

Educating Families of the Head Injured

A Guide to Medical Cognitive and Social Issues

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Preface

To the health care professional:

This book, while written for families of the head injured, is specifically designed to assist you, the professional. It is comprehensive as well as practical in describing and resolving problems. The loose-leaf format allows you to customize the application to each case. Some families may want to read all of the chapters. In other cases, you will need to review certain sections with family members. Whatever procedure you follow, *Educating Families of the Head Injured* presents you with an excellent opportunity to educate families properly and to ensure that those families become effective members of the recovery team.

Chapter 1

Introduction: How To Use This Guide

To the health care professional:

Some families may want to read the entire book; however, this could be overwhelming and much of what they read would be forgotten. In many cases, it will be more appropriate for you to direct them to the chapters that will be of greatest significance to them.

Chapter 1

Introduction: How To Use This Guide

You, the family or primary caretaker, are often the key to the success of your loved one's rehabilitation after head injury. This may seem like an awesome responsibility. In fact, it is. Nevertheless, all research studies, as well as general clinical observations, point to the fact that you are a key player in the treatment team. Why so? Why can't you just leave your loved one's treatment to the hands of those who have been professionally trained and have a wealth of experience handling these issues on a day-to-day basis? Why can't you just have them tell you when he will be ready (fixed) so that you can come back to get him

You could do this leave it to the professionals but it would not be to the best advantage of either you or your loved one. First, your immediate involvement helps you to feel that you are a part of what is going on, and it gives you an opportunity to talk with the therapists who will be a very important part of your loved one's life. Also, once your family member is conscious (or maybe even before), your presence reassures him that these people have his best interest at heart or you would not be there allowing them to participate in his rehabilitation. Moreover, family presence provides a sense of security that allows the individual to maintain his motivation and understand that he must work hard to get better.

Just because the family can be so vital to your loved one's recovery does not mean that we expect the family to do everything. And it does not mean that if rehabilitation efforts over the years meet failure, it is your fault. In some instances, a family will give their all (and maybe too much) with a less than optimum outcome. And in others, a patient will do fairly well in spite of little family support. Nevertheless, the fact remains that an important part of the burden for your loved one's rehabilitation falls on you.

We note that there are times when the primary caretaker is not family by blood or marriage. Sometimes it will be a person who is described as like family or better than family, such as a lifelong close friend. At other times the term family may apply to the staff at an extended-care facility, transitional living facility, or some other type of long-term caretaker arrangement.

Now, here are a few words regarding how to use this book. We could have continued to refine and elaborate the information in this book to the point where it covered just about everything in detail. However, that might mean that families would find it unwieldy to use or that it would not be used at all. Rather, we felt it was important to get the wealth of information contained in the book to families of the head injured in the clearest and most useful format possible. The loose-leaf format was used so that those of you who need only a few selected sections can obtain them from your rehabilitation facility. However, you still have the option to purchase the entire book if you desire to obtain all of the information provided on all areas of head injury rehabilitation. While

your loved one is in intensive care, for example, it is sometimes easier to readjust those sections of the book that pertain to the immediate future, rather than worry about what the recovery status may be 2 years after the injury. Worrying about vocational retraining while he is in intensive care is probably not the best use of your energy at that time. This is not necessarily the type of book that you sit down and read cover to cover, although that is one option. To provide the information that is most pertinent for you at specific points in time, let us pose some typical situations, along with the chapters that are important for these situations:

- Your loved one was recently injured.
 - Read Chapter 2 thoroughly.
 - Skim Chapters 3, 8, and 9.
 - Skim Chapter 18 if a child is injured.
 - Skim Chapter 19 if an older adult is injured.
- Your loved one is in a coma.
 - Read Chapter 2.
- Paying for rehabilitation services is an issue.
 - Read Chapter 7.
- You are trying to choose the most appropriate treatment program.
 - Read Chapters 5 and 8.
 - Contact the National Head Injury Foundation.
- Your loved one stayed in the hospital less than 24 hours.
 - Read Chapter 6.
- The doctor said your loved one had no brain damage but he seems different to you.
 - Read Chapter 6.
 - Skim Chapters 10 and 11.
- Your loved one is ready to go home are you ready for him?
 - Read Chapters 4, 5, 10, 11, and 12.
- You are concerned about legal issues.
 - Read Chapter 7.
 - Read Chapter 8.
- Your loved one is not the person he used to be.
 - Read Chapters 10, 11, and 14.
- You are not the person you used to be.
 - Read Chapter 12.
 - Contact a counselor who knows about head injury.
- You are concerned about and/or do not understand all the medications.
 - Read Chapter 16.
- You are concerned that your loved one's previous drug or alcohol problem may be an issue.
 - Read Chapter 15.
- You are having trouble getting your medical questions answered by someone who knows long-term head injury issues.
 - Read Chapter 13.
 - Read Chapter 14 if a child is involved.
 - Read Chapter 19 if an older adult is involved.
- It seems that you need to play an expert role.
 - Read Chapter 17.

- How do we get him back out into the community?
Read Chapter 20.
- Your home needs a rest from having to care for your loved one 24 hours every day.
Read Chapter 9.
- Someone in your family thinks your loved one is spoiled and could act better if he wanted.
Mark the pertinent behaviors in Chapters 10 and 11 and ask that family member to read those sections maybe he will get interested and read more.

You will find that, as you progress through the different stages of your development and awareness of head injury rehabilitation, the information in each chapter will take on new meaning. This is particularly true if you are involved with a recently injured individual. Try to remember that it may be helpful to go back and reread various sections at a later date.

Throughout this book, we have attempted to present the information in as clear and as easy-to-understand manner as possible. However, you will note that many medical terms are used, particularly in the medically oriented chapters. When at all possible, we have briefly explained what these terms mean. We think it is important for you to be exposed to these words and their meanings. A list of many of the terms is included in the back of the book. As you read along, you can skim the medical terms and just read the descriptions provided.

Although we are quite aware that not all head-injured individuals are male, the male gender is used for the sake of simplicity. We hope that this will not be offensive to any of our readers. Last, we welcome suggestions from our readers. Please send your specific recommendations regarding readability, usefulness, and the possible need for additional information to:

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Chapter 2

Medical Issues

To the health care professional:

This chapter focuses on the many medical issues involved in TBI from the trauma scene, to the emergency room, to intensive care. Although written for the layman, a large number of medical terms are introduced. You may want to present certain sections to family members at appropriate times.

Chapter 2

Medical Issues

TRAUMA SCENE: A CASE SCENARIO

He had one for the road before stepping into his black sports car that holiday weekend. He never liked to wear a seatbelt too confining.

Lights flashed and sirens screamed as the emergency medical team (EMT) raced toward the scene. They found him with the remains of a new black sports car wrapped around him like a hideous coffin. Was he alive and breathing? Yes, although his pulse was weak from so much blood loss.

Carefully, they stabilized his spine on a board, splinted the open bone fractures, and lifted him into the ambulance. They quickly started intravenous (IV) lines pumping fluid into him. Oxygen was given by mask. Fortunately, cardiopulmonary resuscitation (CPR) was not needed in this case.

He was met at the hospital by the trauma surgeon who would coordinate the efforts of a team of physicians and paraprofessionals. His clothes were cut from his body in the emergency room. Blood was drawn to check his blood count, to cross match his blood for transfusion, to determine the ratio of important chemicals in his blood, and to check the level of alcohol or other drugs. Larger IV lines were started and fluids poured in. Arterial blood was drawn to check how well he was getting oxygen. A central venous pressure (CVP) line was placed to check that he was getting enough fluid. This was later switched for a Swan-Ganz tube to give more detailed measurements. Another tube was placed into his bladder and left connected to a bag to measure urine output. A tube was placed through the mouth into his breathing tube to better carry air to his lungs and oxygenate his blood. Electrocardiographic (EKG) leads were placed on his chest to monitor his heart rhythm. A tube was placed through his nose into his stomach and started on suction to drain his stomach contents and prevent vomiting. An arterial blood line was started to follow his oxygen status continuously. Emergency X-rays revealed a collapsed lung. The emergency room (ER) physician inserted a chest tube and connected it to a draining device to reexpand the lung. A stomach tap was performed to determine whether there was internal hemorrhaging (bleeding). The surgeon entered the abdomen by a small incision (surgical cut) near the umbilicus (belly button). Fluid was run into the belly, removed, and examined for the abnormal presence of blood. Fortunately, the general surgeon agreed that no abdominal surgery was needed, as little blood was found. He was also evaluated by the neurosurgeon, the orthopedic surgeon, and the oral surgeon.

Stabilized, he was rushed into radiology for X-rays of the skull, pelvis, and several long bones. He had an intravenous pyelogram (IVP) or kidney and bladder X-ray to rule out any injury to these vital organs. He underwent a computerized axial tomography (CT or CAT) scan of the head and brain. Because of large right-sided hematomas (bleeding), he underwent emergency brain surgery to remove the hematomas before further damage could be done by the blood pressing the brain within the narrow confines of the skull. He underwent a craniotomy (opening of the skull) and craniectomy (removal of part of the skull). He also underwent placement of a tube from the fluid filled cavities within the brain to an outside monitoring device so that intracranial pressure (ICP) in the brain could be monitored. After the brain surgery, his fractured jaw was wired by the oral surgeon. His thigh bone was placed in traction by the orthopedic surgeon. In this case, corrective surgery would be completed several days later. Stable after surgery, he was transferred to the intensive care unit (ICU).

In the ICU, under the care of the trauma surgeon, the various tubes were connected to sophisticated monitoring machines. Nurses recorded his various vital signs regularly and watched for important changes in the readings. He was seen by a pulmonology specialist to check his respiratory status on the ventilator (breathing machine), an infectious disease specialist to help evaluate his fevers, a cardiology specialist to evaluate trauma (damage) to the heart, and a neurology specialist to help manage seizures. The neurology specialist also interpreted results of additional tests used to follow his progress, such as electroencephalogram (EEG), or brain wave test, and evoked potential studies. He was also seen by the ear, nose, and throat (ENT) physician to evaluate effects of injury to his face, the ophthalmologist to review his eye injury, the plastic surgeon to attend to the facial cuts, and the nephrologist (kidney specialist) to follow his temporary renal failure (inability to make urine normally). The physiatrist (physician specializing in rehabilitation) saw him to evaluate nutritional status and body functions and to initiate appropriate therapies.

The neurosurgeon told his family that he might live if he survived the first 24 hours. Yet, what he would be like was still a question. Indeed, his time in the ICU was stormy, and his family longed to know how things would come out. They were frustrated by the doctors for not having the answers and suggesting they wait and see. They prayed for his life, but worried what kind of life it would be if he survived. He lived.

IN THE EMERGENCY ROOM

The emergency room brings images of sudden crisis. Indeed, the role of the emergency room is to make order of the crisis, identify the most important problems quickly, and deal with the most life threatening matters first.

Blessed are You, Lord our God, King of the Universe,
 Who formed man with wisdom and created within him openings and tubes.
 It is obvious in the presence of Your glorious throne
 That if one of them were ruptured, or if one of them were blocked,
 It would be impossible to exist and to stand in Your Presence.
 Blessed are You Lord, Who heals all flesh and performs wonders.

This prayer recognizes the important principle of emergency medicine: the ducts and tubes within our bodies are most important in saving life our airway and lungs for breathing and our heart and blood vessels for circulation. In an emergency, one must first address the airway,

breathing, and circulation (ABC) functions. The blocked airway must be opened and a tube inserted if necessary, artificial respiration with a special bag is needed if there is no spontaneous breathing, cardiac massage is needed if the heart is not pumping, and fluids are needed if too much blood has been lost.

Blood loss is an important component of trauma. Excess blood loss can lead to shock if vital organs are deprived of the oxygen and necessary nutrients carried by the blood. Blood loss is measured by hemoglobin (Hb) and hematocrit (Hct or "crit"). Hematocrit reflects the red blood cells in the blood. For example, Hct = 45 if plasma = 55, and red blood cells = 45.

After dealing with the ABCs, fractures are splinted (held in place with padded boards or other devices) to avoid injury to soft nerves or blood vessels by movement of sharp bony fragments. The fractures are repaired after the more life-threatening areas are addressed. See Figure 2-1. The trauma surgeon then looks for injury to the nervous system by evaluating for possible brain or spinal cord injury. Injury to the spinal cord in the neck can cause arm and leg weakness. See Table 2-1.

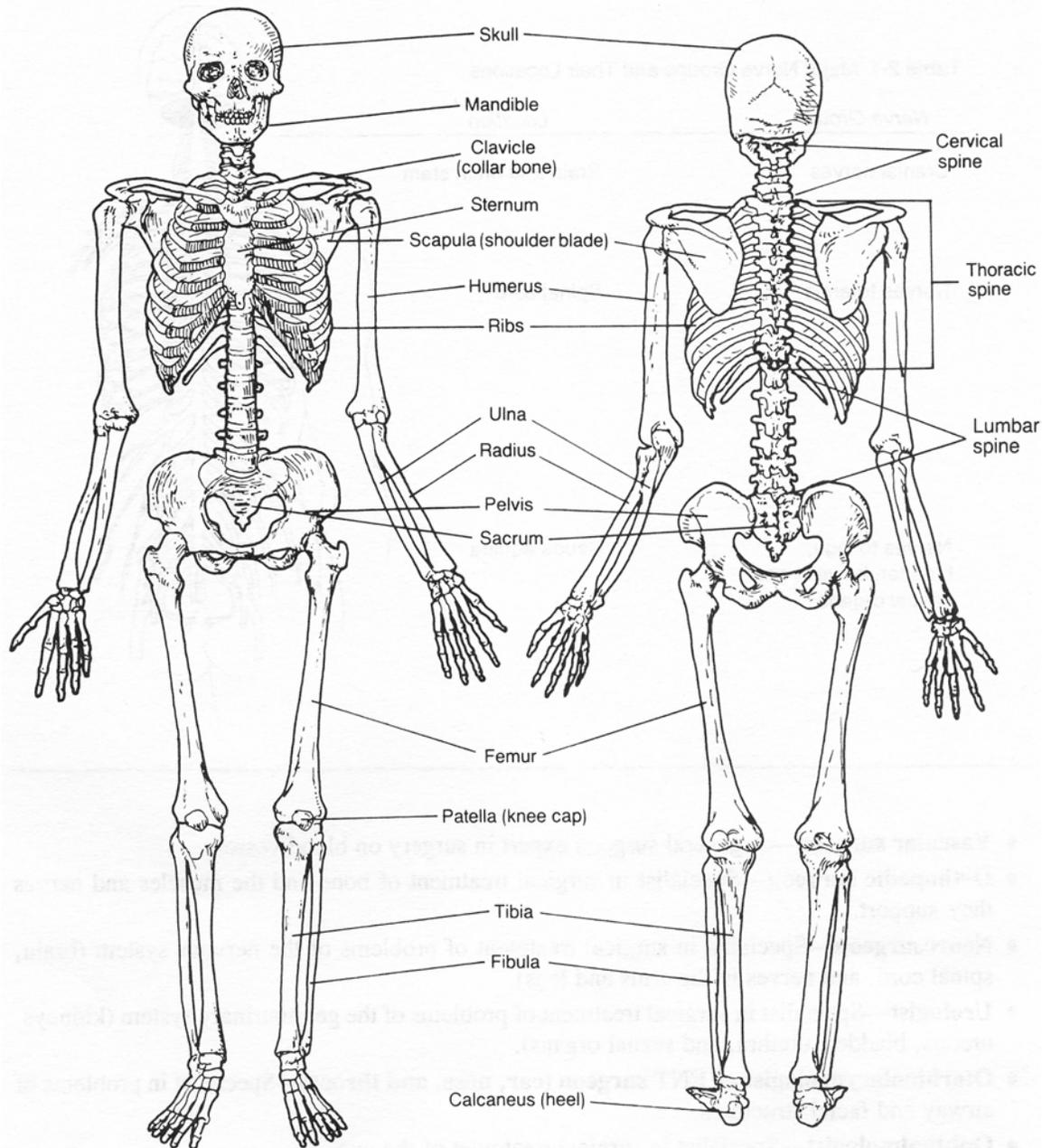


Figure 2-1 The Human Skeleton

As noted in the case scenario, the abdomen is studied to rule out injuries to vital organs that could lead to dangerous blood loss (especially to the spleen or liver) or to infection (in the stomach or intestines). Injuries to other vital organs are identified and addressed. Lacerations (cuts) are repaired early to reduce chance of infection. Again, as noted in the trauma scene, many different medical specialists are involved with your loved one in the emergency room.

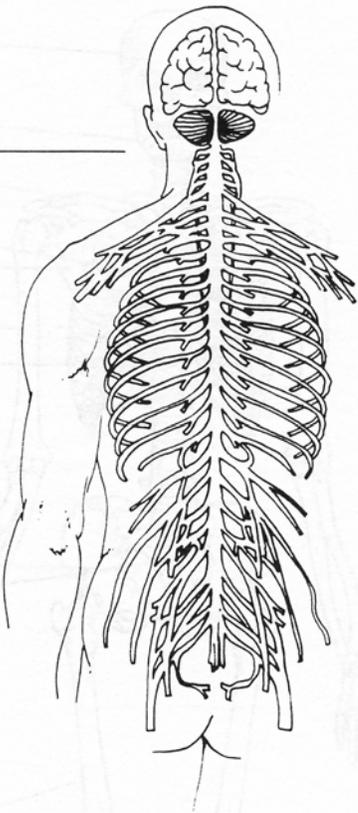
- **Trauma surgeon/general surgeon** Takes over the case from the ER physician and directs the overall care in the early stages while the patient is critically ill. This surgeon is involved with

abdominal and sometimes vascular (blood vessel) surgery. When the patient is stable and has a problem in predominantly one area, a specialist may assume primary care

- **Thoracic surgeon** A general surgeon who is experienced in operating in the chest (lungs and heart).

Table 2-1 Major Nerve Groups and Their Locations

<i>Nerve Group</i>	<i>Location</i>
Cranial nerves	Brain and brain stem
Nerves to arms	Spinal cord
Nerves to legs, bladder, bowels, and sexual organs	Cauda equina



- **Vascular surgeon** A general surgeon expert in surgery on blood vessels.
- **Orthopedic surgeon** Specialist in surgical treatment of bone and the muscles and nerves they support.
- **Neurosurgeon** Specialist in surgical treatment of problems of the nervous system (brain, spinal cord, and nerves in the arms and legs).
- **Urologist** Specialist in surgical treatment of problems of the genitourinary system (kidneys, ureters, bladder, urethra, and sexual organs).
- **Otorhinolaryngologist** or ENT surgeon (ear, nose, and throat) Specialist in problems of airway and facial structures.
- **Ophthalmologist** Specialist in surgical treatment of the eye.
- **Plastic surgeon** Specialist in surgical treatment of the skin, including the treatment of bums.
- **Oral surgeon** A dentist with special training in surgical treatment of the mouth such as repairing fractured jaws and removing broken teeth.

When these doctors have stabilized the condition through medical treatment or emergency surgery, the patient is transferred to the intensive care unit.

IN THE INTENSIVE CARE UNIT

Many family members find their first visit to the intensive care unit (ICU) to be quite disturbing even frightening. You were probably no exception. It truly is a different world brightly lit and inhabited by machines. There is a sense of feeling that "this is not really happening to us." This section is written to help you better understand the tools, tests, people, and purposes of the ICU, so that your fear can be reduced. Rest assured that all families experiencing this are just as disturbed as you.

What Are All These Tubes and Wires? See Figure 2-2.

The respirator is a device that moves air into the lungs of your loved one when he is unable to breathe for himself. It is also called a ventilator. A tube through the mouth or through the nose is placed into the lung. Usually, a respiratory therapist adjusts settings of the ventilator on your physician's orders. Often a pulmonologist (specialist in lung disorders) will be consulted to assist with managing the case. He prescribes the rate of breathing, the depth of breathing, and the pressure of breathing. Sometimes resistance to exhaling is added to keep the lung's air sacs open. Extra large breaths or sighs are also ordered to help keep the lungs expanded. See Figure 2-3.

Being on a breathing machine has a bad image. Some family members fear it means your loved one is brain dead. Actually, in the great majority of patients with head injuries, use of the respirator is only temporary.

Taking a person off a respirator is called weaning. Your physician watches to be sure your family member's own lungs can move enough air, and he also measures the arterial blood gases (ABGs) before weaning is attempted. ABGs record the amount of oxygen and carbon dioxide dissolved in the blood. Too little oxygen or too much carbon dioxide means breathing is inadequate to sustain healthy life.

A tracheostomy (throat opening) is sometimes necessary for patients who need a respirator for an extended period or who have a poor cough response (problems clearing their secretions). To perform a tracheostomy, a small temporary opening is made in the patient's throat. A tracheostomy

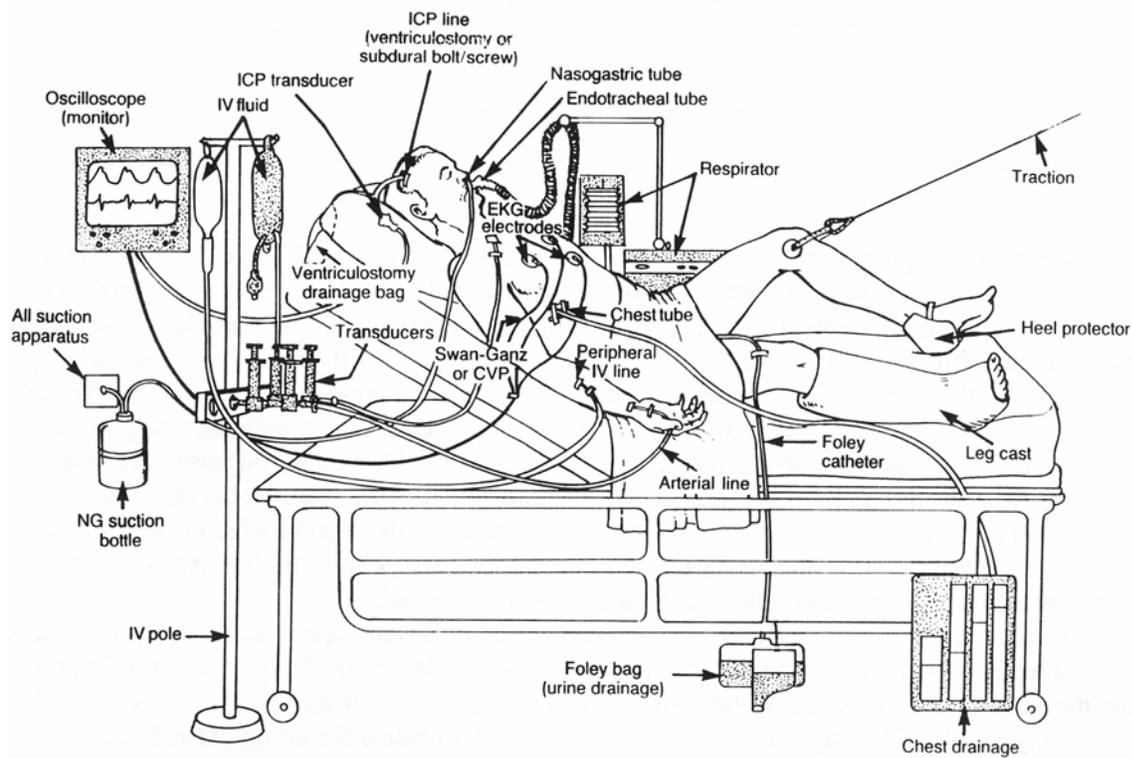


Figure 2-2 Equipment Used during Acute Head Injury. Source: Reprinted from Head Injury by L.F. Marshall, G.R. Sadler, and S.B. Marshall with permission of Comprehensive Central Nervous System Injury center for San Diego County, 1981.

