongly urge you to get family counseling to help work this out.

Work relationships can also prove to be difficult to redefine. Whenever there is a hierarchical relationship that has changed, respect can become a big issue. If a survivor is returning to work in a reduced role, or even in the same role, coworkers and subordinates may not know how to behave appropriately. It may be helpful, on the first day back to work, for the survivor to provide an outline (verbal or written) of her new abilities, what the coworkers can expect, how she would like to be treated, and how they can expect to be treated.

Friendships may fade. At first, some friends will visit often, send cards and flowers, and call to say hi. But as time goes on, these people will carry on with their lives and not think about how difficult life is for someone else. Instead of dwelling on lost friendships, patients and caregivers should encourage formation of new friendships, perhaps with other survivors.

Reforming old relationships is a team effort. The survivor and his family, friends, and coworkers must work together to define and establish each person’s new role. These roles should be clearly outlined, agreed upon, respected and flexible.

Job Placement

One of the most intimidating aspects of recovering for the brain-injury survivor is the prospect of going back to work. If the survivor can return to her prior

job, some of the suggestions mentioned previously about work relationships can be useful. It may also be helpful for the survivor to meet with her employer beforehand to review the job position, duties, requirements, and behaviors expected of the employee. Any accommodations the employer can provide to assist the survivor should be discussed as well.

You may want to consider some of the following:

- Install ramps, handrails, and handicapped parking spaces
- Clear equipment that obstructs pathways
- Provide written job instructions, goals, strategies
- Allow flexible scheduling, including more work breaks if needed
- Provide additional time to learn (or relearn) duties
- Break tasks and assignments into smaller steps
- Provide picture diagrams of problem-solving techniques (e.g., flow charts)
- Set weekly meetings with the employee to discuss productivity and workplace issues. (*Job Accommodations Network*, 2003)

If the brain-injured individual needs to look for a new place of employment, he should seek assistance from community resources, brain-injury organizations, or job placement agencies. It is a good idea for the individual to be truthful about his or her abilities to any prospective employer or placement agency. The individual should ask what the specific duties of any job are, including physical requirements such as lifting, standing for long periods of time, traveling, or anything that may be beyond what the brain-injured individual can do.

The Americans with Disabilities Act (see Chapter Seven) prohibits prospective employers from discriminating against disabled persons. Therefore, being honest about limitations will help ensure the best match between employer and employee. If discrimination appears to be an issue, the person should seek the advice of an attorney. Keep in mind that if a disabled person is not hired because he cannot perform the duties required, it is not considered discrimination.

EMOTIONAL ISSUES FOR FAMILY MEMBERS

“Families also need to grieve the loss of loved ones as they used to be.”

- T.M., Brain-injury Survivor

Living with the Patient’s New Identity

The person a family once knew no longer exists. She is still living, but perhaps in a slightly altered body and with a different identity. In addition to the range of emotions the family will experience, there may also be a sense of loss. The family may feel grief and may even want to mourn their loss. It may be therapeutic for the family to acknowledge this loss together (with or without the patient, depending upon the patient), to grieve, and even to hold some sort of ceremony. A ceremony may be extreme for some, but by allowing yourselves to feel this loss, you will be able to move on and appreciate the new person in your family.

Once the loss has been dealt with, families can now turn their energy toward accepting their new family member. Many of us would prefer to deny that things are different, but we cannot make any progress if we don’t face reality. Get to know the new person in your lives—her likes and dislikes, habits, limitations, abilities, behaviors, and other qualities that make her unique. Learn to accept and appreciate this new person. Realize that this is who he or she is now, and that it may take time to get used to the new identity. You may even like the new identity better than the old one!

GLOSSARY

Abulia—Absence or inability to exercise will-power or to make decisions. Also, slow reaction, lack of spontaneity, and brief spoken responses.

Acalculia—The inability to perform simple problems of arithmetic.

ADL—Activities of Daily Living (dressing, bathing, etc.)

Affect—The observable emotional condition of an individual at any given time.

Agnosia—Failure to recognize familiar objects although the sensory mechanism is intact.

Agraphia—Inability to express thoughts in writing.

Alexia—Inability to read.

Ambulate—To walk.

Amnesia—Lack of memory about events occurring during a particular period of time.

Aneurysm—A balloon-like deformity in the wall of a blood vessel. The wall weakens as the balloon grows larger, and may eventually burst, causing a hemorrhage.

Anomia—Inability to recall names of objects. Persons with this problem often can speak fluently but have to use other words to describe familiar objects.