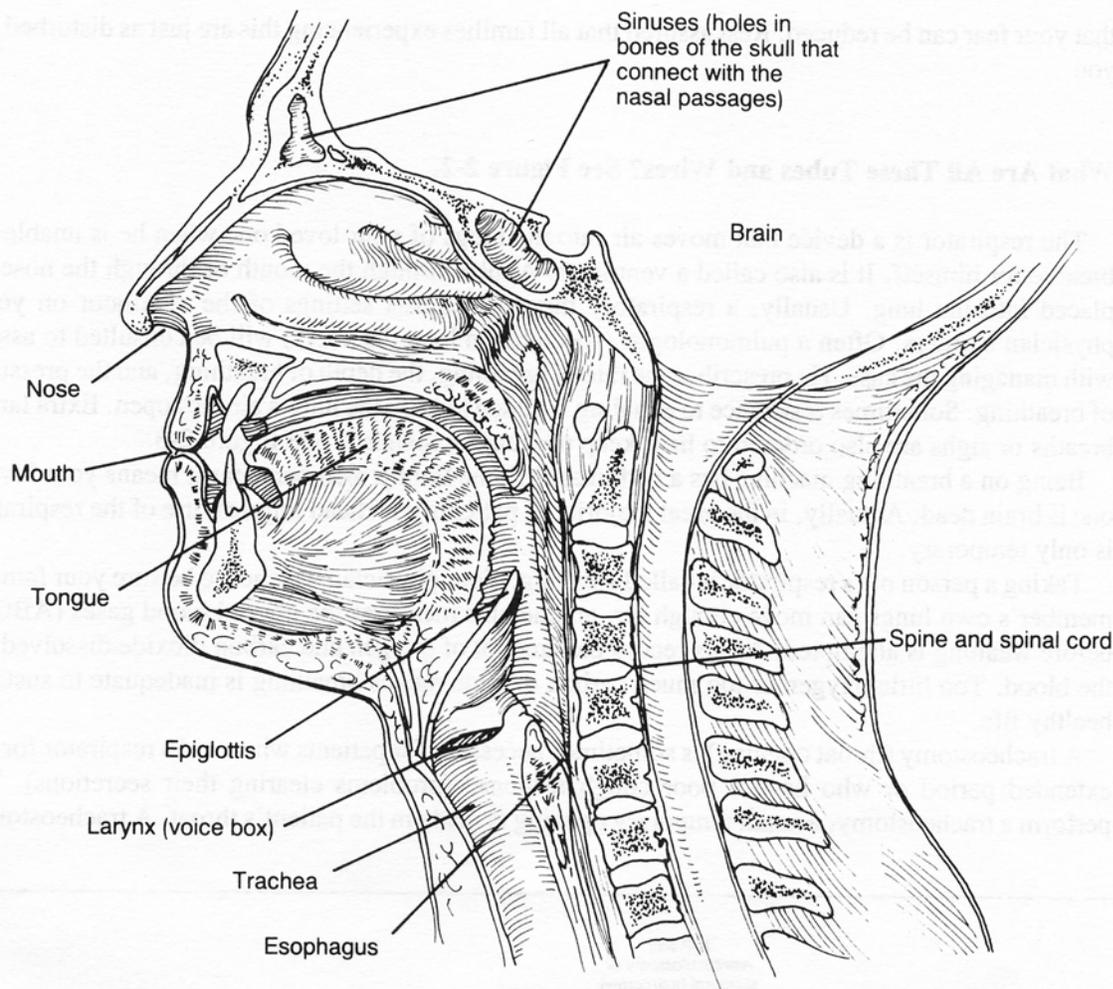


Figure 2-3 Airway Anatomy—Cutout View through Mouth and Throat

tube (trach tube) is placed in the opening. It is either cuffed (with an air-filled balloon surrounding the tube to keep a good seal) or uncuffed (usually with a metal device). The tube is connected either to the respirator, to supplemental oxygen, or to moist air. Nurses keep the airway clear of secretions by suctioning through the trach tube sometimes first placing a small amount of sterile saline (salt water) in the throat to moisten secretions and to encourage coughing. This may look like cruel treatment to you, but it is necessary to help keep the airway clear and to help prevent pneumonia.

You may find the decision to perform a tracheostomy to be a difficult one because your loved one has already been through so much. It looks so unnatural and leaves a scar. On the other hand, there are several advantages when comparing it with a tube through the mouth, which is the alternative treatment. Prolonged use of such a tube can result in a narrowing of the airway. Second, a tracheostomy is more comfortable than a tube through the mouth.

Urinary catheters (tubes used to drain fluid from the bladder) are important, because the severely injured patient cannot readily get up to empty the bladder. Also, in the ICU setting, it is important for the nurses and physicians to be aware of exactly how much urine the kidneys are

making. Various types of indwelling catheters (catheters that remain inside the body) exist, but one of the most common is the Foley catheter, which has a balloon surrounding the end of the tube. After the catheter is inserted into the bladder, the balloon is inflated to prevent the catheter from sliding out. (See Figures 2-4 and 2-5.)

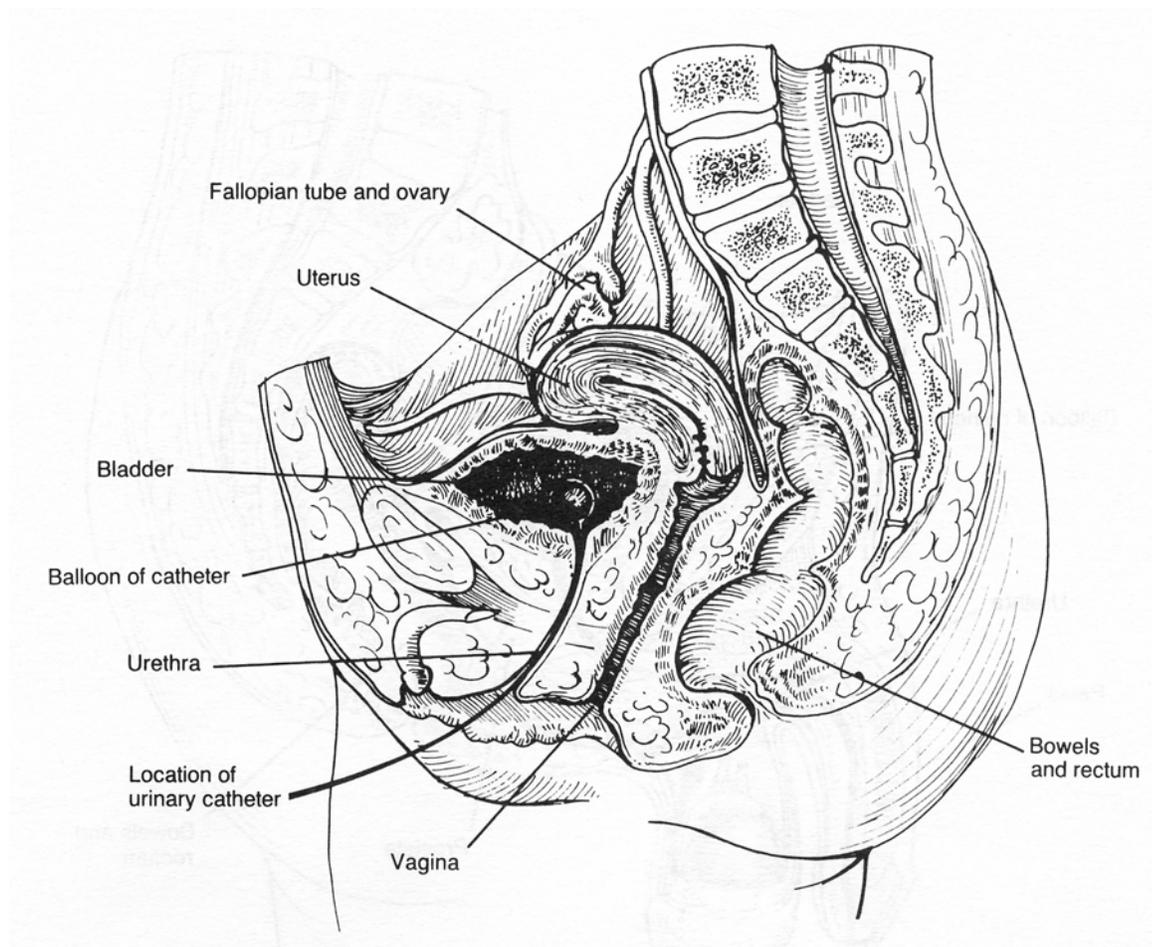


Figure 2-4 Female Genital and Urinary Anatomy

Once there is no longer an urgent need for an indwelling catheter, your physician may try to wean your family member to another system. This is because indwelling catheters are associated with such frequent complications as urinary tract infection (UTI), urethral injury, and a decrease in the volume of urine the bladder can hold. Patients are weaned to diapers, external catheters, and intermittent catheterization. Predominantly used in men, most external catheters are condomlike devices placed over the penis and connected to a drainage tube. Intermittent catheterization (also called intermittent cath or IC) involves passing a catheter into the bladder at regular intervals, draining the urine, and then removing the catheter. Usually performed under sterile conditions in the hospital, intermittent catheterization reduces the risk of infection and urethral injury and allows a more normal pattern of bladder filling and emptying.

Tubes of various types connected to blood vessels are always seen in the ICU. Intravenous lines (IVs) are connected to veins carrying blood to the heart and are used to give fluids and medications. Because IV fluids alone cannot give your loved one enough nutrition, special central

lines are sometimes used. This involves giving solutions containing proteins, fats, carbohydrates, vitamins, and minerals through the vein. It requires a large central vessel such as the subclavian vein under the collarbone or the jugular vein in the neck. Special types of lines may also be placed through a vein in the arm or leg into the chambers of the right heart to help with fluid balance. These special lines include central venous pressure (CVP) and Swan-Ganz catheters.

Arterial (art) lines serve the special purposes of allowing continuous monitoring of blood pressure and access to blood for measurement of arterial blood gases to be sure the lungs are functioning properly. Art lines are connected to arteries draining freshly oxygenated blood just pumped from the heart.

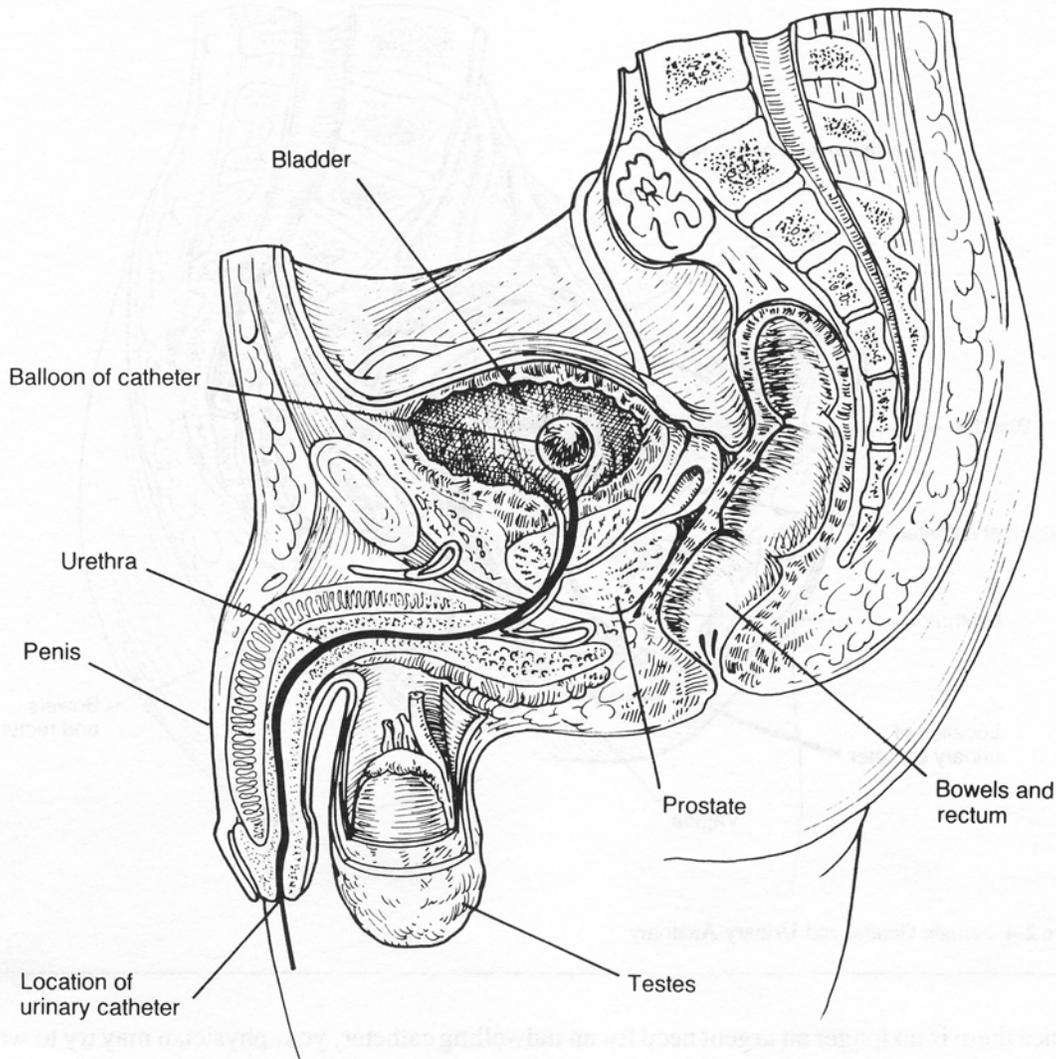


Figure 2-5 Male Genital and Urinary Anatomy

Tubes are sometimes passed through the nose into the stomach for two reasons: (1) suction, to remove substances from the stomach, and (2) feeding. This type of feeding is an important method of providing nutrition to your family member if he is not capable of eating on his own. Feeding

directly into the stomach or intestine is important because IV fluids alone are not enough to maintain good nutritional status. See Figure 2-6.

X-rays are sometimes checked to confirm that the tube is properly positioned in the stomach or intestine. If your physician has ordered such a tube, do not try to feed your family member without checking to be sure it is safe. Sometimes patients with head injury appear to swallow normally, but are at risk for breathing food and secretions into the lungs due to a weak cough or an abnormal swallowing mechanism.

Your physician may recommend surgery for placement of a feeding tube when prolonged internal feeding is necessary. A jejunostomy involves surgery to place a thin tube directly into the intestine. Another operation is usually required when the tube becomes displaced. A gastrostomy involves placing a feeding tube through the abdomen directly into the stomach. There are two major types of gastrostomies. The surgical type is permanent and requires no reoperation if the tube becomes dislodged. The other involves only local anesthesia and is easier to reverse, but is not indicated for all patients.

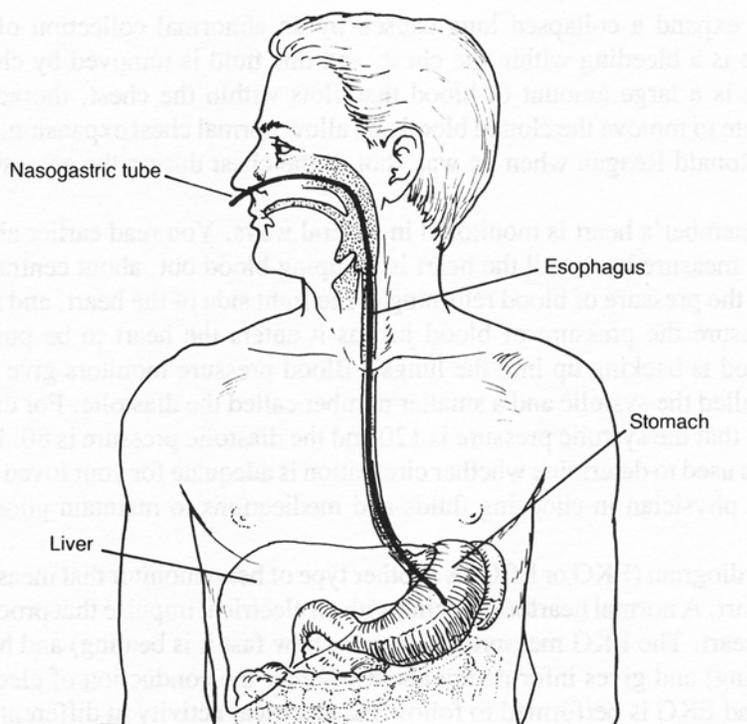


Figure 2-6 Nasogastric (NG) Tube Passing into the Stomach

Intracranial pressure (ICP) lines are passed through the skull to sites near or within the brain. They are connected to ICP monitors that record pressures within the brain. The lines may also be connected to drainage bags to provide a place for fluid to drain from the brain if the ICP is too high. It is sometimes important to measure ICP in severe head injury. This is because a very elevated pressure can interfere with the flow of blood and nutrients to the brain and lead to further brain damage. Pressure increases because brain injury may cause swelling and bleeding within the brain. Because of the hard bony skull surrounding the brain, there is a limited amount of swelling that can occur before pressures begin to rise to a dangerous level. This is like blowing up a large balloon within a small space; you must blow harder and harder (higher pressure) as the balloon expands against its physical limits. Your physician monitors the ICP and uses various treatments

and medications to reduce it if necessary. Although the advantages are obvious, there are also risks with ICP monitoring. Most significant is that the opening into the brain can be a source of infection.

There are two major types of ICP lines. The first is the intraventricular line that goes through the brain into the ventricles, the fluid-filled cavities that normally exist inside (see section on Normal Brain Function in this chapter). The second type extends to the subarachnoid space on the surface of the brain. These are called subarachnoid bolts or subarachnoid screws.

Drowsiness and vomiting are classic signs of increased ICP. The ICU team treats elevated ICP with several techniques. These include raising the head of the bed, increasing the breathing rate on the ventilator to reduce the amount of carbon dioxide in the blood, and such medications as mannitol, urea, and steroids (i.e., Decadron). Barbiturate coma is sometimes brought on to reduce the oxygen needs of the brain in a critical situation. Drainage of fluid from the brain by draining the ventricles is sometimes used. If there is a large mass of blood on the surface of the brain, a neurosurgeon will usually remove it. Although it is more dangerous, because of having to cut through the brain itself, surgeons remove collections of blood within the brain when they are life threatening (see section on Nature of Brain Injury in this chapter).

Thoracostomies are tubes emerging from the chest. They are usually connected to suction to keep the lung expanded. Bubbling is therefore commonly seen in the collection apparatus. This operation is performed to expand a collapsed lung caused by an abnormal collection of air in the chest. Sometimes there is a bleeding within the chest, and this fluid is removed by chest drainage with suction. If there is a large amount of blood that clots within the chest, thoracic surgeons must sometimes operate to remove the clotted blood and allow normal chest expansion. This was the case with President Ronald Reagan when he was shot in the chest during the assassination attempt in 1982.

Your family member's heart is monitored in several ways. You read earlier about using arterial pressure lines to measure how well the heart is pumping blood out, about central venous pressure lines to measure the pressure of blood returning to the right side of the heart, and about Swan-Ganz catheters to measure the pressure of blood just as it enters the heart to be pumped out (and to determine if blood is backing up into the lungs). Blood pressure monitors give two pressures a larger number called the systolic and a smaller number called the diastolic. For example, a reading of 120/80 means that the systolic pressure is 120 and the diastolic pressure is 80. Information about these pressures is used to determine whether circulation is adequate for your loved one's vital organs and guides your physician in choosing fluids and medications to maintain good circulation. See Figure 2-7.

The electrocardiogram (EKG or ECG) is another type of heart monitor that measures the electrical activity of the heart. A normal heartbeat begins with an electrical impulse that proceeds in an orderly way across the heart. The EKG measures heart rate (how fast it is beating) and heart rhythm (how evenly it is beating) and gives information about whether the conduction of electrical impulses is normal. A 12-lead EKG is performed to follow the electrical activity in different parts of the heart (as when looking for heart muscle injury after a heart attack). In the ICU, usually only one lead is connected to the continuous monitor.

Please do not worry about short-lasting changes in the electrical wave or a brief rise and fall in rate of the heartbeat that occurs when your family member moves. This may even briefly set off an alarm or automatically cause a rhythm strip to be made. This is caused by movements of the wires and is normal.

Skeletal traction is another type of wire that may be connected to your family member. The section in the Emergency Room explains that the most life-threatening injuries are treated first. Because the patient is often unstable after major trauma, fractures are first splinted, casted, or held in

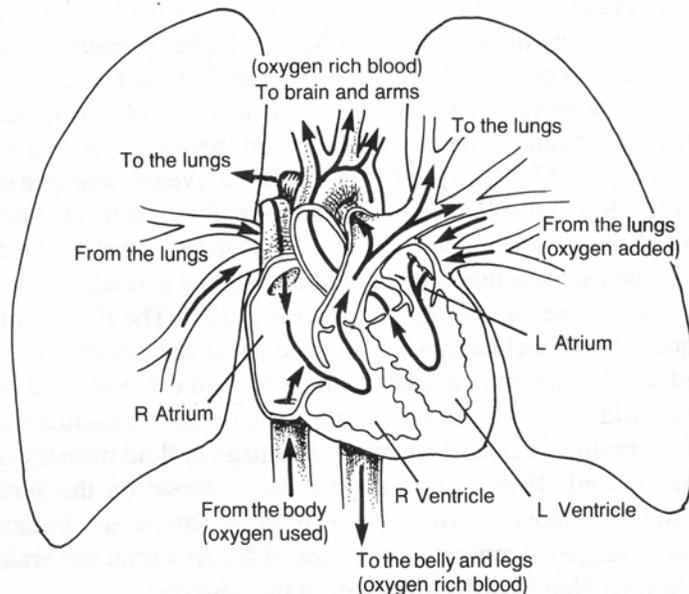


Figure 2-7 Cross-sectional View of the Heart. The two halves of the heart are separated; the atria pump blood to the ventricles on the same side; the lungs act as a filter and keep blood clots from the legs from passing into the left heart.

traction, and then later repaired through surgery. Surgery may be needed to assure better healing or to allow getting out of bed earlier. Open fractures (broken ends of bone sticking through the skin) often require an early operation to clean out the dead tissue and dirt, but surgical repair of the fracture may be delayed until the wound is cleared of infection. Premature use of orthopedic devices, such as screws, nails, or rods, in the vicinity of an open fracture may make it difficult to eliminate infection in the area affected.

Why All These X-Rays and Are They Really Safe?

It is likely your loved one will have many X-rays during the ICU stay and later phases of recovery. These films are important to discover injury to various body parts and to follow the recovery.

- Chest X-rays are used to check on the lungs and heart. They can uncover reasons for breathing difficulty, such as a collapsed lung, pneumonia, or problems with fluid balance. They may need to be taken daily or even more often.
- Bone X-rays reveal the alignment and healing of fractures. They may need to be taken every few weeks or more often in some cases.
- CT scans of the brain check the development of hemorrhages, brain swelling, and hydrocephalus (fluid in the cranial cavity).
- Other special X-rays may be needed. These may include tomograms showing thin sections of a part of the body for more detail or dye studies showing particular organ systems, such as an

IVP showing the kidneys and bladder. Be sure to tell your physician if your loved one has any history of allergic reaction to dye injections or to iodine-containing foods such as shellfish!

If you worry about your loved one getting too much radiation from the X-rays, you are not alone. Each X-ray delivers a dose of radiation to the body. This radiation dose is measured in rads, and too much radiation can be harmful over the long run. However, radiologists are careful to keep the dose as low as possible.

Nuclear medicine describes another type of study that sounds dangerous but is not. Radioactive material injected into the body settles in particular organs and provides a better picture. Examples are bone scans to show areas of bone forming abnormally in the muscles around major joints and fibrinogen scans to detect developing phlebitis (blood clots). Some diagnostic studies deliver no dose of radiation at all. Ultrasound studies and echocardiograms use high-frequency sound waves (like sonar in submarines or a fish detector in a fishing boat). Magnetic resonance imaging (MRI) scans use a strong magnetic field to take very detailed pictures. Generally, it is not used if your loved one has a cardiac pacemaker or iron-containing metal clips in the brain from previous surgery.

In the previous section on the emergency room, we discussed the roles of some surgical specialists. Even more individuals can be involved in the ICU. This can be quite confusing! If you are uncertain who is the primary physician responsible for care of your loved one, ask the head nurse. The nurse can answer questions and, if necessary, call the doctor for you. Some nonsurgical physician specialists often involved at this time include:

- **Anesthesiologist**—Administers anesthesia for surgery.
- **Cardiologist**—Specialist in diseases involving the heart.
- **Dermatologist**—Specialist in skin diseases.
- **Endocrinologist**—Specialist in the hormonal systems.
- **Gastroenterologist**—Specialist in stomach and intestines.
- **Infectious diseases specialist**—Treats various infections.
- **Internist**—Specialist in general internal medicine.
- **Nephrologist**—Specialist in kidneys and body fluid balance.
- **Neurologist**—Studies and treats brain disorders such as seizures.
- **Physiatrist**—Expert in bone and soft tissue (muscle and nerve) disorders as well as rehabilitation of disability.
- **Psychiatrist**—Expert in medical aspects of behavior problems.
- **Pulmonologist**—Specialist in lung and breathing problems.
- **Radiologist**—Specialist in X-rays and other diagnostic tests.

In many teaching hospitals, there may be various types of physicians in training. Medical students are in the first 4 years of medical training. Interns are physicians who have completed medical school. Residents are physicians taking additional years of training in a specialty. Medical students, interns, and residents are supervised by the attending physician who is responsible for the care of your loved one.

Nurses are involved in the minute-by-minute care of patients, carrying out physician orders, and performing other duties within the realm of their professional training. Nurses often get extra training to function within the specialized setting of the modern ICU. At the end of their shifts, they report on problems and progress to the nurses coming on to relieve them. Usually, there is a

head nurse responsible for overall care in the ICU and a primary nurse involved in the care of your loved one. Questions about the overall operation of the unit should be directed to the head nurse.

Many other health care professionals are likely to be involved in care of your patient.

- **Chaplain**—Helps with emotional support and counseling.
- **Dietician/nutritionist**—Expert in feeding and nutrition.
- **Occupational therapist (OT)**—Addresses hand function, splinting, and self-care skills.
- **Physical therapist (PT)**—Expert in maintaining motion and providing exercise needed to slow physical deterioration.
- **Psychologist/neuropsychologist**—Expert in behavior and thinking functions as well as individual adjustment counseling.
- **Respiratory therapist**—Expert in operating breathing machines (ventilators) and providing breathing treatments.
- **Social worker**—Expert in social aspects of illness, locating funding sources and community resources, and family counseling.
- **Speech/language pathologist**—Specialist in receptive (understanding) and expressive language disorders. Swallowing problems are also addressed.

Key Issues in the ICU: Survival, Preserve Limbs, Organs, and Function

Respiration encompasses two of the three ABCs noted in the emergency room section airway and breathing. The airway is maintained and protected, sometimes requiring a tracheostomy as noted earlier. Physicians and respiratory therapists try to wean your loved one to less and less oxygen on the ventilator and to gradually require less and less assistance in breathing. While doing this, they watch for and treat common complications such as pneumothorax, pneumonia, adult respiratory distress syndrome (ARDS) (a dangerous condition treated with proper ventilator support), and blockage of part of the airway (treated by removing the mucus through a bronchoscope). Pulmonary problems are more common in smokers and are more difficult to treat.

Circulation is maintained by eliminating sources of blood and fluid loss and by providing enough fluids to maintain adequate blood pressure. This allows good circulation to arms, legs, and vital organs. Your physician closely watches fluid balance (the amount going in compared with the amount coming out), and he sometimes needs to follow central venous pressures to avoid overloading the heart and lungs. If CVP goes too high, the inflow of fluids is reduced. Sometimes medications are used to make the kidneys pass more fluid.

Intracranial pressure is kept as low as possible by evacuating masses and blood in the brain when needed. The goal is to keep the pressure in the brain low enough so the higher arterial blood pressure will allow adequate blood flow into the brain. Your physician may reduce metabolic (energy) needs of your loved one's brain to minimize injury. Research is demonstrating new treatments that may further reduce the amount of brain injury and improve recovery.

Fractures are repaired surgically when your family member is medically stable. Many are treated with casting alone.

Physicians also monitor for obstructions of circulation. These circulation problems include interruption of arterial flow to a limb, blockage of flow from a limb (called blood clots or phlebitis), and blood clots moving from a leg to the lungs where they cause breathing difficulty. Maximizing the general medical status gets much attention in the ICU. This includes maintaining good nutrition, monitoring for infection, assuring proper bladder and bowel function, and

protecting the skin by using special beds or mattresses and by frequent turning of the patient to prevent bed sores.

Storming, an abnormal reflex response that follows severe head injury, produces rapid pulse, a high blood pressure, sweating, and sometimes fever. Storming is controlled with medications and by removing sources of pain and excessive stimulation.

Therapists are deeply involved in controlling the spasticity (overactive muscles) that often follows severe head injury. Positioning, exercise, casting, and splinting are techniques used to help maintain range of motion and prevent deformity. Your physician may need to add medications or injections to reduce severe spasticity. Untreated, spasticity leads to contractures (permanent joint deformities).

Coma stimulation is a therapy treatment that is sometimes started in the ICU when intracranial pressure is no longer a problem and the patient is still in coma (see the section on Coma in this chapter). With this technique, your loved one's senses of vision, hearing, smell, taste, touch, and motion are bombarded, first to generate any response and then to generate more focused and sophisticated responses. Therapists change treatment as the brain begins to recover and the patient improves. Patients often awake from coma in an agitated state and stimulation must be decreased. Although awake, the patient in the agitated phase is not responsible for his actions and words and must be protected from himself. As the patient becomes more capable of learning, cognitive (thinking) deficits are addressed.

- When will he be well enough to leave the ICU? (Is it too soon?)

Leaving the ICU is both frightening and a relief. The sophisticated life-support equipment necessary for the severely ill patient is no longer needed once the patient is medically stable. This means there is no further need for major surgery, intracranial pressure is normal, blood pressure and breathing are stable (usually the patient is off the ventilator), and infections are under control. However, he may still have feeding tubes and urinary catheters.

- Why go on when he is being kept alive on tube feedings and a breathing machine?

This is a difficult question. The greatest fear of many people is to be kept alive "like a vegetable," suffering and without control of one's body. Yet, most people placed on a ventilator because of traumatic brain injury can be weaned from it. In most cases, then, it is a temporary treatment rather than a life sentence. However, in rare cases of severe injury, the brain may not recover, even though the body does not die.

Brain death is the absence of any brain function whether or not the heart is still beating. Its legal definition varies. Various tests are performed to determine brain death. Clinical examination is first. In brain death, the patient does not breathe on his own, does not move, shows no eye responses, and displays no reactions to touch. An electroencephalogram (EEG) confirms the clinical impression when there is a flat line indicating no brain activity. Evoked potential studies showing no response help confirm the dismal clinical picture.

For patients who are brain dead, there is one gesture that is a true affirmation of life organ donation. There is a great need for various organs among people suffering from heart disease, kidney failure, blindness, and other conditions; yet, there is an even greater lack of organs. Donating organs allows the departed to contribute to the life of another and, in a sense, live on. Because most religions agree that the soul/mind and the body are separate and distinct, there are usually no religious blocks to this great act of faith. On the other hand, just because he is not brain

dead does not mean he will wake up. Unfortunately, some patients fail to achieve much more than mere survival and remain in a permanent vegetative state.

COMA

What is coma?

The word derives from the Greek word *koma*, which means deep sleep. It is a state of unconsciousness from which one cannot be aroused at the time. Further definition becomes cloudy because the word unconsciousness has literary, medical, philosophical, and psychological meaning. As a medical term, there are various levels of consciousness. One may be asleep, yet responsive to certain stimuli and capable of some mental activity such as dreaming. One in coma appears asleep, but is incapable of reacting adequately to his surroundings. One in semicoma is capable of some reflex responses.

There are many causes of coma besides traumatic brain injury. It may be due to an ingested substance or to a substance created by the body because of disease. Ingested substances include alcohol, barbiturates, or other drugs. Some diseases that can cause coma are kidney failure, liver failure, very low or very high thyroid states, uncontrolled diabetes, fluid imbalance, and inadequate oxygenation. A comalike state can be seen following seizures. Also, medications such as curare can lead to such total muscle paralysis that the patient seems to be in coma, but is actually wide awake. This type of medication is used with some ventilator patients and during surgery.

Where coma is related to diseases, it is a medical issue. However, as a stage of recovery from traumatic brain injury, it is more a rehabilitative issue. (See information on coma stimulation in the ICU section of this chapter.) Length of coma is used by some to define the severity of traumatic brain injury. (See Table 2-2.)

In a practical sense, coma ends when the patient opens his eyes and responds to stimulation. Level of consciousness is defined in the Glasgow Coma Scale. On this 15-point scale, coma is a score of 8 or less. Values are assigned for eye opening, movement, and speaking, and then totaled for the three areas. (See Table 2-3.)

The Glasgow Coma Scale represents the three different parts of the brain where injury produces coma. (See Figure 2-8, which shows the brain stem and reticular activity system.) The motor component of the Glasgow Coma Scale shows what part of the brain has been damaged. Injury to the diencephalon and cortex produces decorticate rigidity (arms are flexed and legs extended—motor response = 3). Injury to the midbrain or upper pons produces decerebrate rigidity (arms and legs are both extended motor response = 2). A more severe injury to the lower pons or medulla eliminates these movements (motor response = 1).

Table 2-2 The Length of Coma Defines Severity of Head Injury

Length of Coma	Severity of head Injury
Under 1 hour	Mild
1-24 hours	Moderate
Over 24 hours	Severe

Table 2-3 Glasgow coma Scale

	Response	Score
Eye Opening	Spontaneously	4
	To verbal command	3
	To pain	2
	No response	1
Best motor response to stimuli	Obeys verbal command	6
	Localizes pain	5
	Flexion—withdrawal	4
	Flexion—abnormal	3
	Extension	2
	No response	1
Best verbal response	Oriented, converses	5
	Disoriented, converses	4
	Inappropriate words	3
	Incomprehensible sounds	2
	No response	1

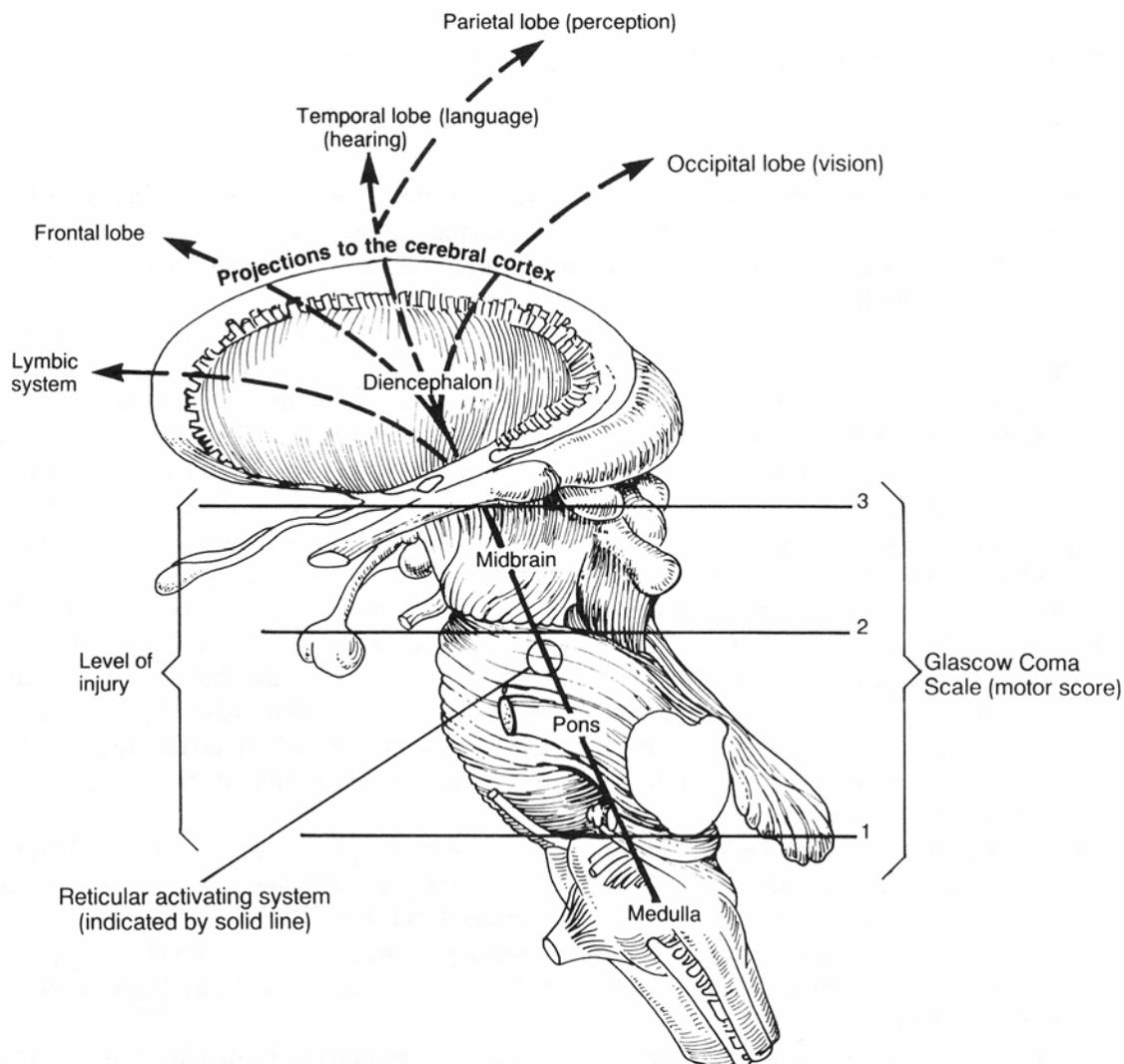


Figure 2-8 Brain Stem and Reticular Activating System

Scores on the Glasgow Coma Scale are used in a variety of ways. Scores of 13-15 are considered to represent mild head injury, scores of 9-12 are moderate, and scores of 8 or less are classified as severe. In addition, many rehabilitation centers use this scale to determine whether an injured person is eligible to enter their program. Although rehabilitation progress may be limited for scores of 8 or less, progress can be made at almost all levels of this scale. The lowest possible score is 3.

Function of the different parts of the cortex and brain stem reflect the status of the reticular activating system (RAS) that lies within. The primary purpose of the RAS is to maintain consciousness. It is injury to the RAS (also known as the reticular formation) that produces coma. Such injury can be caused by local damage to the RAS in the brain stem, outside pressure on the brain stem, or widespread injury to both hemispheres of the brain (see Figure 2-8).

Coma sometimes protects the brain function. Your physician may produce a deeper coma called "barbiturate coma" in an effort to protect the brain by slowing bodily functions and lowering the brain's oxygen and energy needs. Sometimes other treatments are used for the same

effect. This is similar to what occurs when young children fall into very cold water. Their brains are plunged into a state of low functioning due to the hypothermia. This can lead to some children tolerating long periods under water without oxygen with surprisingly little brain injury.

SPECIAL MEDICAL PROBLEMS IN THE ACUTE SETTING

Nutrition

Good nutrition is important to recovery in all medical conditions, and traumatic brain injury is no exception. In fact, severe brain injury can increase demand for calories and nutrients far beyond normal. When calorie and protein requirements are so high and the patient is unable to eat, tube or intravenous (through the vein) feeding is important.

Fluids through the veins are not enough to sustain even a healthy person for long. Your doctor must therefore begin tube feeding for your loved one if he has a healthy stomach and intestinal tract. Tube feeding is usually first attempted by means of a tube passed through the nose and into the stomach. When the tube is securely in place, various types of feedings are used. Tube feedings are given either continuously and gradually by a feeding pump or in large amounts by syringe every few hours. Because tube-feeding formulas can cause diarrhea, they are often started at less than full strength and at a slow rate. If your loved one had problems tolerating milk products before the head injury (bloating, gas, or loose stools), your physician will choose a tube-feeding formula that does not contain milk products. If tube feeding is needed for a long time, your doctor may consider tube placement directly into the belly to avoid complications that may be caused by a tube through the nose. These complications can include irritation of the nose, stomach, and throat, and a greater tendency toward vomiting with a chance of inhaling food or other matter into the lungs. Tubes are placed either directly into the stomach or into the intestine. Diarrhea in the hospital can also be a side effect of medications or be due to a form of bacterial colitis (inflammation of the colon) seen in people who have been on antibiotics.

Intravenous (into the vein) feedings to supply all nutrients are given either when the gastrointestinal (GI) tract is not working adequately or when calorie requirements are too high to be supplied through the GI route alone. This is called total parenteral nutrition (TPN) and is usually given through large IVs in the neck or upper chest. The feedings contain protein, carbohydrates, fats, vitamins, and essential minerals. The patient on TPN is monitored closely by blood tests for tolerance of the formula. The huge nutritional requirement in head injury is caused by an outpouring of adrenalin and other hormones from glands in the body. Sometimes in this hypermetabolic state, there is also elevation of heart rate and respiration, high blood pressure, fever, and sweating. These responses are treated medically. Injury to the hypothalamus can also cause central fever by damaging the body's central mechanism for controlling temperature.

Ventilators

As noted in the ICU section of this chapter, some patients with severe brain injury require ventilator assistance to breathe. The ventilator is also helpful in controlling what gets into the airway, thereby preventing pneumonia caused by food inhalation. Rapid breathing with the help of a ventilator is also used after head injury to reduce intracranial pressure.

Tracheostomy

Prolonged dependence on a tube through the mouth can sometimes damage the airway itself. Irritation from a tube can lead to narrowing of the airway. This is evident later by breathing

difficulty or noisy breathing. It may require corrective surgery. For this reason, a tracheostomy is considered appropriate for some patients. With a tracheostomy, an opening is made in the throat directly into the trachea in such a way as to avoid damage to the larynx (voice box).

Phlebitis and Heterotopic Ossification

Swelling of a limb after head injury, a sign of a significant problem, can be due to phlebitis (inflammation of a vein). Blockage of blood flowing from the legs back to the heart of paralyzed or immobilized patients is often seen. It can be locally painful in the leg but rarely in the arm. It is very dangerous if the blockage breaks off and flows into the lung causing a pulmonary embolus (PE), which can be fatal. Phlebitis is usually treated with blood thinners. Also, a filter (called a Greenfield filter or an umbrella) may be placed to keep the blood clot from moving. Treatment depends on the clinical situation.

Steps are sometimes taken to try to prevent blood clots. These steps include use of support stockings (TED, Jobst, and Juzo hose), variable calf compression, leg elevation, and medications. Swelling of a limb can also be due to heterotopic ossification, a deposit of bone material in muscles and other normally soft tissues around major joints. It occurs frequently in spastic patients with severe head injury, normally around the shoulders, elbows, hips, and knees. This problem can be treated medically in the early stages. Rarely is surgery needed. The exact cause of heterotopic ossification is still unknown.

Seizures

Seizures are frequently seen soon after a head injury and can also occur later as posttraumatic (after the injury) epilepsy. Posttraumatic epilepsy occurs in approximately 5 of all head-injured patients, but it is much more common in certain types of head injury. In one study, patients with intracranial bleeding had a 40 incidence, patients with subdural clots had a 20 incidence, and patients with early seizures had a 15 incidence. Patients with none of these factors had less than 1 chance of late seizures. (See Chapter 18 for further discussion, particularly when children are involved.)

There are several types of seizures. Generalized seizures (commonly known as grand mal seizures) cause stiffening (tonic) and jerking (clonic) movements of the arms and legs. The patient loses consciousness and often loses control of bowels and bladder. Often there is a period of great fatigue following a generalized seizure. Partial seizures (focal motor seizures) cause no loss of consciousness, but are demonstrated by movements of a limb or the face only. Complex partial seizures (commonly known as petit mal seizures) are not commonly seen following head injury. Complex seizures (temporal lobe seizures) result in bizarre repetitive activities of which the patient has no memory. Such activity varies from continually rubbing the head to getting up and turning a doorknob.

Some patients who have suffered head injury are placed on anticonvulsants (seizure medicines) for prevention. Some are considered in the high-risk group and need protection. Several types of anticonvulsants are discussed in Chapter 16. What to do if a seizure occurs is discussed in chapter 13.

NORMAL BRAIN FUNCTION

The brain is the command and control center for the rest of the body. The brain controls breathing, sensation, movement, emotions, and thought processes. It is the part of the central nervous system (CNS) that receives and interprets information, decides on a response, and

coordinates the action through body movements. Information enters through nerve endings throughout the body. Messages are transmitted through nerves to enter the CNS at the spinal cord (the thick bundle of nerves surrounded by the backbone). Messages are transmitted up the spinal cord through the brain stem into the thalamus and into the cortex. There, billions of neurons (brain cells) process information. Messages from the cortex are transmitted down different nerves through the same general areas. The cerebellum (part of the brain responsible for coordinating voluntary muscle movement) often responds to and helps coordinate a motor response. From the spinal cord, motor nerves exit to carry out commands generated from the brain.

The brain can be thought of as divided into two halves or hemispheres. The right hemisphere of the brain controls the left half of the body, and vice versa. That is why an injury to the right hemisphere of the brain produces problems with motion, feeling, and sight on the left side of the body. See Figure 2-9.

The control of the brain over movement can be exerted directly or indirectly. It is somewhat similar to the structure of a large corporation such as Ford Motor Company. Mr. Ford can directly tell the assembly line workers how to build the car. His message will certainly be understood but he will make fewer cars than if he delegated the supervisory duties to vice presidents, division supervisors, and unit supervisors. Similarly, our conscious minds can only perform one or two new complex movements at a time. Yet, once we have learned a task (delegated it to our subconscious mind), it can be carried out without thinking about it, while the conscious mind addresses other matters. This is easily seen in playing the piano. At first, the conscious mind struggles to make the fingers move properly to play the right notes, then scales, then simple songs. Later, as with an accomplished pianist, much of the playing can be done subconsciously with the eyes closed.

This step-by-step learning process also applies to memory. For example, the actress learns her lines word by word, line by line, scene by scene – until she knows her entire role. Later, in the play, her subconscious mind helps her recall the lines with ease so she can concentrate on her acting.

The role of the cortex and subcortical brain in controlling movement of the body can be compared with operating a chariot. Imagine a chariot driver controlling a group of vigorous horses with a set of reins. The horses want to run—sometimes in different directions—and the reins hold them back. The driver is the conscious mind, the reins are upper motor neurons (UMNs), and the horses are lower motor neurons (LMNs) and their respective muscles. If there is an injury to the driver (UMNs or brain), the reins are cut and control is lost over the horses (LMNs and muscles). This results in uncontrolled muscle contraction called spasticity. If there is damage to just a few UMNs, the muscle contractions will make it more difficult to exert control over the remaining LMNs and muscles (i.e., loss of a few reins will lead to loss of control of a few horses making it more difficult to control the chariot. See Figure 2-10.

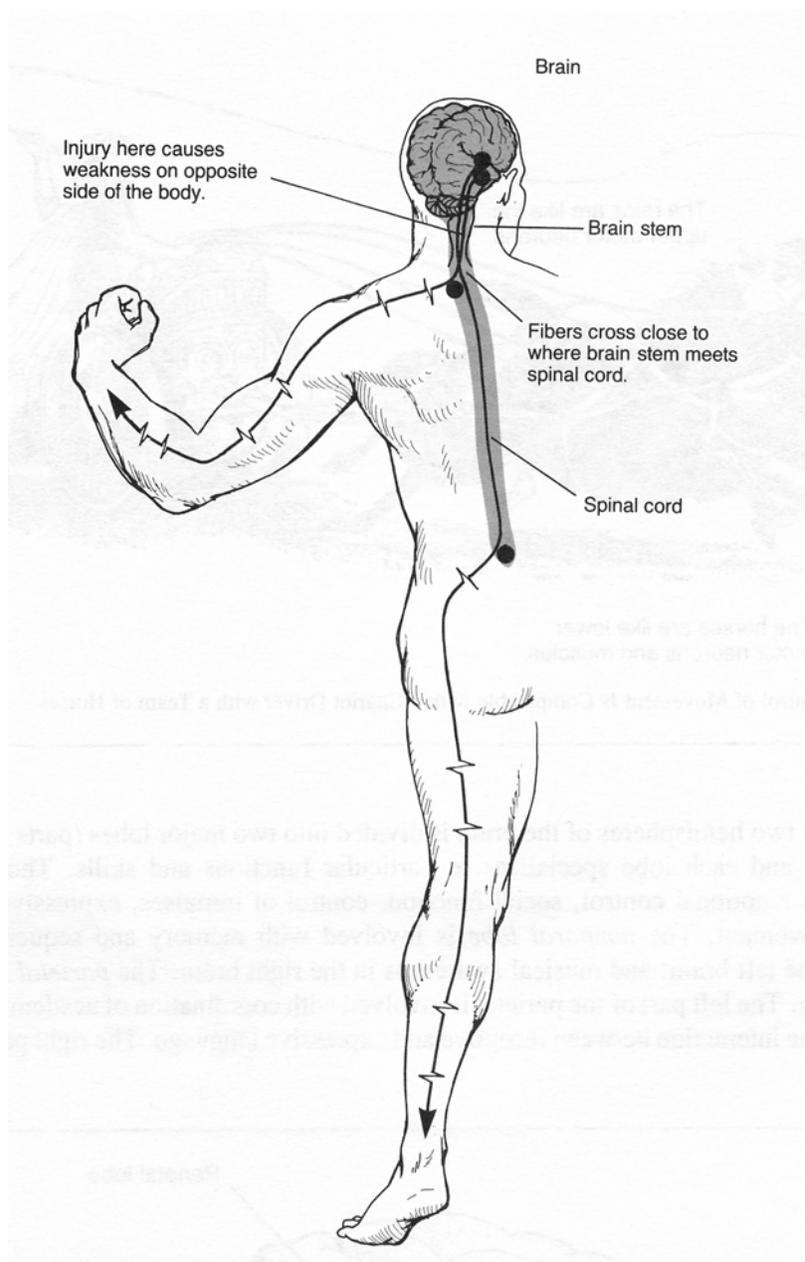


Figure 2-9 One Hemisphere of the Brain Controls the Other Half of the Body

Sensory functions are similarly controlled at both subcortical and cortical levels of the brain. Basic sensory input regarding pain, touch, or position is sent to the subcortical areas of the thalamus. These basic senses are then projected to the parietal lobes (higher cortical areas that interpret what is being felt and attach emotional content to it, such as a feeling of peace in a hot bath). Sensory functions are also vital for normal control of movement. It is through awareness of the exact position of a limb in space that the subcortical areas can allow maximum development of coordination.