Anosagnosia—The apparent unawareness of or failure to recognize one's own functional defect.

Anosmia—Loss of the sense of smell.

Anoxia—A lack of oxygen. Brain cells need oxygen to exist. When blood flow to the brain is reduced or when oxygen in the blood is low, brain cells are damaged.

Aphasia—Difficulty expressing or understanding information in any form.

Apraxia—Partial or complete inability to carry out a planned, purposeful sequence of movements, in the absence of paralysis, sensory changes or deficiencies in understanding.

Aspiration—A swallowing problem when food, liquid or secretions enter the lungs.

Astereognosia—Inability to recognize things by touch.

Ataxia—Interruption of smooth muscular movements, characterized by incoordination.

Atrophy—A wasting away or decrease in size of a cell, tissue, organ, or part of the body caused by lack of nourishment, inactivity or loss of nerve supply.

Bilateral—Both sides (of the body).

Catheter—An tube for draining urine; “internal”: inserted into the bladder (Foley) or “external”: over the penis (condom).

Cerebrospinal Fluid (CSF)—The liquid which fills the ventricles of the brain and surrounds the brain and spinal cord.

Chronic—Marked by long duration or frequent recurrence.

Circumlocution—Use of other words to describe a specific word or idea which cannot be remembered.

Clonus—A sustained series of rhythmic jerks, usually seen in ankles or wrists, caused by the quick stretching of a muscle.

Cognitive Retraining—Developing or relearning the processes involved in thinking.

Coma—A state of unconsciousness from which the patient cannot be aroused, even by powerful stimulation.

Concussion—The common result of a blow or jerk to the head usually causing an altered mental state, either temporary or prolonged.

Confabulation—Verbalizations about people, places, and events with no basis in reality.

Contracture—Loss of range of motion in a joint due to abnormal shortening of soft tissues.

Contrecoup—Bruising of brain tissue on the side opposite where the blow was struck.

CT Scan/Computerized Tomography—A series of computerized X-rays of the brain at various levels to reveal its structure.

Diffuse Axonal Injury (DAI)—A shearing injury of large nerve fibers in many areas of the brain.

Diplopia—Seeing two images of a single object; double vision.

Dysarthria—Unclear, slurred speech resulting from weakness and/or incoordination of the muscles used to produce speech and sound.

Dysphagia—A swallowing disorder characterized by difficulty in moving food from the mouth to the stomach. It may include problems in positioning food in the mouth.

Edema—Collection of fluid in a tissue causing swelling.

Electroencephalogram (EEG)—A procedure that uses electrodes on the scalp to record electrical activity of the brain.

Electromyography (EMG)—An insertion of needle electrodes into muscles to study the electrical activity of muscle and nerve fibers.

Endotracheal Tube—A tube that serves as an artificial airway and is inserted through the patient's mouth or nose. The tube may connect a respirator to the patient.

Extension—To straighten a joint, such as straightening your knee.

Extremity—Arm or leg.

Fine Motor Activities—Complex activities involving the hand, such as writing and manipulating small objects.

Flaccid—Lacking muscle tone; flabby.

Flexion—To bend a joint, such as bending your elbow.

Foley Catheter—A tube inserted into the bladder to drain urine, which collects into a plastic bag.

Gait Training—Instruction in walking, with or without equipment; also called ambulation training.

Gastrostomy Tube (G-Tube)—A feeding tube passed directly into the stomach from a surgical opening in the abdomen.

Gross Motor Activities—Large movements of body parts, such as those involved in rolling, sitting up and standing.

Halo—A metal ring used for patients with upper spinal cord injuries which is bolted into and surrounds the patient's head, allowing for proper alignment of the neck and spinal column.

Hematoma—The collection of blood in tissues or a space following rupture of a blood vessel.

Hemianopsia—Loss of half the visual field in one or both eyes.

Hemiparesis—Lack of muscle control on one side of the body.

Hydrocephalus—Enlargement of fluid-filled cavities in the brain, not due to brain atrophy.

Hypertonic—Abnormal increase in muscle tone, or tension.

Hypotonic—Abnormal decrease in muscle tone, or relaxation.

Hypoxia—Insufficient oxygen reaching the tissues of the body.

Incontinent—Inability to control bowel and bladder functions. Many people who are incontinent can become continent with training.

Intracranial Pressure (ICP)—Cerebrospinal fluid (CSF) pressure measured from a

needle or bolt introduced into the CSF space surrounding the brain.

Intubate—to place a tube through a patient’s mouth to the breathing passage.