The two hemispheres of the brain process information in very different ways. In a right-handed person, the left hemisphere is dominant, which means language function is controlled in

the left brain. The left brain learns by processing information in a step-by-step manner. The right brain learns by grasping multiple concepts of the bigger picture at one time. The left brain processes information linearly, line by line, as if reading a book, while the right brain grasps information as a whole. If you read this book cover to cover, you are doing left-hemisphere learning. If you read by concept or topic as suggested in the introduction, you are applying right-hemisphere processing.

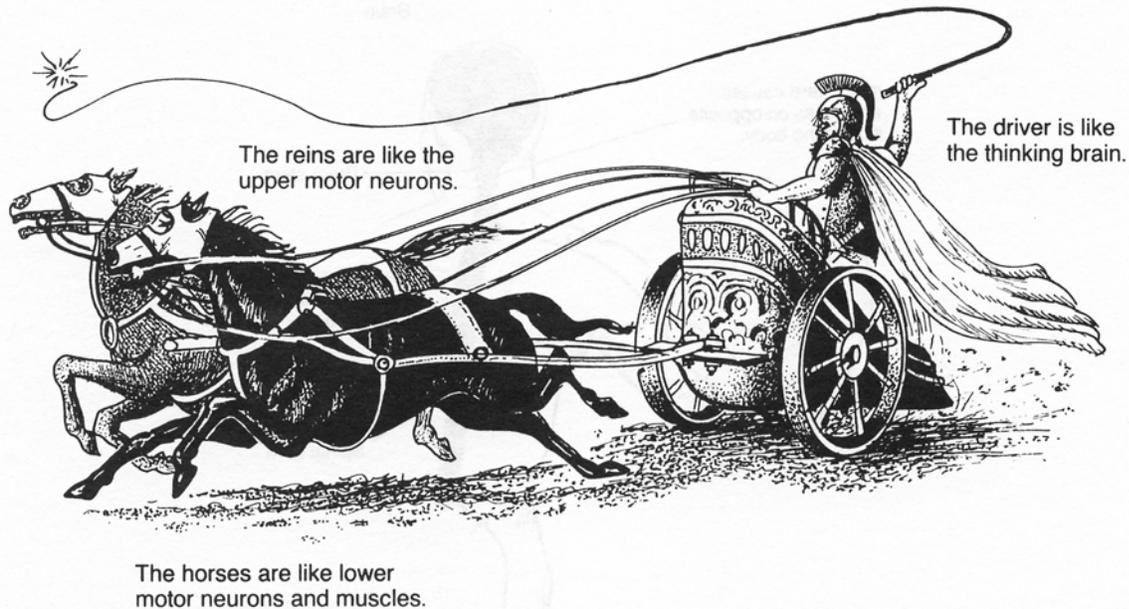


Figure 2-10 Control of Movement Is Comparable with a Chariot Driver with a Team of Horses

Each of the two hemispheres of the brain is divided into two major lobes (parts of the brain, see Figure 2-11), and each lobe specializes in particular functions and skills. The frontal lobe is involved with emotional control, social function, control of impulses, expressive language, and voluntary movement. The temporal lobe is involved with memory and sequencing, receptive language in the left brain, and musical awareness in the right brain. The parietal lobe is involved with sensation. The left part of the parietal is involved with coordination of academic skills, such as reading and the interaction between receptive and expressive language. The right part of the parietal

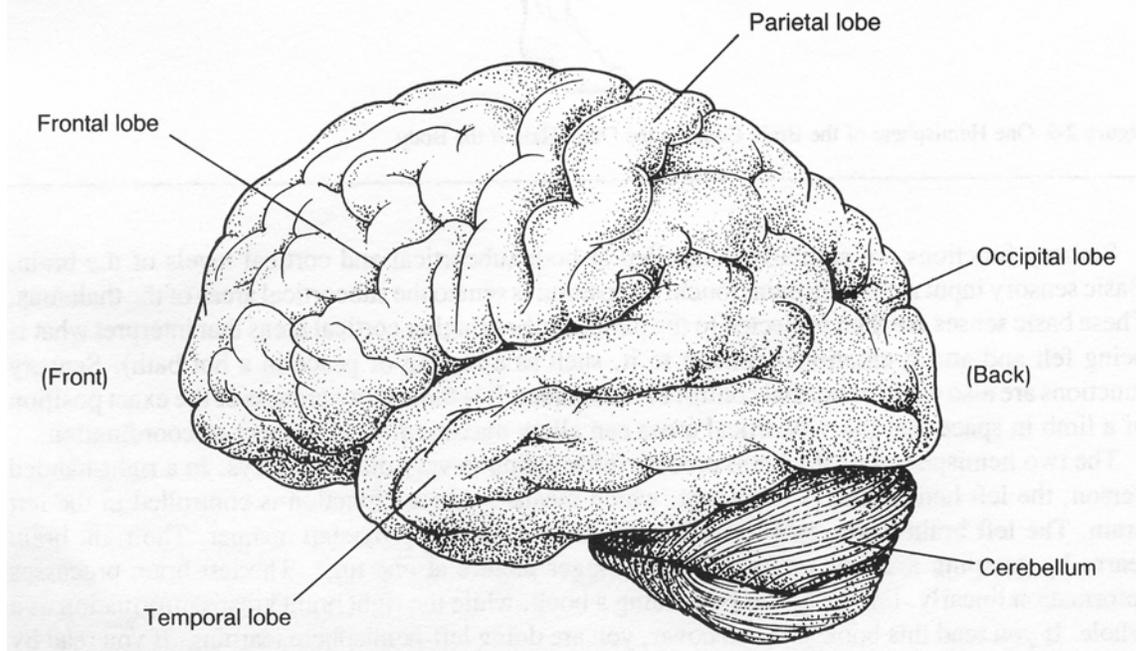


Figure 2-11 The Lobes of the Brain

is involved with awareness of special relationships, recognition of faces, time awareness, judgment, and awareness of the significance of things that have happened. The occipital lobe is involved with reception of the visual image in both eyes.

The dominant left hemisphere controls verbal function, such as comprehension, language, speaking, reading, and writing. The right hemisphere controls visual-spatial functions, such as visual memory, copying, drawing, rhythm, and musical appreciation.

The processing areas of the lobes are made up predominantly of gray matter. The largest group of these subcortical (below the cortex) structures are the basal ganglia. This includes the thalamus, hypothalamus (diencephalon), and limbic system. The cerebellum also represents gray matter that is involved with processing information.

The subcortical structures project into the brain stem, a critical structure involved with consciousness and arousal, as well as such vital life functions as temperature, heart rate, blood pressure, and respiration. The brain stem includes three major areas the midbrain, the pons, and the medulla (see Table 2-4). The cerebellum (concerned with muscle coordination and bodily equilibrium) sends projections into the brain stem at the level of the pons. Twelve important lower motor neurons called cranial nerves, which are involved with functions of the head and neck, project from the brain stem. The brain stem and these cranial nerves are particularly susceptible to injury, because so many important functions are confined to a relatively small space. The brain stem exits the skull through the foramen magnum (opening in the skull).

These important brain structures are protected by a hard, bony skull. The bones in the skull have holes inside called sinuses. These drain outside to nasal passages, but normally do not connect with the inside of the skull near the brain. If they were to connect, infection could be carried from the outside to the inside of the brain causing meningitis (brain infection). (See Figure 2-3.)

The inside surface of the skull near the occipital lobe is smooth. The inside surface of the skull near the frontal and temporal lobes is rough. Greater injury can occur more readily to those parts of the brain near rough surfaces, and this will be discussed later.

The brain is covered and its major parts divided by a firm tissue called the dura. The falx (a fold of firm tissue) separates the right and left hemispheres of the brain. The tentorium cerebelli (another firm tissue) separates the cerebellum from the cerebrum. Trauma (excessive pressure) in the brain against the foramen magnum or the tentorium cerebelli can cause brain-stem injury, enlargement of the pupil, stopping of breathing, and death. With injuries that cause more lateral (sideways) movement of the brain, there will be movement of the inside of the hemisphere against the falx causing more damage to this area. This produces more leg than arm weakness on the opposite side of the body.

Another protective structure for the brain is cerebrospinal fluid (CSF). CSF serves to support the brain by allowing it to "float" within the bony skull and cushion it against trauma. CSF circulates on

Table 2-4 Function and Location of Cranial Nerves

Cranial Nerves	Functions	Part of Brain Stem
I	Smell	Midbrain
II	Vision	
III, IV, VI	Control of eye movement	
V	Sensation in face	Pons
VII	Movements of face muscles	
VIII	Hearing and inner ear function	
IX, X	Swallowing	Medulla
XII	Tongue movement	

the outside of the brain and inside the brain through four open structures called ventricles. The normal adult has 3 to 4 ounces of this clear, colorless fluid. CSF also serves to promote circulation of certain important chemicals in and out of the brain. This fluid is produced so rapidly that it is renewed approximately five times every day. Produced by the blood, it is resorbed by special structures designed for this purpose (choroid plexus) within the ventricles. If there is a blockage to this circulation of fluid, the volume of spinal fluid will build up within the brain, thus enlarging the ventricles, and produce hydrocephalus.

Besides circulating chemicals in the brain through the CSF, the brain neurons produce over thirty chemicals, or neurotransmitters. For each neurotransmitter, there is a specific receiving site. These are as specific as a lock is to a key. A wide variety of all types of neurotransmitters has been found. Narcoticlike neurotransmitters produced by the brain, called endorphins, have even been discovered. Medications used by physicians affect the receiving sites and act to change the chemical make-up of the brain for therapeutic purposes.

NATURE OF BRAIN INJURY

A concussion (blow to the head) can lead to temporary or permanent damage. A mild concussion can occur from bumping the head and "seeing stars" or it can cause a brief period of confusion without loss of consciousness. A full concussion causes loss of consciousness. Traumatic brain injury requires a blow serious enough to overcome the protection of the skull and CSF. The brain is soft and is surrounded by a hard bony skull somewhat like Jell-O in a bowl. A hard blow to the bowl will shake the Jell-O inside, pulling parts away from each other. Similarly, with a blow to the head, the brain bounces and swirls within the skull causing widespread trauma a little bit of damage everywhere.

Billions of nerve cells are compressed, stretched, twisted or torn by these violent forces. It is this generalized injury disrupting the fine connections between neurons and shearing other neurons that makes traumatic brain injury different from diseases such as a stroke, where only one part of the brain is affected. The most severe injury of this type is called diffuse axonal injury.

Now imagine half of the inside surface of the bowl of Jell-O is rough like a cheese grater. The same hard blow noted before will cause more injury to the Jell-O next to this rough area because of the rough surface. Similarly, the inside surface of the skull next to the frontal and temporal lobes of the brain is rough. In most cases of traumatic brain injury, there is more damage to the frontal and temporal poles areas involved with attention, memory, and emotion. See Figures 2-12 and 2-13.

Now imagine that all of the Jell-O is free-floating in the bowl except for a half-dollar-sized portion stuck to the bottom. Twisting the Jell-O in the bowl will cause more damage to this fixed area. Similarly, the brain is fixed by the brain stem, which exits through a hole called the foramen magnum to enter the neck. Twisting of the upper brain on the fixed brain stem causes injury to the pathways to and from the brain stem and spinal cord. It often causes loss of consciousness. (Another cause of loss of consciousness is diffuse and bilateral cortical injury widespread injury to both sides of the brain.) Extreme injury of this type causes severe paralysis and spasticity of the arms and legs. See Figure 2-14.

Anoxic (or hypoxemic) brain injury is another type of generalized damage that can occur. It is caused by a lack of blood flow to the brain depriving the brain of oxygen and nutrients vital for its survival. Stopping blood flow to the brain for more than 3 minutes causes brain damage, and stopping blood flow for 10 minutes can cause brain death. Although most common in those who have suffered a cardiac arrest or a respiratory arrest (the heart stops pumping, the lungs stop breathing), anoxic brain injury can occur with traumatic brain injury. It is most common when there is massive blood loss, injury to the breathing apparatus, or such severe swelling in the brain that blood flow into the brain is seriously reduced. Anoxic brain injury affects deep-brain structures and certain other sites most severely memory, sensation, coordination, and vision.

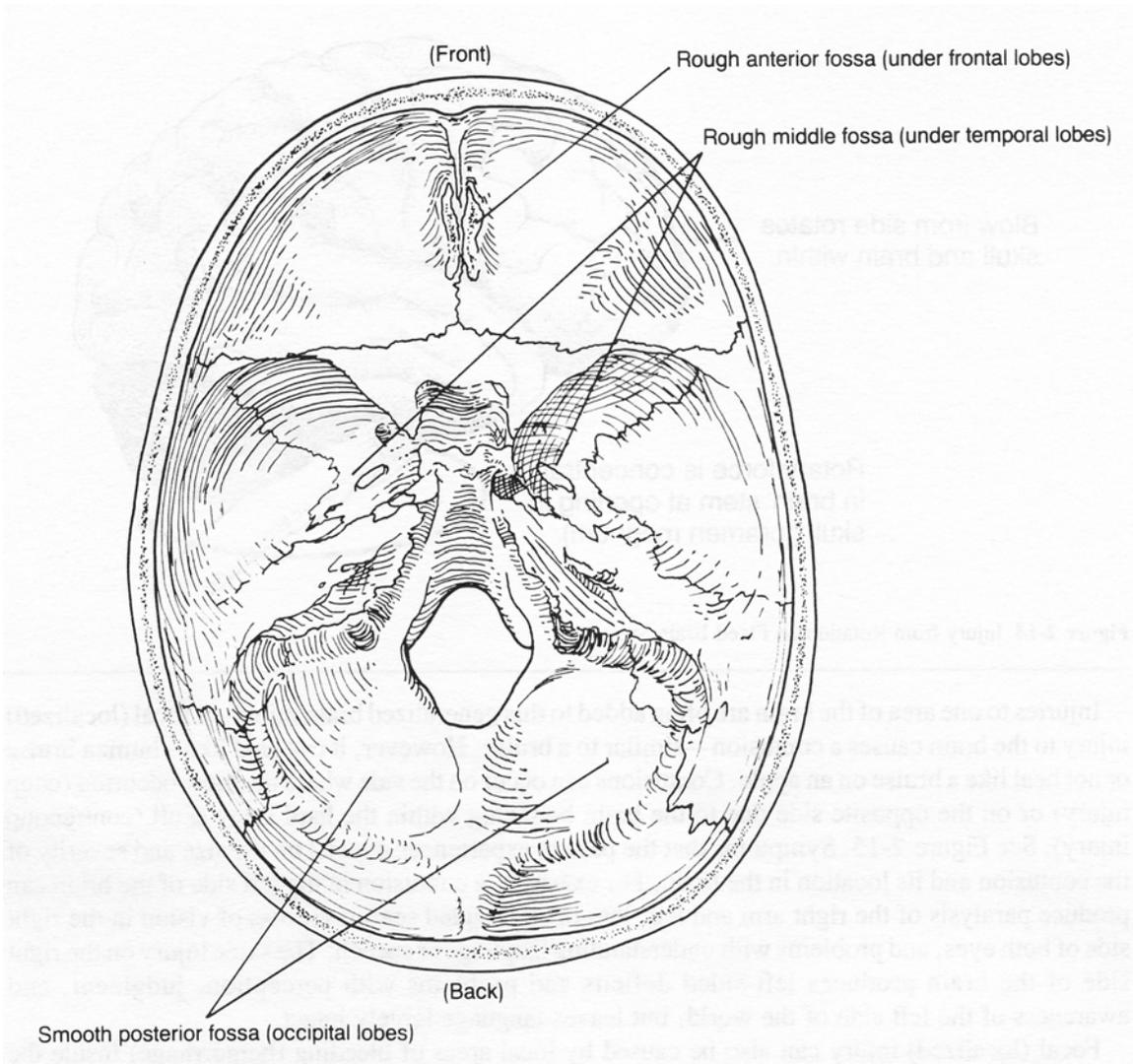


Figure 2-12 Bones at the Base of the Skull

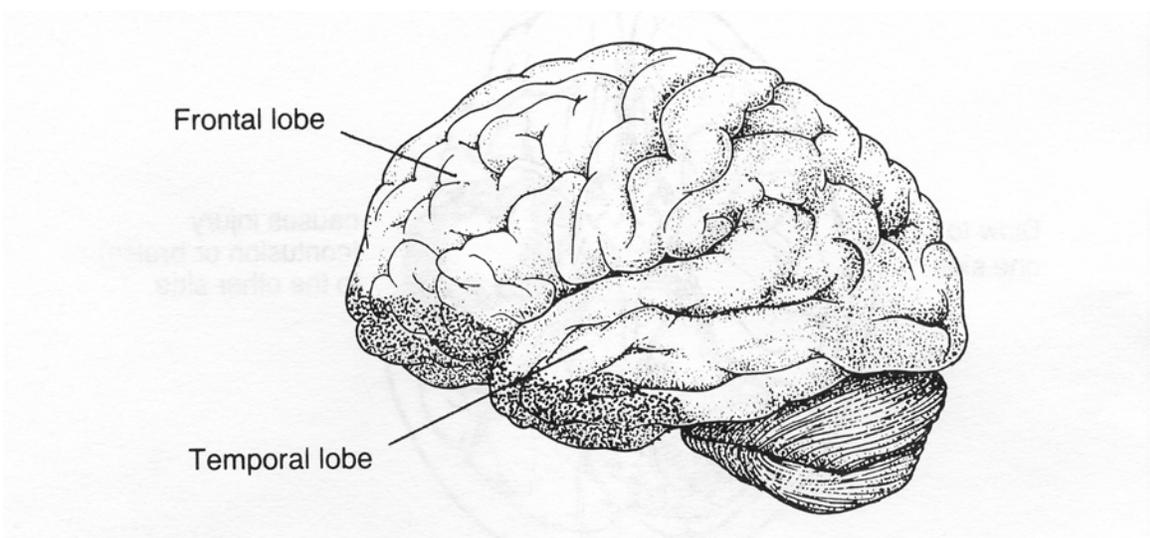


Figure 2-13 Areas of Brain Most Damaged by Rubbing against Rough Surfaces of Underlying Skull at the Base of the Brain

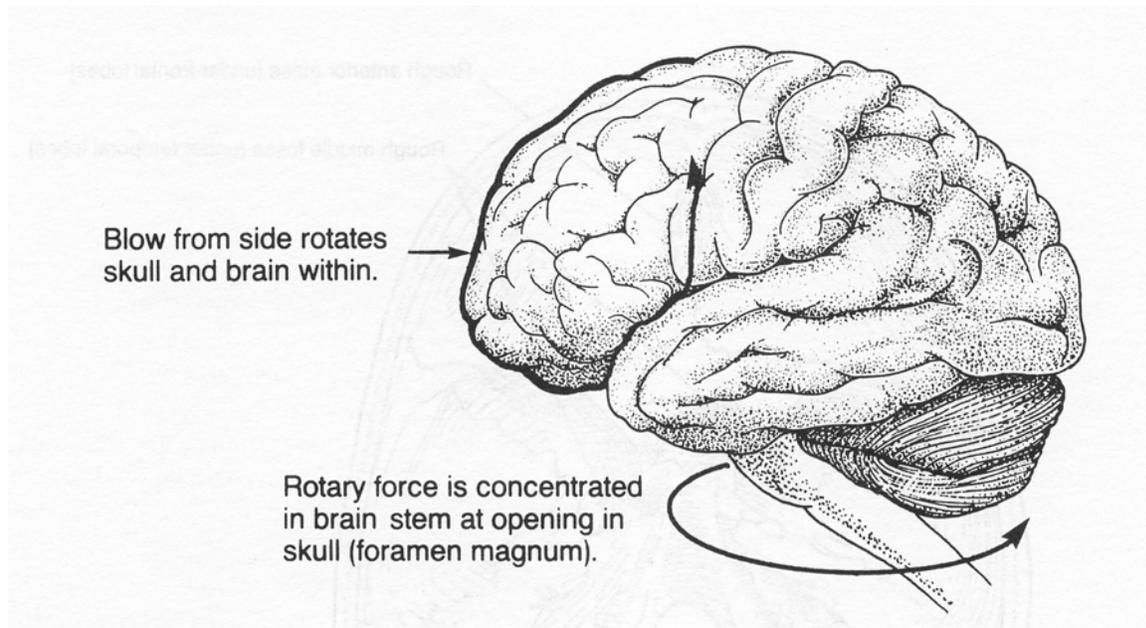


Figure 2-14 Injury from Rotation on Fixed Brain Stem

Injuries to one area of the brain are often added to this generalized brain injury. A focal (localized) injury to the brain causes a contusion similar to a bruise. However, it can heal like a human bruise or not heal like a bruise on an apple. Contusions can occur on the side where the blow occurred (coup injury) or on the opposite side due to the brain bouncing within the hard bony skull (contrecoup injury). See Figure 2-15. Symptoms that the patient experiences depend on the size and severity of the contusion and its location in the brain. For example, a contusion in the left side of the brain can produce paralysis of the right arm and leg, loss of right-sided sensation, loss of vision in the right side of both eyes, and problems with understanding language or speech. The same injury on the right side of the brain produces left-sided deficits and problems with perception, judgment, and awareness of the left side of the world, but leaves language largely intact.

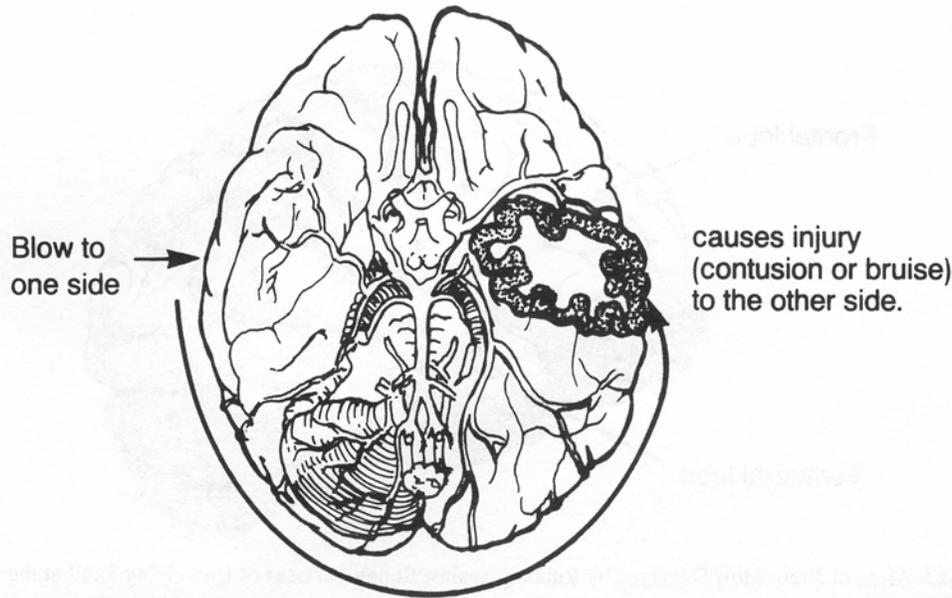


Figure 2-15 Contrecoup Injury

Focal (localized) injury can also be caused by local areas of bleeding (hemorrhage) inside the skull. The growing mass of blood within a closed space (hematoma) puts pressure on the underlying brain disrupting function or causing damage. A hematoma can also cause severe injury by building intracranial pressure (ICP) (pressure within the brain) to such a degree that further generalized brain injury or even death can occur. Hematomas are of the following three types, named for their site and cause: intracerebral, from blood vessels within the brain; subdural, from blood vessels on the surface of the brain (and under the dense covering of the brain called the dura); and epidural, from blood vessels under the surface of the skull (and above the dura). Sometimes hematomas will not be obvious after the initial head injury, but will show their effects later.

Subarachnoid hemorrhage (SAH) is due to bleeding of arteries on the brain's surface and is most commonly associated with abnormal dilatation of a blood vessel (aneurysm) or abnormal connection between blood vessels (AV malformation) rather than with traumatic head injury. However, SAH can lead to generalized brain injury by the irritant effect of blood on the surface of the brain. Spasm of major blood vessels can occur causing a lack of blood flow to an area of the brain that results in brain damage similar to that produced by a stroke. Focal hemorrhage can lead to cerebrospinal fluid build-up within the brain and dramatically increases the risk of posttraumatic epilepsy (seizures) at a later time.

A broken skull bone can also produce focal brain damage if the pieces of skull are exerting pressure against the brain (depressed skull fracture). Depressed skull fractures are also associated with a higher risk of developing epilepsy at a later time.

Infrequently, an apparently closed head injury will be open to the outside environment when a fracture opens a connection between the sinuses and the brain (especially, fracture to the base of the skull). It can be unrecognized, as it does not show up well on X-rays. This can lead to serious infection such as meningitis. An early sign in an unsuspected case is a cerebrospinal fluid (CSF) leak. It is seen as clear fluid draining from the nose when the patient sits up. It is treated with antibiotics to prevent infection and with surgery to repair the leak.

Objects that penetrate the skin and skull into the brain, such as a gunshot or knife injury, cause focal injury, but can also produce additional generalized brain damage by introducing infection and greatly increasing the risk of meningitis and encephalitis. Penetrating injuries can also produce CSF leaks and an increased risk of seizures. They always require surgery to clear away dead and contaminated tissue. Penetrating missile injuries generally produce more permanent focal injury and less generalized injury than do closed head injuries. Closed head injuries are the more common of the two types of head injuries in civilians.

Certain underlying factors may make the brain more susceptible to serious injury. Relatively minor trauma can produce severe damage if the person has had a previous brain injury. One can rebuild an engine just so many times. Other factors associated with poor outcomes are alcoholism, drug abuse, malnutrition, and older age.

Traumatic brain injury (TBI) is very different from stroke. TBI causes generalized injury throughout the brain, with certain areas more affected due to forces caused by movement of the brain within the skull. On the other hand, stroke causes focal injury due to blocked circulation in a particular blood vessel. TBI often causes simultaneous problems in such functions as attention, memory, judgment, and emotions, and also severe motor, sensory, and language problems in some patients; stroke causes focal deficits, but leaves other functions completely unaffected. Also, recovery continues over a longer period in TBI than in stroke.

TYPES OF FOCAL DEFICITS

As previously discussed, head injury is particularly distinguished as a process that involves the entire brain rather than being a focal process involving only one or a few parts of the brain. Yet, added to this can be a number of local injuries more severely involving specific parts of the brain that lead to more prominent deficits. These types of deficits are related to the anatomy (see the discussion of Normal Brain Functioning in this chapter). We now discuss some of these specific deficits.

Problems with Movement and Coordination

Motor deficits involve abnormal movement. As discussed previously, there are several levels of control over muscles. The lower motor neurons (LMNs) starting in the spinal cord pass into the muscle these are like the horses in the chariot analogy, which means they want to go all the time (see Figure 2-11). Above these are upper motor neurons (UMNs) that control the LMNs (like the reins in our analogy). UMNs are at several levels within the spinal cord, passing from the basal ganglia or cerebellum to the spinal cord, and passing from the cortex to the basal ganglia or directly to the spinal cord level (corticospinal tract). Although some of these UMNs stimulate the LMNs, the sum total are inhibitory, which means they want to go slow all the time. Injury to the LMN (root avulsion, brachial plexus injury, peripheral nerve injury, muscle injury) causes the muscle to be limp and have decreased tone. Injury to the UMN (spinal cord, brain stem, thalamus, and cortex) initially causes reduced tone, but ultimately leads to increased tone and spasm. Both types of injury lead to weakness. See Figure 2-16.

Motor pathways are crossed one half of the brain controls the other half of the body. Injuries at the brain stem or a higher level cause weakness on the other side of the body; injuries below the brain stem cause weakness on the same half of the body.

Problems with movement can also be caused by apraxia (or dyspraxia). In apraxia, a person is

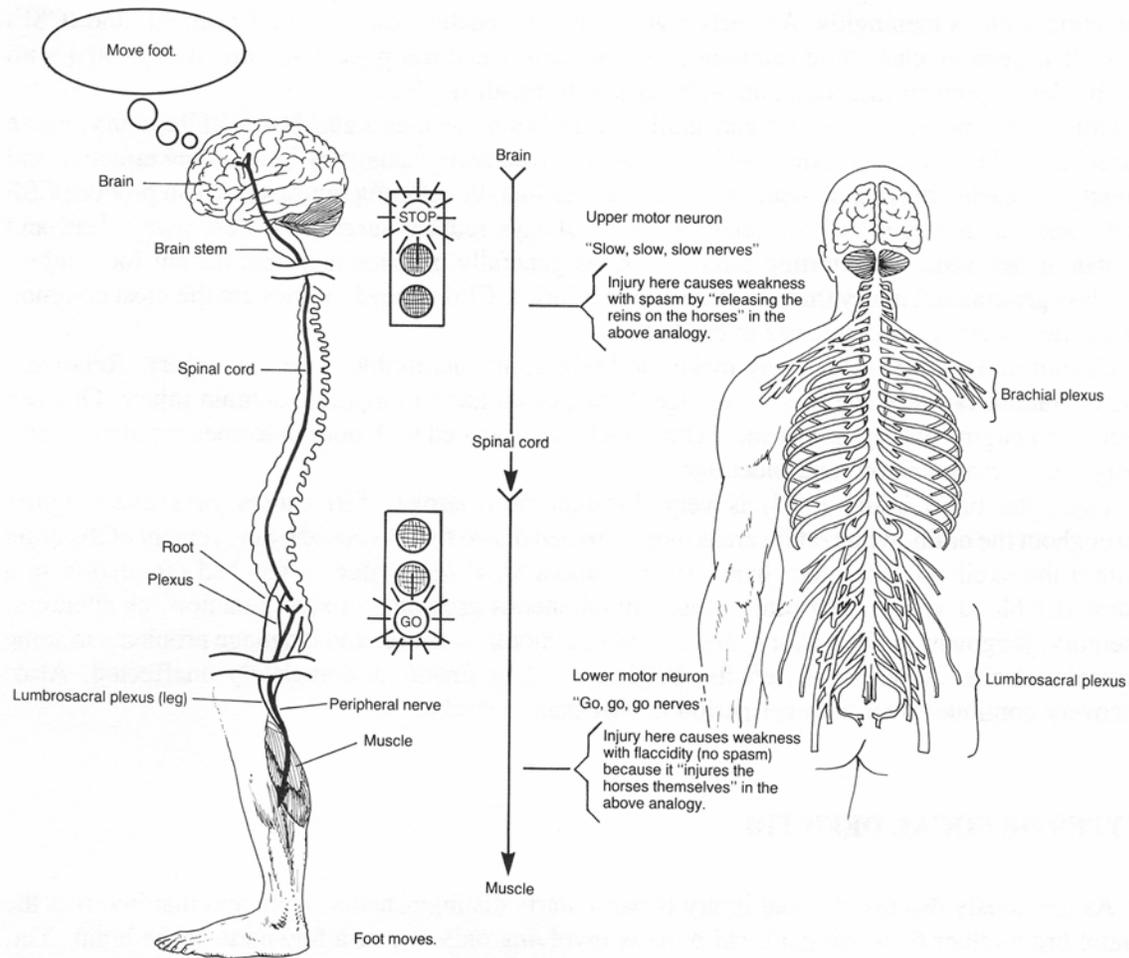


Figure 2-16 Types of Motor Injury Leading to Weakness

otherwise normal. People with apraxia appear to be not trying, as they can perform an activity spontaneously, but are unable to do it when they are concentrating on it. Apraxia is caused by brain injury

Coordination deficits are caused by disruption in pathways involved with fine control of movement. Any injury causing some weakness will affect coordination to some extent. Injuries to certain areas of the basal ganglia will cause more problems with coordination than with strength, all on the opposite half of the body. This type of movement disorder is called ataxia. Ataxia is an inability to coordinate the muscles in carrying out a voluntary movement. Ataxias originating in the basal ganglia are often associated with other abnormalities of movements: tremor (regular trembling movements not under voluntary control like Parkinson's disease), chorea (irregular spasmodic movements), ballismus (more vigorous jerking movements), and myoclonus (twitching of muscles). They are also sometimes associated with rigidity and bradykinesia (slowing of all movements). Injuries to half of the cerebellum or its pathways through the pons (part of the brain stem) cause ataxia on the same half of the body.

Coordination is also impaired in conditions in which sensation is affected particularly those that involve awareness of the position of the arm or leg

Problems with Sensation

As with motor function, sensation is served by several levels of the brain. Injuries to pathways carrying messages from sensory fibers in the skin to the spinal cord and, ultimately, to the basal ganglion (thalamus) cause loss of the ability to feel touch, pain (like a light pin poke), temperature, position, and deep pain. (These various sensations are carried by different fibers, so it is possible to have problems in one type of sensation more than in another). Sometimes injuries to the thalamus cause a distortion of sensations so that light touch or other normally pleasant sensations are felt as pain. This can be especially severe with injury to the posterior lateral nucleus of the thalamus, producing severe pain spontaneously or with minimal contact (Dejerine-Roussy or thalamic syndrome). Basic sensation is perceived in the thalamus, but is interpreted in the parietal lobe of the cortex. Injury to one side of the parietal cortex causes decreased feeling and an inability to recognize objects felt on the other side of the body.

Problems with Perception

Injury to the right parietal lobe often causes a variety of sensory and perceptual deficits. Although touch and sight may be relatively normal, they are inaccurately interpreted by the brain because of the brain injury. These can be severe enough for a person to be unable to recognize his own left hand in front of his face, to be unable to recognize he has paralysis of the left arm and leg (leading to attempts to walk alone with potential falls), and to ignore persons and events on the left half of his world. He may have anosognosia (denial that he has any problem at all) or prosopagnosia (trouble recognizing familiar faces). Even if he recognizes his wife's face, he may be disturbingly insensitive to the emotions spelled out on her face, in her voice, or in her body language. He may have impaired judgment, but yet be unwilling to take advice or wait his turn in conversation (poor listening skills). Not uncommonly, he will blame others for his deficits ("If they'd only let me get up, I could walk" or "If they'd just let me go home, I'd be better"). The patient with a right parietal lobe injury can seem fairly normal because language skills and logic are relatively preserved, but the ability to perceive the world clearly is devastated. It is as if he were seeing the world in a shattered mirror one small part at a time and is incapable of putting the pieces together.

Problems with Eyesight

Vision originates with a message perceived in the retina at the back of the eyeball and carried along the optic nerve to the optic chiasm. There, the nerve fibers split so that vision from the left side of both eyes is carried to the right brain and vice versa. Thus, an injury to one cortex can often cause blindness of the opposite half of both eyes. A hemisphere injury does not cause blindness in one eye. (Blindness in one eye is caused by injury to the eye itself or to the optic nerve.) Vision is interpreted in the occipital lobe. Destruction of both occipital lobes leads to central blindness. In central blindness, the pupils of the eye respond, as the eye itself is normal, but the person sees nothing.

Problems with Language

Language is almost always a function dominated by the left hemisphere of the brain. Injury to parts of the left temporal, parietal, or frontal lobes often causes aphasia (disordered language). There are several types of aphasia. These are usually divided into expressive or Broca's aphasia (problems with speaking), receptive or Wernicke's aphasia (problems with understanding), anomic

aphasia (problems with word finding), or global aphasia (problems in all areas). Some speech and language pathologists use a diagnostic system that recognizes the specific deficits, but does not group them into specific categories such as these. Not uncommonly, language can be affected without aphasia. Dysarthria is a problem with coordination of the oral muscles. Dyspraxia or apraxia is a problem with speaking that occurs without aphasia or loss of coordination.

Mutism is another type of speech disorder. Patients emerging from coma may not speak, although their oral musculature is functioning and they do not appear to have aphasia. Sometimes, they will spontaneously start speaking in sentences. Mutism also occurs when there is injury to the deep frontal brain, as in a ruptured anterior communicating artery aneurysm. In akinetic mutism, a person will not speak unless spoken to and will not initiate any activity spontaneously.

Problems with Behavior and Thinking

Injury to the frontal lobe often causes problems in cognitive (thinking) functions and can cause changes in personality. Cognitive deficits include problems with attention and concentration on the tasks at hand, combined with inflexibility (difficulty accepting changes in the routine) and perseveration (difficulty switching from one topic to another). The patients have a problem retaining new memories and recalling them later. There may be difficulties with problem solving and decision making, yet they deny or show lack of concern about these problems, even though they are confused and disoriented as to what is going on around them. (See Chapter 10 for a thorough discussion of cognitive deficits and how to manage them.)

Personality changes occur in the context of the underlying personality. Different people are affected differently by an injury in the same part of the brain. Most of them experience an increase of a personality characteristic they had before the injury. For example, if the person had problems with control before drinking, arguments, anger he will often show these characteristics even more after the injury. This is due to disinhibition. As in the chariot image described earlier, the horses are the emotions and the frontal lobes are the reins holding them under social control. Some people keep a tighter rein on their horses (emotions), while others have more vigorous horses. Loosening the reins (or throwing away the whip) may lead to inappropriate sexual behaviors (or a reduced sex drive in others), to irritability and being overly emotional (or apathy and lack of interest in pleasurable things in others), and to hyperactivity (or need for more sleep in others). The limbic system (and hypothalamus) lies close to and deep in the frontal cortex. It is also involved in regulation of sleep cycles, temperature, hunger, fluid balance, emotions, and hormonal

Problems with Cranial Nerve

Cranial nerves were discussed and listed in Table 2-1 in the section on Normal Brain Function in this chapter. When injured, the cranial nerves contribute to confusion and disorientation by changing the way the world is perceived. Anosmia (loss of smell) is the most common cranial nerve deficit and is often unnoticed. Diplopia (double vision) is frequent. This is due to an injury to one of the nerves controlling eye movements. Patients often complain of problems tolerating bright lights. Some with a hemianopsia (loss of vision on one side of both eyes) complain that they need new glasses. Abnormal vision should be corrected where possible, but hemianopsia will not be improved by glasses. Loss of hearing or a problem with dizziness (due to a disturbance of vestibular function inner ear problems) is very disturbing. Dysphagia (a swallowing problem) is not always obvious, as some will not cough when food enters their lungs. Dysphagia is diagnosed by special X-ray studies (modified barium swallow), which are helpful in documenting the presence of aspiration (food entering the trachea or lung) and guiding treatment

PROGNOSIS

Computerized Axial Tomography

Various tools exist to enable your physician to assess the extent of brain injury for use in prognosis (predicting how the patient will recover) as well as in diagnosis and treatment. The computerized axial tomography (CAT) scan has, in the past few years, given physicians a way to see inside the skull.

The CAT (or CT) scanner is a large machine with X-ray projectors arranged in a circle. The patient's head is placed in the center of the large doughnut-shaped device and X-rays are taken from various angles. A computer then analyzes the pictures, mathematically subtracts out the bone, and yields a picture of the brain. However, the picture is not perfect. If your loved one has had previous surgery, artifacts are produced that can distort abnormalities in the picture. Yet, the CT scanner is useful for recognizing large areas of bleeding and large cerebral contusions and for determining the size of the ventricles in the brain. A normal CT scan, however, does not mean there is not brain injury. On the contrary, many patients with severe brain injury due to hypoxic encephalopathy (lack of oxygen causing brain damage) will have normal or nearly normal CT brain scans. Abnormalities noted on the CT scan are statistically related to a poorer long-term outcome, but cannot accurately predict the outcome for the individual.

Magnetic Resonance Imaging

The magnetic resonance imaging (MRI) scan yields a more detailed view of the brain than the CT scan. Yet, it is not useful early in brain injury, as it will not demonstrate bleeding in the early stages. Also, the patient must lie still for a longer period with the MRI scan than with the CT scan this can be a problem in the confused or agitated patient. Because of its use of strong magnetism, the MRI scan cannot be used in patients who have metallic clips within the brain or who have cardiac demand pacemakers. However, MRI scans have the advantages of giving no X-ray doses. The MRI scan can document smaller and more subtle brain injuries some of which do not show up on the CT scan. See Table 2-5.

How They Work

CT and MRI scanners present an image of a slice through a solid object, not unlike a slice through a bruised apple. The extent of the bruise is not apparent from this single slice. The CT scan, because it reveals only relatively large structures, can miss important, but smaller, abnormalities. It is similar to a view of the earth from the moon. Continents and oceans are seen, but not specific mountains, rivers, smaller islands, and bodies of water. The MRI scan is similar to a view of the earth from a satellite. Here, one sees more details, such as mountains, rivers, and forests, but still cannot see enough detail to recognize individual roads, homes, shopping centers, cars, and people.

Table 2-5 MRI vs CAT Scans

Feature	Type of Scanner	
	CAT	MRI
Blood	Shows earlier	Shows later

Ischemia	Shows later	Shows earlier
Detail	Less	More
Speed to perform	Faster	Slower
X-ray dose	Yes	None
Cost	Less expensive	More expensive

Other Tests of Brain Function

Other studies are used to determine the extent of brain injury and to help with prognosis. The positron emission tomography (PET) scanner is a new technique used to gain insight into the metabolic (energy processing) function of the brain. Important chemicals used by the brain, such as glucose (sugar), are tagged, and the brain's ability to use them is studied with the PET scanner. The full value of the PET scanner in traumatic brain injury has not yet been determined.

The electroencephalogram (EEG) is another test of brain function. The EEG measures the electrical activity of the brain and compares the readings in various settings such as awake and sleeping. A brain electrical activity mapping (BEAM) study is a kind of EEG in which the electrical impulses are averaged by computer and used to draw an electrical picture of the brain. The study is used to detect the more subtle abnormalities that can be missed on routine EEG. It is also called brain mapping.

Like EEG, evoked potential studies measure the electrical activity of the brain. The difference is that they measure the brain activity evoked (or caused) by outside impulses of sight, sound, or touch. Visual evoked potentials (VEPs) measure the response of the visual cortex to light flashes or to changing patterns of light (the latter used when the patient is able to watch and pay attention). Brain-stem-auditory evoked responses (BAERs or AERs) measure the response of the pathways of hearing from the auditory nerve to the brain stem. Severe disruption of these hearing pathways is associated with severe brain-stem injury, and a total absence of hearing is a criterion for the diagnosis of brain death. Somatosensory evoked potentials (SSEPs) measure the response of the sensory pathway through peripheral nerves, spinal cord, brain stem, thalamus, and into the sensory (parietal) cortex.

Clinical Factors

Arriving at a prognosis is aided by all of these tests, although they cannot replace the judgment of an astute physician and neuropsychologist. Measurements indicating severe abnormalities generally correlate with worse outcomes, although this does not apply to specific prediction of the future for an individual. Among individuals who have recently experienced traumatic brain injury, certain clinical factors are felt to relate to a less-positive outcome. People with severe head injury (defined as coma over 24 hours) may have more difficulty than those with shorter comas, although some with shorter comas can do worse. Coma over 4 weeks is associated with poor outcome, although there are miracle stories that are exceptions. Negative factors include long antegrade amnesia (loss of memory for events before the accident), long posttraumatic amnesia (lack of ability to remember events after the accident), and when many abnormalities appear on the CT scan

For patients still in coma, no one can tell when they will wake up. When they do awaken, it is often seen first in subtle actions such as eye opening, doing purposeful activities, or making sounds. Some remain in coma, and some enter a persistent vegetative state (breathing, heart beating, ability to handle food by tube feeding but unable to respond with purpose to outside events). Some take weeks, months, or years to respond, and others wake up quickly to make a nearly complete recovery. For each individual, one can only wait and see. This uncertainty is often the most difficult for the family to accept.

Measurement of Cognitive Functioning

Prognosis is also estimated by certain clinical tools, in addition to the tests previously mentioned. Generally, a higher value on these measurements is correlated with better outcome. These tools include the Trauma Score of the American Trauma Society, the Glasgow Coma Scale (GCS) developed in Glasgow, Scotland, and the Levels of Cognitive Functioning (Rancho Scale) developed at Rancho Los Amigos Hospital.

The Trauma Score is used in the emergency setting to estimate the patient's chance of survival. Scores range from a total of 1 to 16, with the higher scores indicating a better prognosis. The score is based on respiratory function, circulation, and the Glasgow Coma Scale. See Table 2-6.

The Glasgow Coma Scale (GCS), previously described in the Coma section of this chapter, uses observation and examination to measure the amount of brain injury. It contributes from 1 to 5 points to the Trauma Score. As a tool itself, it is scored from 3 to 15, with points given in three categories: eye opening, movement, and speech. Sometimes other injuries can cause an individual to have a lower score. For example, eye swelling can interfere with eye opening, paralyzing medications or casts for fractures can interfere with movement, and various breathing tubes can prevent speech.

Patients are grouped into five broad categories: good recovery, moderate disability, severe disability, vegetative state, and death. Although the Glasgow Coma Scale is a useful predictive tool, it cannot perfectly estimate the degree of recovery for an individual hence, the need to maintain a "wait and see" attitude despite the frustration it implies

The Levels of Cognitive Functioning (sometimes called Rancho Scale) is a clinical evaluative tool used for prognosis, to measure progress, and to help guide treatment in the rehabilitative setting. See Table 2-7. The levels of this tool group patients into eight categories based on the performance of basic cognitive (thinking) functions. These cognitive functions include attention, concentration, memory, categorization, organization, discrimination, and analysis. These functions are necessary for the learning, reasoning, and problem-solving situations of everyday life. Improvements in cognitive and emotional functions are more subtle than such things as the healing of a wound or a bone, but they are more important factors because they make the difference between ultimate independence and dependence.

Table 2-6 Use of Trauma Score in Prognosis

Trauma Score	Chance of Survival (%)	Trauma Score	Chance of Survival (%)
16	99	8	26
15	98	7	15

14	96	6	8
13	93	5	4
12	87	4	2
11	76	3	1
10	60	2	0
9	42	1	0

Table 2-7 Levels of Cognitive Functioning

Level	Response	Patient Function
I	No response	Patient reacts to the environment, but not as a specific response to the stimulus responses are often the same despite change of stimuli. The earliest response is often gross movement to deep pain.
II	Generalized response	Patient reacts in a specific manner to the stimulus, but may inconsistently turn head to sound, withdraw an extremity to pain, squeeze fingers placed in the hand, or respond to family members more than others.
III	Localized response	Patient is in a heightened state of activity, but is still severely detached from the surroundings. Internal confusion and very limited ability to learn is combined with short attention span and easy fatigue. The patient is unable to cooperate and may be aggressive, combative, or incoherent.
IV	Confused, agitated	Patient is in a heightened state of activity, but is still severely detached from the surroundings. Internal confusion and very limited ability to learn is combined with short attention span and easy fatigue. The patient is unable to cooperate and may be aggressive, combative, or incoherent
V	Confused inappropriate/nonagitated	Patient appears alert and is able to respond to simple commands. Responses are best with

familiar routines, people, and structured situations. Distractibility and short attention span lead to difficulty learning new tasks and agitation in response to frustrations. If physically mobile, there may be wandering. Much external structure is needed. Initiation and memory are limited.