Jejunostomy Tube (J-Tube)—A feeding tube surgically inserted into the small intestine.

Lability—Frequent shifts in emotional state (may manifest as uncontrolled laughing or crying).

Magnetic Resonance Imaging (MRI)—A diagnostic procedure that uses magnetic fields to create pictures of the brain’s soft tissue.

Malingering—To pretend illness or inability in order to avoid duty or work.

Motor Control—Regulation of the timing and contraction of muscles to produce smooth and coordinated body movement.

Motor Planning—Action formulated in the mind before attempting to carry it out.

Muscle Tone—Used in clinical practice to describe the resistance of a muscle to being stretched.

Nasogastric tube (N/G Tube)—A tube which is passed through the nostril and into the stomach to carry food directly to the stomach.

Neglect—Paying little or no attention to a part of the body.

Neologism—Nonsense or made-up word used when speaking. The person often does not realize that the word makes no sense.

Neurodegeneration—**damage or death to nerve cells in the brain, often cause by diseases such as Alzheimer’s.**

Orthopedics—The branch of medicine devoted to the study and treatment of the skeletal system, its joints, muscles and associated structures.

Orthosis—Splint or brace designed to improve body function or provide stability.

Paraplegia—Paralysis of the legs (from the waist down).

Paresis—Lack of control of a muscle or group of muscles; partial or incomplete paralysis.

Perceptual Motor—Interaction of vision with motor (muscular) activities such as eye-hand coordination, eating, picking up objects, etc.

Perseveration—Uncontrolled, involuntary repetition of speech or activity (See Motor Planning).

Persistent Vegetative State (PVS)—A long-standing condition in which the patient utters no words and does not follow commands or make any response that is

meaningful.

Plateau—A temporary or permanent leveling off in the recovery process.

Post Traumatic Amnesia (PTA)—A period of hours, weeks or months after an injury during which the patient exhibits a loss of day-to-day memory.

Premorbid—A term to describe the patient's condition before the injury.

Prosthesis—An artificial limb.

Prone—Lying face down.

Quadripareisis—Lack of control of all four limbs of the body resulting from an injury to the brain (See Paresis).

Range of Motion (ROM)—the range of movement available in a joint, measured by degrees.

Respirator—(see Ventilator)

Seizure—An uncontrolled discharge of nerve cells which may spread to other cells throughout the brain. The sudden attack is usually momentary, but may be accompanied by loss of bowel and bladder control, tremors, and/or aggressiveness.

Sensorimotor—Refers to all aspects of movement and sensation and the interaction of the two.

Shunt—A surgically placed tube connected from the ventricles which deposits fluid into the abdominal cavity, heart or large veins of the neck.

Somatosensory—Sensory activity having its origin elsewhere than in the sense organs (such as eyes and ears); conveys information to the brain about the body and its immediate environment.

Spasm—A sudden, abnormal, involuntary muscular contraction.

Spasticity—A marked involuntary increase in muscle tone (tension) characterized by hyperactive reflex and shortening of the muscle.

Splint—A metal, plaster or plastic support used to position one or more joints properly to reduce muscle tension, increase range of motion and/or allow greater use of the body part.

Strabismus—Uncoordinated movement of the eyes, usually resulting in double vision.

Subdural—Beneath the dura (tough membrane) covering the brain and spinal cord.

Supine—Lying on one's back.

Synergy—Combined action of two or more muscles to form an abnormal pattern of

movement. The person cannot move one without the other.

Tactile Defensiveness—Being overly sensitive to touch; withdrawing, crying, yelling or striking when one is touched.

Tracheostomy (Trach)—A surgical opening at the front of the throat providing access the trachea or windpipe.

Tremor—Rhythmical movements of a body part that become intensified the harder one tries to control them.

Tremor (Resting)—Rhythmical movements while at rest; may diminish during voluntary movement.

Unilateral Neglect—Paying little or no attention to one side of the body.

Ventilator—Machine that does the breathing for the unresponsive patient by delivering air with the right amount of oxygen at the right rate.

Verbal Apraxia—Impaired control of proper sequencing of muscles used in speech (tongue, lips, jaw muscles, vocal cords).

Vestibular—Pertaining to the vestibular system in the middle ear and the brain which senses movements of the head. Vestibular disorders can lead to dizziness, poor muscle tone in head and neck, and inability to detect quick movements of the head.

Void—To urinate.

(Glossary references: *Brain-injury Glossary*, HDI Publishers, 1996; Long Island Head Injury Association)

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