VI Confused, appropriate

Patient shows goal-directed behavior, but still is dependent on external structure and direction. Simple directions are followed consistently and there is carry-over of relearned skills (like dressing), yet new learning progresses very slowly with little carry-over. Orientation is better and there is no longer inappropriate wandering.

VII Automatic, appropriate

Patient appears appropriate and oriented within familiar settings such as home and hospital, but is confused and often helpless in unfamiliar surroundings. The daily routine can be managed with minimal confusion as long as there are no changes. There is little recall of what has just been done. There is only a superficial understanding of the disability, with lack of insight into the significance of the remaining deficits. Judgment is impaired with inability to plan ahead. New learning is slow and minimal supervision is needed. Driving is unsafe; supervision is needed for safety in the community or in school and workshop settings.

VIII Purposeful, appropriate

Patient may not function as well as before the injury, but is able to function independently in home and community skills, including driving. Alert, oriented, and able to integrate past and present events. Vocational rehabilitation is indicated. Difficulties dealing with stressful or unexpected situations can arise, as there may be a decrease in abstract reasoning, judgment, intellectual ability, and tolerance of stress relative to premorbid capabilities.

The specific levels are used as a tool for classifying patients and as a guide to treatment. Treatment strategies change as cognition improves. Patients in levels II and III need periods of stimulation and rest, patients in level IV need control of external stimuli to avoid overstimulation, and patients in levels V and VI need increasing demands from their environment. However, a specific patient will not jump suddenly from one level to another, and will sometimes show aspects of more than one level during the continuum of recovery.

INCIDENCE AND PREVENTION OF BRAIN INJURY

Your loved one is not alone. He joins the largest minority in America the disabled. He joins nearly half a million other Americans this year who will suffer head injuries that are significant enough to cause death or require admission to a hospital. You join with the families of more than 50,000 people whose head injuries are severe enough to keep them from returning to normal life. The National Head Injury Foundation (NHIF) calls it "the Silent Epidemic." Every person has a 1 in 10 chance of suffering a significant head injury.

The most common causes of head injury are falls and motor-vehicle accidents. Although head injury from guns is the third most common cause nationwide, this cause is first or second at many inner-city hospitals. Readily available handguns are a major factor in many large American cities. On the average, both the very old and very young suffer from a higher proportion of falls. Unfortunately, child abuse is a too-common cause of head injury in children. The 15- to 24-year olds represent a proportionately higher incidence of head injuries. One head injury often is followed by another. Unfortunately, the effects of two injuries are multiplied rather than added producing much more damage than the sum of the separate injuries. Lifestyle factors, as well as increased impulsivity and impaired judgment following head injury, may play a part. Drug abuse (especially alcohol) frequently contributes to causing head injury.

Factors that can prevent head injury are no secret. Car seats for children and seatbelts with shoulder harnesses or airbags for adults can reduce head injury. Bicycle and motorcycle helmets would prevent many injuries, but they are rarely used in some parts of the country. Drunk driving continues to occur much too frequently, and enforcement of penalties is relatively mild considering it is implicated in half of all serious auto accidents! Despite the head injury of Secretary James Brady by a bullet that was meant for President Ronald Reagan in 1982, hand guns continue to be easily obtained.

Head injury is incredibly expensive! Measured in direct medical expenses, rehabilitation, indirect support services, and lost wages (and taxes) by patient and family, four billion dollars a year is a conservative estimate.

What Is Being Done To Prevent Head Injury?

The National Head Injury Foundation (NHIF) was founded in 1979 by a head-injury victim's parents, Marilyn and Martin Spivak. The NHIF is a center for disseminating information about head injury. It is actively lobbying for programs to prevent head injuries and to expand legislation to improve the lives of head injury victims. The address of the NHIF is:

NHIF
333 Turnpike Road
Southborough, Massachusetts 01772
The NHIF telephone number is: (508) 485-9950
The NHIF Family Helpline is: 1-800-444-NHIF

In addition to the national organization, many states have their own chapters, and there are many local groups in separate cities or towns. A publication prepared by the national group gives telephone numbers and contact people for these state and local groups. Getting together with other families of the head injured can be very helpful. They can be both a source of strength and information for you. There is no one who better understands what you are going through right now than other families of head-injured loved ones. They are there to help you.

Mothers Against Drunk Driving (MADD) and its associated organization Students Against Drunk Driving (SADD) offer support groups for victims of drunk driving. They also lobby for stricter laws to help control drunk driving. The national address of MADD is:

MADD
Box 541688
Dallas, Texas 75354

As with the head injury groups, there are local MADD groups in many communities.

Hand Gun Control (HGC) is a political organization that supports legislation to limit access to hand guns. Its president is Pete Shields. Sarah Brady, wife of James Brady, has given her support to HGC, and several Chiefs of Police have also supported the "Brady Bill," which requires a waiting period, to check police records, before a hand gun can be purchased. Other legislation to prevent head injuries includes mandatory helmet use by motorcyclists and bicyclists, mandatory use of seat belts, and mandatory use of car seats for children. Requiring air bags will likely reduce head injuries without relying on compliance by the car's occupant. It is controversial as to the extent that highway speed limits reduce head injuries.

Chapter 3

Inpatient Rehabilitation

To the health care professional:

Some family members may find it difficult to understand inpatient rehabilitation that it is different from being in a hospital for an operation. You may want to personally review sections of this chapter with the family so they are fully aware of what is being done and can become members of the team.

Chapter 3

Inpatient Rehabilitation

If your loved one has had a severe head injury (as described in Chapter 2 Glasgow Coma Scale score of 8 or less or coma duration of more than 24 hours), he may be involved in inpatient rehabilitation following intensive care and acute hospital care. Although the rehabilitation center may look like any other hospital or may actually be located in the wing of a major hospital, the program philosophy and goals are quite different from the care given to people with broken legs or some type of major surgery. The following sections are geared toward helping you to understand rehabilitation theory and practice. Topics addressed are medical aspects, therapy areas, the team approach, and behavioral issues involving patients and families. Remember, the focus is on helping your loved one become independent. The staff is there to help him help himself, not to do everything for him. Their job is to make your head injured survivor capable of going back out into the world by doing things for himself.

MEDICAL FOCUS

Definition of Rehabilitation

Rehabilitation is the process of providing, in a coordinated manner, those comprehensive services deemed appropriate to the needs of a person with a disability, in a program designed to achieve objectives of improved health, welfare, and the realization of one's maximum physical, social, psychological, and vocational potential.

This definition is from the Commission on Accreditation of Rehabilitation Facilities (CARF) an organization established by rehabilitation professionals to certify rehabilitation facilities according to uniform standards. Rehabilitation is inherently optimistic it hopes for the best.

Rehabilitation is a different type of medical care. It is the third stage of medical care, following preventative medicine (first stage) and curative medicine (second stage). Rehabilitation steps in to maximize function and quality of life when cure (complete recovery) is a questionable issue. Yet, rehabilitation concepts are important at all stages of medical care to keep patients functioning at their maximum. It should begin in the emergency room with efforts to prevent any secondary disability that could follow from the initial disability condition.

Important Concepts in Rehabilitation

The same disease or injury can lead to different levels of disability in different people. For example, a man falls and suffers a broken right arm with wrist drop. The diagnosis is clear—

fractured humerus with radial nerve palsy. The diagnosis of disability, however, requires better knowledge of the patient. The disability is devastating in a right-handed laborer, but the disability is minimal in a left-handed accountant.

Disability is not solely due to the primary condition. Many factors contribute to and worsen the disability. Although complete recovery (cure) may not be possible, removal of the contributing factors lessens the disability of the primary condition. The primary condition is but one slice of the pie. See Figure 3-1.

Other factors may pertain to the rehabilitation process.

- Nutrition--Obesity or malnutrition can limit progress.
- Medications--Some medications can cause depression, drowsiness, nausea, tremor, and weakness.
- Psychological factors--Depression or a hopeless attitude can be a self-fulfilling prophecy.
- Educational factors Training in new ways to do old activities can be liberating.
- Social factors--A patient's ability to cope is influenced by a wide variety of social issues, including family support systems and financial stability.
- Medical problems--Anemia causes weakness; pain is distracting.
- Orthopedic--One could cope with leg-length inequality before this disability.
- Deconditioning--Strength is lost quickly and rebuilt slowly; bed rest can be devastating.

Physical problems are not the most disabling factors. Many other factors play an even greater role in disability than does the inability to move an arm or leg. The perceptual, cognitive, and emotional problems following head injury are usually harder to treat than physical problems and are more directly related to successful community integration and employment.

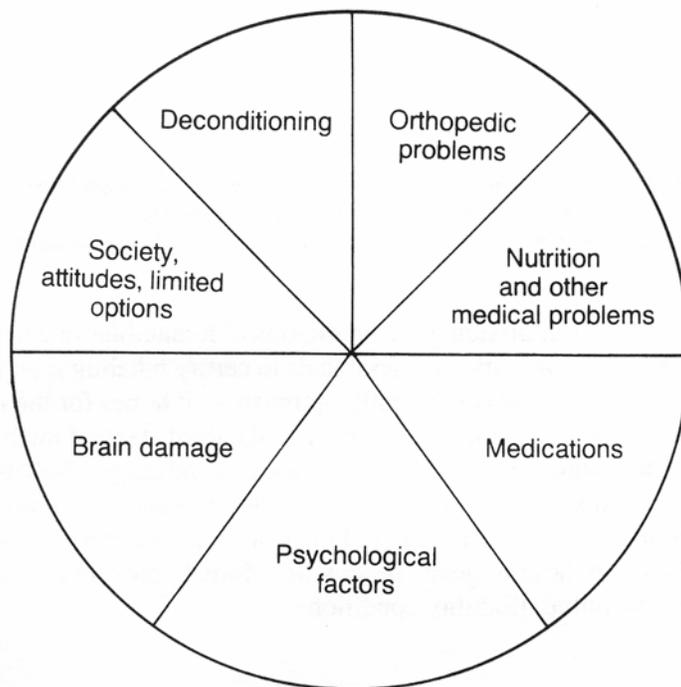


Figure 3-1 Total Disability Represented in Pie Diagram in which the Brain Damage is Just One Slice

The Physician's Role in the Rehabilitation Team

Although your loved one most likely will be defined as stable before coming to rehabilitation, he has the potential for numerous medical problems. Your physician looks ahead into preventative medicine to assure his optimum health while he undergoes rehabilitation. It is estimated that 40 of patients leave a rehabilitation unit with an additional medical diagnosis.

Your doctor is also the medical team leader, balancing various medical, nursing, therapy, and psychosocial issues, particularly when rehabilitation impacts on medical needs.

Concepts of Why Recovery Occurs in Brain Injury

In the initial days and weeks following brain injury, swelling is resolved and blood from areas of bruising is resorbed. As pressure in the brain decreases, blood flow can begin to be restored. Outlying nerves sometimes go into a neuropraxia (state of shock), but may be restored during the subsequent weeks or months. Damage to sections of the brain requires additional time for recovery

One theory of recovery is that nerve pathways undergo unmasking and sprouting. With unmasking, it is speculated that seldom-used pathways become more active when the primary pathway is injured. This is the same as taking a detour on back roads if the highway is closed or using a secondary system to make a phone call from New York to Los Angeles if the main phone line has been disrupted. See Figure 3-2.

In sprouting, parts of one nerve move out to join another establishing a new communication link. This is the slowest of pathways for recovery. In Chapter 19, we discuss how sprouting occurs normally, as one grows older, to maintain cognitive (thinking) abilities as nerve cells are lost. See Figure 3-3.

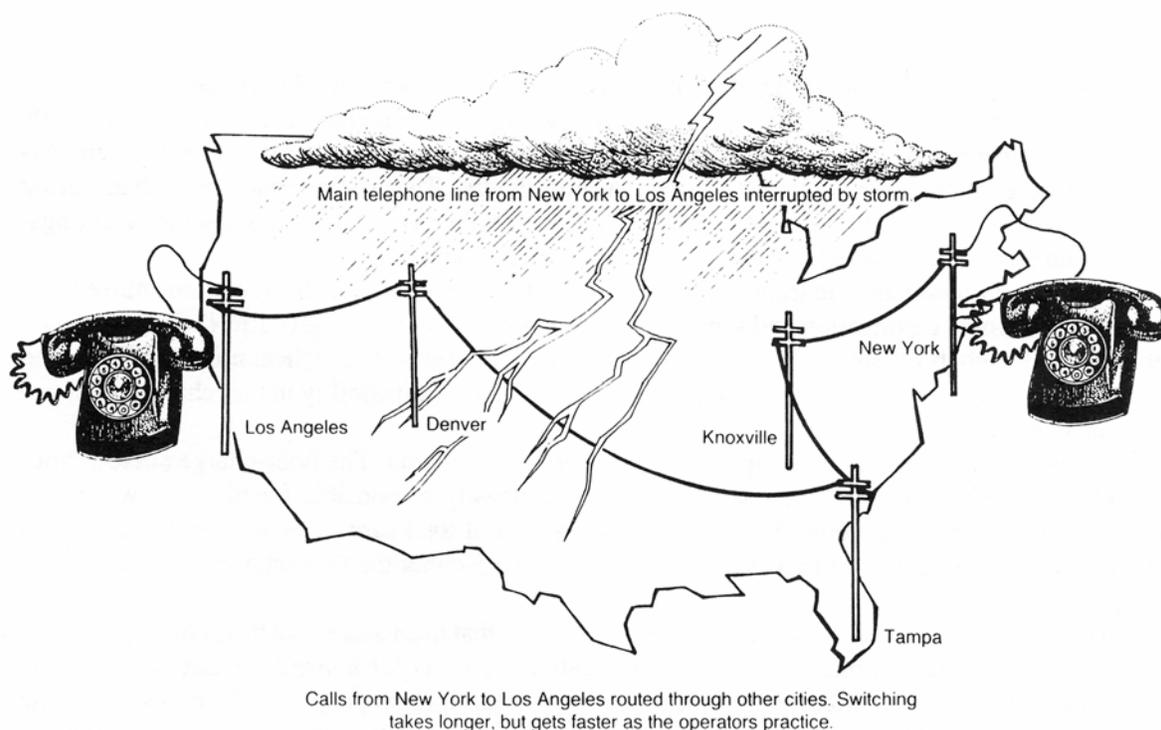
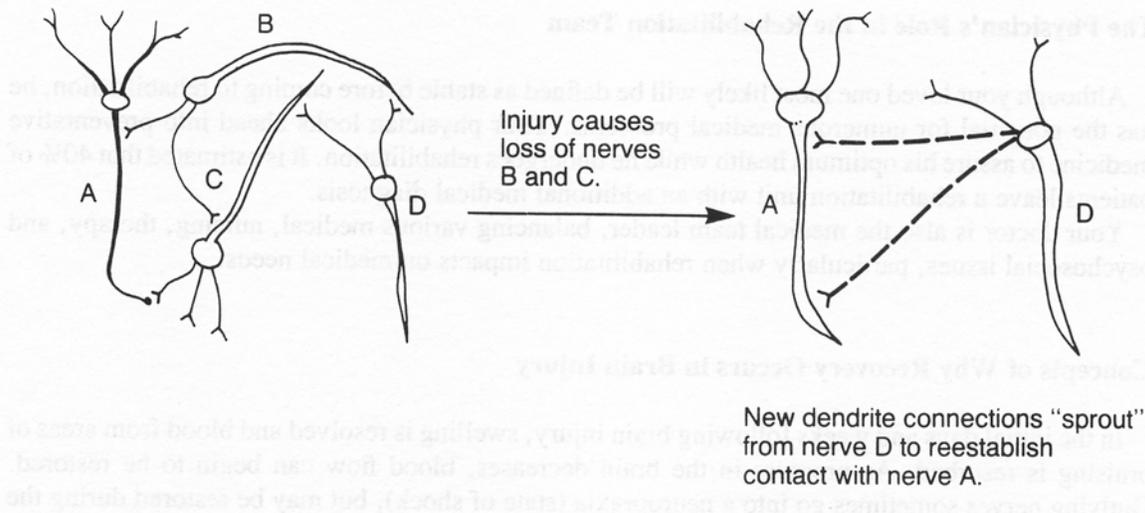


Figure 3-2 Unmasking Theory Compared with Telephone Line Disruption**Figure 3-3** Sprouting Theory of Nerve-Cell Replacement

THERAPEUTIC FOCUS

During the period of time in which your family member is an inpatient at a rehabilitation center, you will be exposed to a new set of terminology and a new set of effaces as you learn more about head injury rehabilitation. To assist you in understanding the terminology and philosophy of the therapists involved in your family member's care, we will, in this section of the book, address the therapeutic focus of the services provided within a rehabilitation setting.

Nursing

Nursing plays a major role in the rehabilitation of your family member. Nurses spend many hours with your loved one when he is not involved in other structured therapy programs. Your family member's nurse may be the one to provide you with information on his progress. Many therapists may not be available when you visit in the evening hours. This means that, other than during structured staffings (meetings of staff members working on the case) and other scheduled meetings, your main source of information may be your primary-care nurse.

Many rehabilitation units in traumatic brain injury (TBI) are staffed with a registered nurse (RN) who has additional certification and specialization in rehabilitation nursing (CRRN). Depending on the size of the rehabilitation unit, it will be staffed with RNs, licensed practical nurses (LPNs), and nurses' aids. Each level of nursing assumes a certain level of responsibility in the rehabilitation and care of your family member.

The floor-charge nurse will be happy to explain the system to you. The floor-charge nurse or your family member's primary-care nurse (the one who is usually responsible for his care) will be an excellent source of information for you regarding aspects of total care. You are considered a team member in this rehabilitation process. Do not hesitate to ask either the floor-charge or primary-care nurse any question you may have.

The nursing focus in a rehabilitation center differs from that in an acute care hospital. The focus is not to *do for the patient*, but rather to assist the patient in *doing for himself*. In that way,

nursing provides the necessary continuity for the carry-over of rehabilitation programs. Nurses serve as the cement that holds the program together. Additionally, nursing is responsible for your family member's general health care. In the rehabilitation setting, these health-care needs consist of assessing self-care skills, bowel and bladder programs, skin integrity, hygiene, and working with the physician in managing all health-care matters.

As you are making discharge plans for your family member, nursing will be able to provide information in regard to self-care skills of grooming, dressing, and toileting. They will also give you feedback on the expectations you may have for your family member in the home. Nursing will be able to offer you a wealth of information regarding all aspects of your family member's recovery.

Physical Therapy

A physical therapist (PT) has a role that encompasses much more than just aiding your family member in regaining his physical strength or teaching him to walk again. Initially, and on an ongoing basis, the PT evaluates the case and plans the therapy needed to improve walking, balance, muscle tone, endurance, strength, and coordination. The PT makes certain that, physically and neurologically, the patient has the ability to coordinate the muscles and actions needed for movement such as sitting, standing, or walking.

In the more severely involved and long-term patient, the PT may focus on both preventing muscle contraction and increasing range of motion. With those patients who do not have strength, coordination, and balance for standing or walking, the PT will exercise the muscles to prevent contraction from lack of use. They also move the arms and legs in an attempt to increase the range (level) that the arms and legs can be moved. This process keeps the arms and legs exercised and conditioned.

An important aspect of the PT's job is to help determine your family member's highest level of motor function. This determination is made by the PT and your physician. Together, they attempt to answer the question as to whether your family member will walk alone, need assistance (walker), or use a wheelchair. It is possible that your family member may be able to walk again. In that case, he may spend only a short amount of time in a wheelchair. Painstakingly, he may regain the skills needed to walk, beginning with standing for extended periods of time, using parallel bars, and then possibly using a walker, then walking with assistance, and, eventually, reaching the ultimate goal of ambulation without assistance (real walking).

If your family member needs a wheelchair when he leaves the rehabilitation center, the PT will make certain that the most appropriate equipment is ordered and that you and your loved one are aware of its proper usage. The PT will instruct you in helping your family member to transfer (get in and out of the chair).

The PT will be able to answer questions regarding the amount of time the patient should be walking, when to use the wheelchair, and the necessary safety precautions you will need in your home and in public. You will be instructed on how to get the chair up curbs and ramps and how to get the chair in and out of the car. The PT will be able to advise you regarding necessary home renovations. You may need to redesign the entrance to your home, widen doorways, or redesign your bathroom. The PT can work with a contractor and your insurance company in designing the necessary changes.

Although at times it may seem as if the PT is setting very strict limits, he is concerned about your family member and that he not develop bad habits or cause physical damage to himself by

walking too soon or too far. The PT has the overall well being and safety of your family member in mind.

Occupational Therapy

The focus of the occupational therapist (OT) traditionally is to provide strengthening and coordination of upper extremities (arms, upper body); however, in head injury rehabilitation, the OT plays a more active and vital role. A major emphasis is placed on your loved one's ability to regain the functional skills needed to survive day-to-day activities through rehabilitation of fine motor, perceptual (seeing and hearing), eye-hand coordination, and cognitive (thinking) skills. An OT will address the activities of daily living (ADLs), such as feeding, dressing, grooming, toileting, and personal hygiene, to facilitate functional use of thinking skills. Another important component of the occupational therapy program is to design and obtain special adaptive equipment and to train patients in its use. This may include such items as long-handled aids for dressing, specially designed forks and spoons for eating, and special cushions, such as wedges and supports, for sitting. They also regularly provide for needed splinting and wheelchair modifications. Together with the PT, they assist family members in learning how to transfer (move a patient from one place to another).

As your family member improves, the OT has a vital role in the carry-over of the functional skills into the home and working environment. Therapeutic activities such as cooking, working with tools, completing household tasks, and managing money may be added to the OT program. The OT is an excellent resource person to answer questions regarding what activities your family member may be able to do at home. The OT will also be able to give you suggestions in regard to which household responsibilities your family member will be able to assume, such as the checkbook, budgeting, housekeeping, and maintenance. Later in the recovery process, the OT is a vital link in the outpatient and community reentry program (back to the home, back to work, or back to school).

Speech/Language Therapy

The speech/language pathologist (SLP) plays a varied role in resolving difficulties in articulation (speech) and language (understanding and expressing the spoken/written word) in TBI patients. Speech and language skills encompass all aspects of our daily living. These skills are central to higher level cognitive functions (thinking skills). Cognitive functions will be addressed by the SLP working with your family member.

An intensive speech/language evaluation is extremely important to determine the overall needs of your family member. This evaluation will address his speech patterns, receptive and expressive language skills, and the need for any further evaluations, possibly from an audiologist (hearing specialist) or otolaryngologist (ear, nose, and throat specialist). The SLP may also request a swallowing study for your family member to determine what consistency of food he is able to tolerate without aspirating (choking). This is extremely important for both safety and nutritional needs.

In some instances, your family member's speech problems may be quite evident. He may not speak at all for quite some time. He may not be able to control muscles needed for speech, resulting in dysarthria (a slow, labored, uneven rate). He may not be able to articulate specific sounds, or the overall intelligibility of speech may be poor (possibly due to apraxia). He may have aphasia (inability to understand or use language) or anomia (inability to recall words on request).

You may not be aware of the fact that your family member has any speech problems because he may appear to be speaking normally. Speech/language therapy in that instance will be directed toward developing such things as attention, concentration, or verbal reasoning (see cognitive rehabilitation therapy). Pragmatics, defined as appropriate use of conversational speech, sustained eye contact, and use of appropriate body language, will also be evaluated and treated.

The SLP will be able to explain to you the differing aspects of your family member's speech/language difficulties. The SLP is an excellent resource person to give you information regarding your family member's ability to understand and use language in his daily environment.

If your family member is in need of an augmentative (additional) communication device, such as a lap/wheelchair board or a computer to use for communication, the SLP, in conjunction with the other therapy services, will help determine the needs. He will explore the best means of accessibility as well as the appropriate response mechanism (any special switches that may be needed to activate the device).

Cognitive Rehabilitation Therapy

Cognitive rehabilitation therapy is a relatively new field that has been developed to meet the needs of TBI patients. The purpose of cognitive rehabilitation is to help the person with head injury to learn how to learn. Therapy is based on the premise that particular cognitive functions (thinking skills) are affected when someone suffers a head injury. Some of these cognitive functions include attention/concentration, memory, sequencing, reasoning, perceiving, planning, initiating, monitoring, and motor speed. Deficits in these cognitive functions are discussed in depth in Chapter 10.

A cognitive rehabilitation program focuses on the processes involved in relearning cognitive tasks. This will require your family member to be involved in repetition of exercises to the point of overlearning. He may complain about the repetition, but it is essential to his rehabilitation. A cognitive rehabilitation program also addresses the higher-level cognitive skills of reasoning, planning, and monitoring for correct answers. Therefore, your family member may be involved in brain-teaser types of activities for this purpose. Computerized programs are also used, but only under the close scrutiny of the person responsible for the cognitive rehabilitation therapy.

The most important aspect of a cognitive rehabilitation program is generalization (teaching your family member how to adapt these skills to situations other than in the therapy setting). To accomplish this generalization, the person responsible for cognitive rehabilitation therapy will make certain that your family member has the opportunity to practice his relearned cognitive skills in the home or work environment before he is discharged. In other words, reasoning skills will be applied to such home situations as scheduling, budgeting, and planning home and work activities. As a family member, you play a vital role in the generalization process. It may become your responsibility to make sure that your family member follows through on these cognitive activities. You will need to check his progress at home regularly, both through encouragement and providing time and opportunity for him to follow through on his home program.

Two basically different models have been established in the area of cognitive rehabilitation. Some centers provide these services through an interdisciplinary approach, and goals are usually established by occupational therapy, speech/language therapy, and psychological services. Other centers provide these services through a specialist who is designated to serve as the cognitive rehabilitation therapist (CRT) in the rehabilitation center. Regardless of the model used in your rehabilitation center, it is imperative that these skills be addressed in a systematic manner and that your loved one's progress be closely monitored.

Neuropsychology/Psychology

A psychology department within a rehabilitation center may be staffed by licensed psychologists, neuropsychologists, and counselors. A neuropsychologist is a psychologist with specialized training and experience in evaluation and rehabilitation of people who have suffered some form of insult or injury to the brain, either at birth or acquired later in life.

Because of the specialized training, the information provided by the neuropsychologist is paramount in planning your family member's rehabilitation program. A neuropsychological evaluation (an extensive battery of tests) is given to aid in determining cognitive, intellectual, and behavioral indicators that result from the head injury. Your family member may not be ready for this type of evaluation until just prior to discharge or until he is an outpatient. A typical neuropsychological evaluation will provide information regarding attention, concentration, memory, problem-solving skills, abstract reasoning, motor speed, sequencing skills, and executive functions (planning, organization, and completion of a task). The information provided by the neuropsychologist is particularly important to the person who is responsible for the cognitive rehabilitation therapy.

The neuropsychologist, psychologist, and counselor in the rehabilitation center also provide a wide range of services other than purely evaluative measures. Your psychologist will be able to provide individual counseling and family support while your family member is both an inpatient and an outpatient. Your psychologist, as well as your social worker, can provide good sources of information in regard to selecting particular self-help manuals and in locating head injury support groups that may be meeting in the area. Many rehabilitation centers have a support group that meets to discuss family issues.

In group and individual therapy, issues such as sexuality or substance abuse may be addressed by those providing psychological services. In TBI rehabilitation, these are important issues in the recovery process (see Chapter 15).

At a later time during the rehabilitation process, the psychologist will play a vital role in counseling your family member in regard to community reentry and establishment of lifelong goals.

Recreational Therapy

The recreational therapist will evaluate your family member's leisure time activities and attempt to involve him in structured activities during his free time. These activities may include arts and crafts, games, group outings, planned meals, or sports. This is done in an attempt to reintroduce him to the real world. The ability to participate in social situations is an important aspect of head injury rehabilitation. The recreational therapist can provide you with essential information regarding your family member's skills in this area.

Social Work Services

The social worker is an important communication link between you and the rehabilitation treatment team. This person will obtain the initial information, including family history, work history, social and recreational interests, and family structures, as well as information regarding any past psychological or social problems (alcohol, drugs, or legal confrontations). It is important to remember that this information is extremely important in determining rehabilitation goals for your family member. These are necessary questions.

The social worker is also responsible for providing ongoing family support and is instrumental in the discharge-planning process that will return your family member home or to another appropriate facility. Your social worker is able to provide you with information in regard to financial assistance and management of your family member's resources, as well as information about outpatient postacute rehabilitation facilities, Social Security benefits, and home health-care agencies. As a family member, you can benefit from the wealth of information provided by the social worker.

Case Management

The case manager is responsible for three-way communication between you, your insurance carrier, and the rehabilitation center. He serves as the "watchdog" for your family member's resources. A case manager can be instrumental in making certain that your family member receives the therapies allowed for in your insurance policy, and he will work with the insurance carrier to ascertain that the funds are being expended wisely. Additionally, the case manager is responsible for monitoring the team that works with your family member. He will monitor schedules and treatment plans and work with social services in planning for appropriate discharge.

In some rehabilitation settings, the social worker also serves as the case manager. Depending on other job responsibilities and the size of the social worker's/case manager's case load, this can be a workable situation. In this case, all clinical, fiscal, psychosocial, and discharge-planning aspects of your family member's case will be the responsibility of the social worker/case manager.

Vocational Services

The certified rehabilitation counselor (CRC) or certified vocational evaluator (CVE) plays an integral role in the rehabilitation program. However, as an inpatient, your family member may not be ready for direct services from this department. The CRC then serves as consultant for the rest of the team. A vocational specialist assists in developing prevocational activities to prepare your family member for work. The majority of vocational-services work is part of a community reentry system. This system will be discussed at length in Chapter 5 of this book.

Educational Therapy

An educational specialist, either from the local school system or the rehabilitation staff, assumes the responsibility for addressing the educational needs of school-aged children in the rehabilitation setting. The educational specialist provides evaluations and academic instructions to make certain that your child or adolescent will be able to resume his educational path on completion of the rehabilitation program. One of the major goals of the educational specialist is to facilitate a smooth transition to the school setting. This role is discussed in greater length in Chapter 20 of this book.

INTERDISCIPLINARY TEAM APPROACH

In the preceding section of this chapter, we described the various therapy areas and their individual roles. Now we will discuss how these separate areas work together as a team, along with the physician and most important you, the family. We are all familiar with the team concept the idea that working together as a team brings the best results. In the following sections, we use the example of a Little League baseball team. It is something to which you can relate because of

your experiences either in playing Little League yourself, having children that have played, or possibly just by having heard friends talk about the interactions on a Little League field.

Beyond Territoriality

Twenty years ago, the "team approach" in the medical and educational fields became an up-and-coming concept. The term multidisciplinary team was used, and the concept of the team was that a wide variety of experts would be involved in the rehabilitation of your loved one. The focus was on the positive aspect of having a team of experts. As you well know from life in general, varying opinions are bound to occur when a group of experts get together, and there will be overlapping in their specialty areas. To use a baseball example, when a pop fly falls between short stop and third base, who would get the ball? It is quite likely that both players possess the ability to catch the ball, but who has the best chance or is in the best position? It may clearly be the third baseman's ball, but, for some reason, the third baseman is out of position (possibly he came up to get a suspected bunt). In this instance, the short stop goes out of position to catch the ball.

Likewise, to be effective, each member of the rehabilitation team must remove any thoughts that expertise is possessed solely by his area. Each must be willing to attend to the issues of other therapies, as well as be willing to allow an opinion about his expertise from another professional. The true meaning of interdisciplinary is that all disciplines interact for the purpose of meeting goals, taking into account medical, psychosocial, communication, physical, family, and discharge issues.

As you might imagine, the leadership of this team is quite important. As you explore inpatient rehabilitation options, you may find a wide variation in this leadership role. Some centers have the physician as the team leader (baseball manager) with another professional acting as the therapy coordinator (coach). Other centers pride themselves in saying that the team is run by the therapy areas and that the traditional medical model is not used. It is our opinion that a variety of structures can be effective. The most important thing is that the team members work together to obtain maximum results for your loved one. Using the baseball analogy (see Figure 3-4), a player may be the pitcher in one game and may sit on the bench (substitute) in another game. To relate this to rehabilitation, the educational specialist may be a substitute in the case of head injury of a 25-year-old man, but he may be the pitcher when the patient is a 9-year-old child. As the child gets ready for discharge, it would then be appropriate for the education specialist to be the case manager at that point. If your loved one remains in a semicomatose state (Rancho Level II), it will be quite likely that the physician, physical therapist, occupational therapist, and speech/language pathologist will play the dominant roles. These are just a few examples to show that the interdisciplinary approach allows for flexibility in team management.

Family Rights and Expectations

As a family member, what is your role in the interdisciplinary team process? First and foremost, you have a responsibility to be a team player. This means you need to be open in your communication of concerns, goals, and expectations for your family member. You must also help in the problem-solving area and aid the rest of the team members in developing the most appropriate program for your family member. It is beneficial if you approach team meetings with an open mind, are a careful listener, and openly ask for clarification of any issues you may not understand. Do not

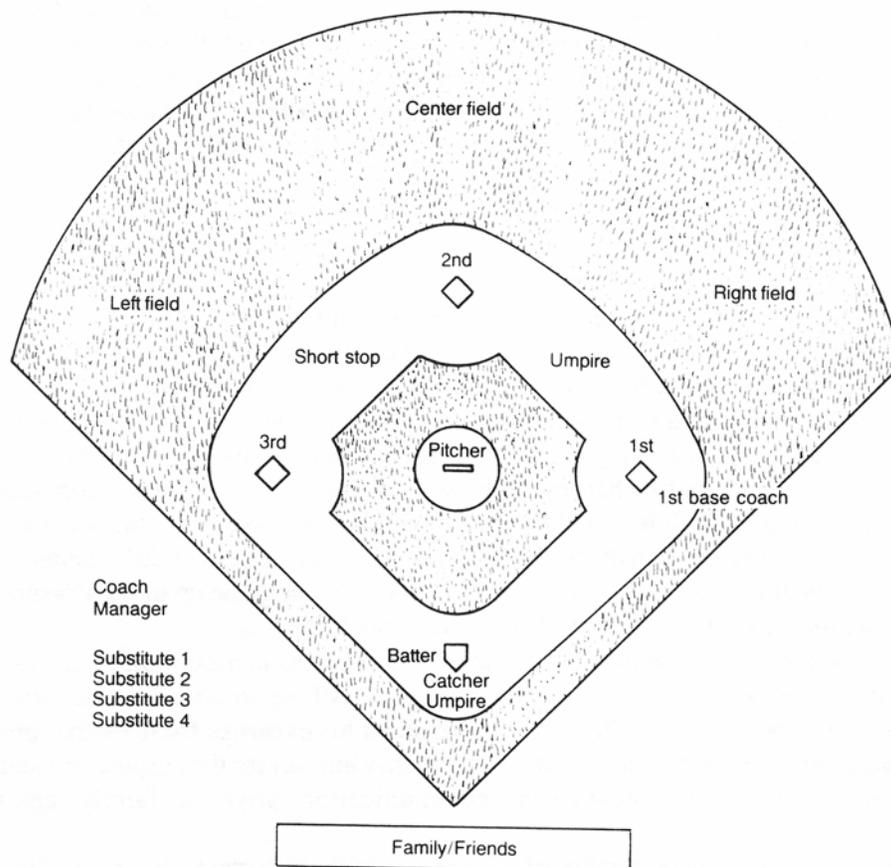


Figure 3-4 The Interdisciplinary Approach on the Little League Baseball Field

allow yourself to be intimidated by either the expertise or the number of other team members. Open communication is the key.

Using the baseball example, we can see that family and friends can have a very important influence on the team. This influence can be positive when you, the family, support the goals of all the players on the team. There can be times when you do not understand why a certain strategy is used. If all you do is gripe from the sideline and hassle the coach, the team spirit is not maintained. It is your job to consult with those who are aware of the strategy so that you can better understand the game plan. Get in the game and be a positive member of the team.

The Rule Keepers

At times you will find that certain team members have discussed rehabilitation options with you, but it may turn out that the rule keepers of the facility do not allow for the proposed strategy. These rule keepers, often known as the administration, are similar to the umpires in baseball. You and other team members may not agree with the call, but the call must be made. The team is a unit that must work within the policies and procedures of the facility.

BEHAVIORAL ISSUES INVOLVING THE PATIENT

All of the members of the interdisciplinary team should be involved with managing the behavior of your loved one. It is not solely the job of the psychologist or behavioral specialist. He may take a lead role with a patient who is having significant behavior problems, but it is very important that all therapies, as well as you and your doctor, work together in the overall management. We will now try to help you understand some of the methods that may be used in the rehabilitation center

Restraints and Restrictive Procedures

Because head injury so often affects behavior, it is likely that your loved one is neither himself nor is he in control of his own actions. For this reason, he may need to be protected from harming himself or others. Protection is needed especially in the confused-agitated phase (Ranches Level IV see Chapter 2), in which patients must be helped until they begin to respond to outside cues from the surroundings and other people.

Rehabilitation professionals have responded to this need to protect their patients by developing various restraints and restrictive procedures to safely control behavior and prevent harm. Restrictive procedures are designed to restrain, reduce, or eliminate inappropriate or dangerous behaviors. These procedures may:

1. restrict an individual's movement
2. restrict an individual's ability to obtain positive reinforcement (things that make one feel good)
3. restrict an individual's ability to participate in programs

Several types of passive restraints are used to confine the patient to bed, room, unit, or hospital environment. Bed restraints are used for the most agitated patients. They are used especially in the intensive-care setting, where various tubes must be protected from removal by your loved one. Tying wrists or ankles with straps (cloth or leather) to the bed are some of the most restrictive devices, but they provide the most control. Problems involved include sores under the restraint due to the rubbing that occurs when the patient moves. Physical restraints sometimes increase agitation and confusion in the patient (some patients are so confused that they might feel they are in prison). Large mitts or mittens over the hands can protect tubes from removal and allow for more freedom of movement, yet prevent use of the fingers.

Various restraint jackets may be used. One of the most common is the Posey vest. This device slips over the arms, is crossed in the back, and has straps that can be tied to the bed or chair. Sometimes, agile patients can slip down out of some restraint jackets, with possible injury to themselves. Sleeved jackets that fasten in the back provide some additional restraint. Another option is using a double restraint jacket or double Posey. In this procedure, one jacket is used in the normal way, but the straps are tied near the foot of the bed; the legs are brought through the sleeves of another jacket, and those straps are tied near the head of the bed. This can sometimes provide additional safe restraint, yet allow the arms and legs to be free. Additional safety is provided by padding the bed rails, keeping the rails up, and keeping the bed in a low position to minimize the harm if there is a fall.

For some patients, indirect restraint of the environment itself is enough. Padded rails suffice for some, but others need a larger environment. This is the case in some (Ranches Level IV confused-agitated) patients when physical restraints increase their agitation (making them more active, more vocal, and, sometimes, more violent). In this case, some rehabilitation centers may

allow your loved one to sleep on one or more mattresses placed side-by-side on the floor. Sometimes, therapy mats are used. Somewhat more protection is provided by a room with padded walls. More frequently, acute rehabilitation centers are using variations of large adult padded cribs ("Craig beds"). These allow freedom of movement with relative safety.

Sometimes, family members are upset by the thought of their loved one in a crib: "Why do you have him locked up in a cage?" If this applies to you, please remember that the rehabilitation team has chosen this device for safety and because it is better for him than any other restraint. Use of devices that minimize agitation are believed to help the patient pass more quickly through the confused-agitated level.

Some agitated patients respond to short periods of time away (timeout) from the overly stimulating environment. Timeout is also used as a powerful behavioral tool whereby rewards are withdrawn from a patient for a period of time.

For the patient who needs even more control, one-on-one attention by family or a paid attendant is recommended. Sometimes, agitation and potential for violence may become so severe that an agitation team will need to be called. This is especially important when a nurse, therapist, or a family member is alone with a confused-agitated patient who gets violent. In this situation, trained staff members converge on the individual and quickly restrain his behavior with conversation and gentle, but firm, physical means. Often, the sudden presence of four large adults will itself lead to a reduction in agitation, as if your loved one senses that order has been restored.

Medications

Medications are used as a last resort to control agitation and violence when changing the patient's environment has failed. Improving brain function by using medications makes sense. Well over 30 chemicals in the brain have been found to be active for transmitting information. With medications that imitate these chemicals, physicians can affect brain function by changing the chemical environment of the brain. Unfortunately, we are in relatively early stages of understanding the complexity of the brain's chemical environment. Medications can sometimes slow mental functions in addition to controlling agitation. A psychiatrist is sometimes consulted to help with medication choice and adjustment of doses. Consulting a psychiatrist does not mean your loved one is crazy. Rather, it means that more expert help is needed from a physician skilled in working with medications that change the chemical environment of the brain. Medications sometimes chosen include Vistaril, Inderal (propranolol), phenothiazines, benzodiazepines, tricyclic antidepressants, and lithium (see Chapter 16). Typical side effects include low blood pressure, slowing of thought processes, abnormal movements, dry mouth, blurred vision, constipation, and trouble in urinating. Rarely, the side effects may be more dangerous than the agitation neuroleptic malignant syndrome (high fever with confusion), abnormal blood cell count, and late development of tardive dyskinesia (abnormal movements or tics that may be irreversible).

The Role of the Psychiatrist in Addressing Behavioral Problems

One of the factors that make rehabilitation of traumatic brain injury so complex is that there is much overlap between physical and psychiatric aspects. As discussed in the preceding section, there is a growing awareness that changes in the chemical environment of the brain produced by brain injury can cause many of the behavioral problems. However, it is only in recent years that psychiatric clinicians have become aware of how head injury differs from standard psychiatric diagnoses.

The psychiatrist must modify the standard psychiatric approach when treating the head injured. Classically, the physician-patient relationship is primary and the interview and examination the main source of information. The skillful psychiatrist recognizes that behaviors of the head injured vary greatly, so that a brief clinical examination will not give the whole picture. The family, nurses, and the multidisciplinary team then become a primary source of information about the behavior. The family is the primary source of information about the premorbid (preinjury) coping methods and personality styles that are so important to later outcome after head injury.

The psychiatrist plays an important role in diagnosis. Patients with head injury may have had premorbid personality or psychiatric disorders that develop into behavioral problems, and these can respond to treatment with medication. These include anxiety, nervousness, depression, risk taking or wild behaviors, bizarre thinking, and drug or alcohol abuse. Be sure to tell your loved one's doctors about any of these behaviors. Family and staff can help the psychiatrist identify signs of depression such as poor sleep, awakening early in the morning, poor appetite, low energy level, and important mood changes. It is important to determine whether there is an overall depression or merely a normal adjustment to a life change that can be managed with counseling and family support. Depression can be treated effectively with medications. Patients may also have unrecognized medical conditions that existed before the accident. If medical conditions are present, such as hypothyroidism or pernicious anemia, treatment will allow a better recovery.

Agitation or violent behaviors can usually be well treated with a combination of behavioral approaches, environmental support, and medication. The psychiatrist can advise which factors to emphasize and help select medications with a minimum of sedation or other side effects. Sometimes, the psychiatrist will recommend that medications given for other conditions be changed because they may be causing confusion or sedation.

The psychiatrist can also be an ally in the family-counseling efforts of the treating team. Family members themselves may have severe problems with coping and need anxiety or antidepressant medications. Questions may arise, such as how to share bad news, and the patient or family may need a medication for stress over the short term.

Acting together with the family and the multidisciplinary team, a thoughtful and creative psychiatrist can have a vital role in rehabilitation of traumatic brain injury.

Wandering

Confusion and agitation can lead to wandering around on and off the rehabilitation unit. This occurs most commonly in patients who are physically mobile (Ranches Level IV or V patients, and sometimes Level VI). Patients in these levels may be confused or have a poor sense of direction. Dangers are obvious; they could get into any imaginable type of trouble when away from the protected environment.

Wandering is controlled by restraint within the rehabilitation unit itself. Units can be extensions of the protected environment and are modified, depending on the patients served. Some units lock the head-injured area, using either a lock controlled from the nursing station or access by card, code, or key. A locking system needs a safety backup in which fire doors will unlock in the event of an emergency. Other units keep their doors unlocked, but have an alarm that sounds when perimeter doors are opened. Still other units use alarms on the patients themselves. With this system, the patient is 'tagged' (e.g., with a special wrist band) so that a buzzer or alarm sounds when he passes a certain point. This is similar to the type of system used in department stores,

where the merchandise is tagged to prevent shoplifting. A sophisticated computer-based system now exists that can track patients with radio-emitting bracelets on a TV screen. A backup system of color-coded wrist bands or badges is used in some centers to indicate to staff throughout the hospital that a patient has strayed off the unit. Whichever system is used, it is important that your family member has a safe and secure environment in which to recover.

Therapeutic Home/Community Visits

Lord, I'm 500 miles from my home

Bob Dylan

Homeward bound, I wish I was . . . home with the thoughts escaping . . .

Paul Simon

Sometimes when a person with brain injury has shown substantial improvement and his family shows a good understanding of the care required, a therapeutic community visit (TCV) is considered. A TCV is sometimes called a pass or a leave of absence (LOA). However, these terms do not reflect the true nature of what is supposed to be happening when the patient is given a short trial period at home. Rather than a leave or a pass, the time away from the rehabilitation center is a structured trial of family application of behavioral programs. It is a time when a patient's thinking, physical mobility and self-care skills can be evaluated in a familiar environment. It is a trial to see if your family member can generalize skills relearned at the rehabilitation unit to the home setting. TCVs are not a right, they are earned; TCVs are not a privilege, but a responsibility. The rehabilitation team and your physician will make the ultimate decision as to when you and your family member are ready for a home visit, but they appreciate your input. Keep in mind that a visit that is too early is hard on your loved one because of the disappointment at not being the same as he was, and it is hard on you because it is hard work!

Home/Community Visits Things To Do

Before the first home visit, review with each therapist, your nurse, and your physician all you need to know about mobility, self-care skills, behavior, medications, and precautions. Review what to do in the event of a seizure (see Chapter 13). In advance, review your home plan for accessibility with your therapist and ask appropriate questions. Should you try to get him into every room? How will you get into the house with a wheelchair? Be sure to lock away knives, guns, and car keys. Bring someone to ride next to your family member while you drive. Be sure to know how and when to give medications. Be sure you know how to walk and transfer your loved one. If a wheelchair is needed, know how to get the wheelchair up and down ramps, curbs, stairs, and into the trunk of a car. Do not forget to have everyone wear a seat belt.

On the first visit, it is important to avoid taking on too much, whether that be too much time or too many different activities. This is a first trial, so we recommend only a few hours. Because agitation and confusion can be problems, be sure to keep things simple and quiet. On the first pass, avoid coming-home parties, large birthday parties, family reunions, attending church, and visiting shopping centers. A good first day outside the hospital is 4 to 6 hours spent with a few of the closest family members in a familiar environment.

Family members should make carefully written notes on their observations of behaviors, areas of frustration, sources of agitation, and times of confusion. Please observe how the patient handles advice, criticism, and direction from you. How does he handle options and choices? How does he

deal with frustration, with losing, with children, and with pets? Was there any violence? You should report any obstacles in the home, not previously noted, to the rehabilitation team. How are stairs, ramps, and bathrooms handled? Are throw rugs a problem? Were there any dangerous items or areas knives, guns, gas ranges, open fireplaces?

If confusion is a problem at home, remember to "sterilize" the environment. Give him space. Have visitors leave, and have children go outside or into another room. Turn off the TV and radio. Speak to him in a relaxed and calm voice. Sometimes a gentle but firm touch is helpful. Remember that agitation sometimes means that he needs a nap.

After the visit, review what you have learned with the therapists and ask for their recommendations for the next home or community visit. Things to explore on later passes will be more stimulating and more complex situations, as suggested and deemed appropriate by your rehabilitation team. Look for opportunities to carry out and review activities learned in therapy that week (generalization). One can use the private time of a home visit to develop feelings of closeness, love, and intimacy. Feel free to discuss these issues with your physician, case manager, and treating therapists.

Home/Community Visit Things Not To Do

Home visits can be dangerous. In general, avoid new types of activities that have not been first attempted by the therapist (or permitted by them for you to try). In particular, avoid dangerous activities such as the use of knives, guns, ovens, stoves, fire, and power tools. Avoid dangerous locations such as steep stairs, high balconies, horseback, and bars. Your family member must not drive! Your family member must not drive! Please keep your loved one under supervision at all times. Remember, a home visit is a responsibility.

BEHAVIORAL ISSUES INVOLVING THE FAMILY

Any time a family member is in the hospital, there is hardship and stress on family members. This is magnified with an inpatient rehabilitation program because of all the uncertainties that exist. Day by day you hope to see significant progress, but sometimes the rate of recovery is very slow. Added to this, the evident change in personality or physical capabilities makes the hospital stay a hotbed for family discord.

Hours and hours are spent focusing on the patient's health, sometimes to the detriment of your own health. Sometimes families think that they must give 200 now that they can rest later when things get easier. However, managing head injury is a lifelong proposition, and it is important that you not burn out in the front end. This is a time when therapists and nurses are with the patient around the clock. This will not be the case later, so take time for yourself now.

Family Types

Families are as different from each other as individuals are different from each other. Some families are able to rally together effectively in a time of crisis, yet others completely fall apart. Suggestions that may be appropriate for one type of family may not be helpful for another type. Because of these differences, it is difficult to provide a blanket step-by-step process for handling a head injury in your family.

An attempt will be made here to describe some basic family types so that you might be able to identify your category, and possibly assist in altering aspects of this style that may be counterproductive to the rehabilitation process.

"We Have Always Handled Our Own Problems"

This is representative of the private family. They have always taken care of themselves and their loved ones with little or no assistance from others. They pride themselves in being able to handle anything that comes along. This type of family does very well under most conditions. If grandmother has a broken hip, all members rally and care for her until she is back on her feet. If she needs to live with someone for an extended period of time, there are multiple options. See Figure 3-5.

Head injury, however, is rarely something that families can handle themselves with only some assistance from the physicians and nurses. Pride and privacy may need to be shelved for awhile, as these traits can be counterproductive to providing your loved one with the necessary comprehensive program. The social worker is not there to snoop into your family secrets, but rather to provide you with the needed guidance and support to look into the future and plan for what is needed down the road. If you are not sure what or how much help you may need, consult the social worker, psychologist, counselor, or any other team member with whom you feel comfortable.

"Life Does Not Give You Anything You Cannot Handle" ('God Will Take Care of Us')

Faith is extremely important in many families. We, as professionals, are not ignoring the powerful assistance this provides. We do, however, believe that there are times when important decisions are stalled or halted because families are relying on someone or something other than the rehabilitation personnel. Hope for a miracle can be a problem when it interferes with treatment.

It is best to look at this as a team effort with numerous players needed to reach the goal. You and your family members may not have all the resources and back-up strength to last day after day and year after year. Head injury is more than a 3- to 6-month medical crisis. It is often a lifetime proposition, so use all the help that is available through the interdisciplinary team members.



Figure 3-5 "We Have Always Handled Our Own Problems"

Denial

If the physician and other therapists have told you your loved one is ready to go back to work, that is one thing. However, if you yourself have determined that this is the way it will be, or if the patient is telling you he is going back to work right away, this is representative of denial. Families often hide the fact that they are in a state of denial. Some people believe that simply talking in this positive manner encourages the patient to do his best.

On the other hand, this type of denial can lead families to ignore statements that may help them to prepare for what lies ahead. Yes, some patients do better than was originally expected, and your loved one may fall into this category. We hope he will. Nevertheless, take a minute to listen to what others are saying. If it is very different from what you are thinking, allow yourself to at least listen to the others. Otherwise, you could inadvertently keep your family member from obtaining the care he needs to get better.

It is very difficult for family members to recognize denial because of its protective quality. This protection is helpful at times, and it allows you to face the large undertaking in head injury recovery. To determine if you are holding on to false hope you might ask the opinion of one of the team members you particularly trust.

"He Will Be Fine Once We Get Him Home"

When a patient has been through weeks or even months of inpatient care and has not progressed as you once imagined he would, you will naturally look for elements that might be interfering with his progress. Families often believe there will be significant improvements when he gets home to familiar surroundings. Sometimes there are positive effects, but these are not necessarily of the magnitude expected. At other times he can actually get worse until he acclimates to his new environment.

Underlying some of this thinking may be the feeling that even though all of these trained people have had all of this time, the progress you expected has not been made. It is here that some frustration and confusion may develop. You may think that you should have chosen another center or you should have taken him home earlier where those who really care about him could take care of him. Although there are differences in inpatient facilities, as well as differences in therapist personalities, the fact remains that the rate of recovery is related more to the degree of injury than to some significant flaw in the rehabilitation program. Some patients do make great strides when they go to other centers, but it is usually because they were developmentally ready to make progress at that time, whereas they were not ready before.

"Woe Is Me How Will We Ever Manage?"

This statement is most likely posed by a family that has not yet established an effective support system within their own family unit. More often than not, they will constantly ask for help, and there will be no cohesive plan for caring for the patient once he is discharged from the inpatient setting. This is partially due to the fact that no one in the family believes he can manage all that is needed.

If you think your family falls into this category, ask for assistance from the social worker, psychologist, or counselor. Admit that you may be overwhelmed, and ask for specific steps on how to prepare for and manage all the issues. Suggest that your entire family come in for some therapy. Ask for help and accept it when offered.

"If Only I (You) Had . . ." "If Only I (You) Had Not . . ."

Pure, unadulterated guilt exists here. Some families are so torn apart by feelings of guilt that they focus on what could have been avoided rather than what exists today. It is normal to look back and have regrets, but it is not normal to let these guilt feelings consume your existence. Moreover, it is very detrimental when families focus on making someone else feel guilty, such as saying, "I would never have allowed him to go skiing that day. I can't believe you gave him permission.

If you feel that your family has fallen into the guilt trap, ask for help to turn this around. Guilt is something that is difficult to turn around on your own, but the inpatient facility will have professionals trained to assist. You will need to work through the guilt or anger that you have harbored. These feelings may be difficult to give up, but you must do it to be able to provide effective support for your loved one. See Figure 3-6.

"Our Son Would Do So Much Better if You Folks Would Let Him Have a Nap after Lunch"

This type of statement often represents a controlling family style. Individuals who have been accustomed to telling most family members what to do and how to do it will have a difficult time relinquishing control over the rehabilitation process. Moreover, head injured patients are very good at exaggerating reality and getting families in an uproar about some transgression that may actually have been very minor. They are also good at getting the family to believe that they would

do so much better if only a few changes were made. For example, you might hear, "I would be doing better in speech if I had a new therapist; I don't like to work with the one I have now." The reality is probably that the speech pathologist is asking him to do something that is difficult or frustrating, and he is hoping to change this by getting rid of that particular therapist.

The fact exists that you must let go of your need to be in control to allow the team to work effectively. You are a member of the team, but you cannot be the leader at this time because of your lack of experience with head injury rehabilitation. Yes, you know the patient better than anyone else, but in this instance, you should share the control with others in the treatment team. Take time to share your feelings with a social worker or counselor within the facility. In this way, you may be able to begin to feel comfortable about letting go. See Figure 3-7.

“Our Lives Are Ruined. What Will Become of Us?”

This extremely depressed state will most likely not appear until after the inpatient process, primarily because of the lack of definite answers about the rate of recovery. However, some families (or one significant family member) may go into severe depression immediately, the type of depression that overwhelms and leads to inertia. If this is happening to you, it would be fairly easy to recognize because you cannot seem to function in terms of making decisions about the future. You may feel confused, disoriented, and completely fatigued. Excessive sleep or becoming a couch potato are some recognizable signs.

In all likelihood, you will need some professional assistance in working through this depression. Ask the social worker or psychologist for assistance. You must get yourself together so that you can provide the proper guidance and support for your loved one.

Family Behaviors that Can Interfere with Rehabilitation

No matter what your particular family style entails, two behaviors can be detrimental to effective inpatient rehabilitation—*overoptimism* and *stressing out*.

Overoptimism

It is important to be optimistic regarding the recovery of your loved one. This hopeful attitude helps you and your loved one proceed in a positive direction. However, if you fail to consider that your family member may have some long-lasting changes, you may present an obstacle to the rehabilitation process. Overoptimism can be detrimental. When you know absolutely that someone ought to be able to walk when a broken leg heals after a specific amount of time, then it is appropriate to say he will be able to throw away his crutches after that time. Unfortunately, the time lines for recovery from head injury are not that clear-cut. It may take one person 10 weeks to accomplish walking and another person 10 months to do the same.



Figure 3-6 The Guilt Trap



Figure 3-7 A Controlling Family

If the body is not ready, your enthusiastic encouragement that he will be able to drive again by summer will only accomplish the opposite of what you have in mind. If he thinks that you expect him to walk independently within a specific time, he will be mighty discouraged if he does not meet your expectations. This can cause a depressive reaction that, of course, is counterproductive to any therapy program.

You may have dates in mind regarding progress, but try to keep them to yourself. Better still; discuss whether your time lines are practical with the therapists. It is best to take things a day at a

time and allow the patient to progress at his own pace. We are sure you do not want him to feel like he is failing.

Stressing Out

Are you trying to be everything for everybody? Are you running on nervous energy? Have you driven home from the hospital and do not remember getting in the car and driving? Do you sometimes step outside yourself and you appear to be a total stranger? You are stressed out. Many families look back on these days of inpatient rehabilitation and are surprised that they survived. Some people say it is like a blur in their life. They remember things about the hospital, but they have little recognition of what went on outside the hospital during those months.

For you to be helpful to the head injured loved one, you must take care of yourself. Your mental and physical health is just as important, or maybe even more important, than the patient's. Do not force yourself into thinking that you will rest after he gets out of the hospital. If that is what you are thinking, do away with it now. Remember how anxious you were to get that new baby home when you had your first child? Now remember how haggard you felt after the first week at home. This is a similar situation—*rest now*.

If you find that the stress is becoming overwhelming, or a friend points this out when you did not recognize it, get help. Do not be afraid to seek help. It is normal for family members to need guidance through this period of rehabilitation. Ask for assistance with stress management and relaxation techniques. Skip going to the hospital one night a week. Go out and do something for yourself. In essence, take care of yourself—your health is important to the patient.

Chapter 4

Preparing for Home

To the health care professional:

This chapter should be introduced to the family well before discharge so that they can be fully involved in discharge planning. The purpose is for them to understand the issues, ask questions, work as part of the team, and assume the key role in the continued progress of their family member.

Chapter 4

Preparing for Home

DISCHARGE/RETURN TO THE HOME

There are a number of places that your loved one may go on leaving the inpatient rehabilitation facility. These are described in detail in the following chapter. The options depend on a variety of factors, including severity of injury, medical stability, progress to date, funding, and the feasibility of returning home. In this chapter, we look at what is involved in preparing for a return to the home.

The long-awaited day arrives, and you are ready to take your family member home. There are many questions you may need answered before you are ready for the discharge of your loved one. When we think of the word discharge, we think of someone coming out of a long-time commitment, such as the military, in which he underwent a great deal of change. As a family member, you may do well to consider the discharge of your loved one in the same light. The person you are taking home is not the same person who was injured; it will help you if you are prepared for that.

Discharge Planning

In the discharge-planning process, the key team members are you, as the primary caretaker, and the discharge planner. The discharge planner may be a social worker, case manager, team leader, or any other designated person whose main responsibility is to see that there is a smooth transition from the rehabilitation setting to the home.

With effective discharge planning, you will be able to gather as much information as possible to enable you to properly care for your family member at home. The discharge staffing (meeting of the therapy team including you) is the usual mechanism used to provide this information. Each therapist will be able to provide you with specific information. This information should be coordinated into a workable plan for you to use to maintain home care. For example, the occupational therapist will provide information regarding such functional skills as cooking and housekeeping. The physical therapist will instruct you in transfers, endurance, and safety, either in the wheelchair or during walking. The speech/language pathologist will give you information regarding possible swallowing difficulties, language comprehension, or expressive difficulties. The cognitive rehabilitation therapist will give you information on possible problem solving, attention and concentration deficits, and how these difficulties will affect the patient's behavior at home. The psychologist may devise a home behavior management program. The social worker will provide information regarding community resources and funding sources. The physician will

give you medical precautions and will provide you with any necessary prescriptions. This is a lot of information to absorb in one meeting, so bring your notebook (you should be using one frequently by this time).

You will do yourself a big favor if you gather as much information as possible about head injury. Get every book, manual, and resource material that you can beg, borrow, or buy. Make certain you have a contact with your local chapter of the National Head Injury Foundation, and plan to attend a meeting, even if you think you do not need support at this time. Another important aspect of the discharge planning is arranging for outpatient therapies. Ask your discharge planner to help you find such a program that is convenient for you. Outpatient programs will be discussed in Chapter 5 of this guide. As you are the person reading this guide, you have most likely assumed the role of the primary caretaker for your family member. As the primary caretaker, consideration must be given to legal and medical issues that relate to you and your family member.

Legal Issues

At some point during the inpatient stay, a guardian may have to be appointed for your family member to handle his financial and personal responsibilities. Requirements for this vary from state to state. Again, your discharge planner will be able to give you information regarding that procedure. As the primary caretaker, you may well be the guardian of your family member for a period of time. Each guardianship situation differs; therefore, you may need to consult your attorney with regard to the particulars of your case. The guardianship can be ended when your family member is again able to handle his own affairs.

An issue closely related to guardianship is competency. At any time in the rehabilitation process, a person can be declared legally incompetent (not capable of making decisions). This procedure, which varies from state to state, may require the recommendation by a physician, usually a psychiatrist, and a court order. Information from your psychologist, therapists, and social worker may well be used in making the determination. This is not a permanent status. Often this occurs when a person is still in a coma. Someone who has been declared incompetent is not allowed to borrow money, apply for a driver's license, or sign any legally binding contract. For competency to be reinstated, your family member will again be evaluated by a physician. The matter will then be returned to the courts for a final decision.

Your family member was most likely a wage earner and will not be able to return to work for the time being. You, as the primary caretaker, will need to aid him in applying for Social Security disability benefits. The procedure is not complicated, but does take persistence on your part. These are benefits to which you are entitled, and it is well worth going through the bureaucratic red tape to pursue them.

Legal issues and procedures vary from state to state. Often it is beneficial to get help from an attorney who can assist you with the issues that may develop during your family member's recovery. In reviewing the past section of the book, you have probably determined that, as the primary caretaker in the home environment, you have assumed a major responsibility on the discharge of your family member. The best piece of advice that any professional could give you at this point would be to tell you to take care of yourself. The stronger you are, the stronger you will be for your loved one.

MEDICAL ISSUES

Discharge from the rehabilitation center begins another stage in the recovery process. It is part of the long-term plan of care for your loved one. Development of that plan should begin at admission to the rehabilitation center and continue to evolve as your family member progresses.

For the family taking their loved one home, "How are we going to take care of him?" is a question that should be gradually answered as you observe the rehabilitation process in action. During the hospital stay, you will observe many nursing-care procedures. You may be asked to accompany him to therapies. Before discharge, you will need to spend several days with nurses and therapists learning how to care for your loved one. You will need to find answers to all of the following questions:

- What are the medications? When should they be taken (at what times, on a full or empty stomach)? For what are the medications prescribed? What are the potential side effects? How long should the medicines be taken? Can he take over-the-counter medications, such as vitamins and aspirin, with these prescriptions? How will I pay for the medication? If you cannot afford all of them without defaulting on your house payments or utility bills, please tell your doctor! Does the local pharmacy have the special medications or tube-feedings that are needed
- What special nursing treatments are needed? How do we handle bowel and bladder function? How is constipation to be handled? What do I do if there is vomiting? What do I do if there is a seizure? (See Chapter 13.) What if he develops a swollen limb? (This suggests deep vein thrombosis see Chapter 2.) What is the daily nursing care for the various tubes? These include tracheostomy for breathing and catheters for bladder emptying. Feeding tubes include gastrostomy and jejunostomy each involves different care and potential side effects. If the feeding tube comes out, what should I do? Usually, it can be just slipped back in, but ask the physician. A tube placed through the nose needs to be checked to be sure it is still emptying into the stomach. If a feeding pump is used, be sure you know how it works and what to do if the warning lights flash. Ask what the schedule is for turning the patient in bed, if necessary.
- What special equipment is needed?—Be sure to check with therapists and your physician before purchasing equipment. Items purchased too early may not be needed as improvement occurs. Ask what type of bed is needed. Are rails necessary? Should any special mattresses be used? How are casts and splints to be worn? Can I transfer him alone or is a lift (such as a Hoyer lift) necessary?
- How do I use all this equipment?—For the severely disabled patient, it sometimes seems as if an engineering degree is needed to handle all the stuff! Be sure you know how to operate the wheelchair and how to get it in and out of a car. Know how to position the arms in slings and the legs in splints, if needed. If he walks with a cane or walker, should he walk alone?
- What home modifications are needed? Ask the team before you tackle expensive additions or changes to your home.
- What therapy do I need to do at home?—What are my "home programs" for occupational therapy, physical therapy, and speech pathology? What types of cognitive rehabilitation should we be doing at home? (See DeBoskey et al., *Families Without Funding: Home-Based Cognitive Rehabilitation Program*.)
- What therapy services will be provided at home/as an outpatient?—Home health services by specialists allow continued therapy on a less intense basis.
- What therapy and special education services should the school system provide to my child?—Public Law 94-142 requires school systems to provide services for disabled children up to age

21 who are unable to attend a typical classroom environment. Be sure you know what is needed so that you can represent your child's interests when you meet with the school personnel. A specific category for head injury does not exist. Work with the school system to determine your child's needs, and find appropriate home tutoring, special-education classes, a residential program, or regular classes. If you disagree with the school system, the law provides other avenues in which to make your concerns heard. This procedure is called "due process." Attorneys or other special advocates may need to be consulted on this issue.

- What transportation is available?—Are appropriate transportation services available in your community? How do you qualify? How do you contact them?
- What relief can I get?—Who will help with the care of our loved one? How can I get out to shop, attend church, visit friends, or take a break? Can we ever vacation again? Is a respite-care program available anywhere? What happens if I get ill?
- What type of medical problems does he have?—What kind of problems might develop? What are the symptoms (the patient's complaints) and signs (outward evidence of a problem) of urinary tract infection, pneumonia, or seizures? How do I contact the physician if a problem occurs? When do I contact my family physician, and when do I contact the rehabilitation physician?
- What is the daily routine?—How is he going to sleep at night? When does he get up, wash, eat, nap, and do toileting? How do we handle free time? What if he does not want to participate in therapy? How will he call for help? What is his usual breathing pattern? Is suctioning needed?
- How do I handle safety issues?—How do I keep him away from stairs, from guns and knives, from car keys? What if he gets depressed or suicidal? What if he gets abusive to me or the children? How do we handle severe behavioral outbursts? Will medications be needed at times?

Many questions regarding the home can be answered before discharge by means of a home evaluation performed by your therapists. There may be obstacles that could make it difficult to move about safely or independently in the home. If your loved one will need a wheelchair, the therapists will need to know the width of doorways and corridors. They may need to know about the bathrooms to help with decisions about support bars, special elevated commode seats, and access to the shower or tub. In severe disability, special environmental control devices help the disabled individual to independently turn lights on and off, control the television, or answer the telephone. A therapeutic home visit or "pass," as discussed in the previous chapter, is often helpful before actual discharge. This allows you a "hands-on" experience in caring for your loved one's needs. Some centers have independent living apartments or private rooms where you can participate in daily care under the supervision of nurses and therapists. Another helpful exercise is a community outing. Many centers coordinate trips to shopping malls, restaurants, or theaters as part of the therapy for higher-level patients. With therapists' permission, family members can sometimes join such trips to better understand how their loved one will function outside the home.

PRACTICAL ISSUES FOR THE FAMILY

At times, the excitement of bringing your loved one home interferes with the practicality of learning absolutely everything you might possibly need to make the transition a smooth one. The ideas presented here were originally developed in *Coming Home: A Discharge Manual for*

Families of the Head Injured (see DeBoskey in the bibliography). The following topics address issues that you are very likely to face if your loved one is being discharged to your home. Not all may apply to you, but it is often helpful to be familiar with the potential areas of concern.

The New Parent Syndrome

If you have had children, remember back to the time when you first brought the baby home. Because we all have some amazing protective devices for remembering the good and forgetting the bad, you may have to really dig to bring up these remembrances. These will refresh your memory:

1. Someone constantly needs you.
2. Running out to the store becomes a major project.
3. Reliable baby-sitters are suddenly a necessity and at times are impossible to find.
4. Humans urinate and defecate far more than you imagined.
5. Your time is never your own.
6. Life is centered around this new person.

Examples

1. You find that every minute of every day belongs to someone else your time is not your own.
2. You did not realize what it would be like to assist with the bathroom day and night.
3. You find yourself unable to rest because your mind is so full of worries about what you should be doing next.
4. You now think of a million questions that you should have asked before he left to come home.

Management Techniques

1. Make sure that you have some back-up help lined up before the loved one is discharge
2. Do *not* allow yourself to believe that you can take care of everything.
3. Beware if you are thinking, "There's no one I can trust to care for him while I am away."
4. Do *not* allow yourself to think that your loved one should have a break and not go to outpatient therapies immediately on coming home. If therapy has been recommended, start it as soon as possible.
5. If you find your blood pressure rising, or any other symptom of increased stress, consider seeking counseling support in the community.

Dependency at Its Ultimate

Your loved one may be coming home from an acute care hospital or an acute care rehabilitation facility where the purpose was to foster independence. In any event, there will be particular aspects of his having been in a facility that will lead the individual to have certain expectations regarding what should happen at home.

Because head injury patients sometimes distort reality or have spotty memories with regard to what has happened recently, it is important for you to find out exactly what your loved one is capable of doing. If you start assisting him or actually take over things that he can do, you may

find yourself in the difficult position of insisting the individual develop and maintain the independence of which he is capable.

Unless your loved one is completely dependent when he is discharged, you must not think of him as someone who will need constant care from all family members. If you set the precedent of taking complete care of this recuperating individual, you may find that he will act like a sick person forever.

Examples

1. The loved one expects dinner at exactly 4:00 P.M., regardless of what is happening at home.
2. He constantly calls on you to bring him things that he is perfectly capable of getting himself.
3. The individual makes the following statements: "The nurse always reminded me to take my medicine." "The occupational therapist always helped me get my shoes on." "The physical therapist said I need to take it easy with my exercising and not overdo it."

Management Techniques

1. Do not allow the head injured individual to take control you must be the controller.
2. Get a list from each therapist regarding what he should be able to do at home.
3. If possible, spend an entire day going through the facility's routine so that you can see first hand what his capabilities are.
4. Talk to the night crew and find out about his nightly habits, such as frequency of need to urinate, possible sleepwalking, and how many times he wakes up at night.
5. In essence, find out everything possible about his routine.
6. Write down the names and numbers of the therapists so that you can telephone them if questions come up.

Ask the Right Questions Regardless of Position or Experience

Because of your position, education, background, or experience, you may find that some physicians, nurses, and therapists assume that you are knowledgeable in many areas of head injury care. This is similar to someone who thinks that a child-psychologist's children should be under perfect control or that a counselor should be adept at managing his own stress.

Management Techniques

1. You might want to say to everybody, "Forget that I am Director of Nursing at St. Joseph's Hospital; do not assume that I know all the basics."
2. Make sure you gather information from all of the therapists involved in the case. Do not let them assume you are familiar with what your loved one can do, cannot do, needs, or does not need.
3. Show your need for information by asking thoughtful questions and writing down what you think you might forget.
4. Say to everyone involved, 'Is there anything you think I need to know that I have not asked?'

The Overprotection Syndrome

Anytime someone comes home from a hospital or residential facility, there is a tendency to provide too much assistance, in keeping with the true caretaker role. This is understandable in

light of all you have been through; however, it is counterproductive in head injury rehabilitation. You must keep in mind that the goal is for your loved one to do as much as he can for himself and to get back out into the real world. You need to get involved with all efforts at community reintegration. Start by asking him what he wants to do and try to accommodate as much as possible. If he rejects outings, begin a management system that will encourage him to go out into the world. You may have to begin with very short, brief excursions, such as a ride to the 7-Eleven to get a soda. Gradually increase these occurrences, using all the help you can muster from old acquaintances and friends.

Examples

1. You avoid taking him to the mall because you are not sure how he will react.
2. You continue to cut his meat for him because you do not like to see him get frustrated.
3. You will not leave him alone for more than 5 minutes, even though the therapist told you that he could be at home on his own for 1 to 2 hours.
4. You are embarrassed by how messy he is when he eats, so you do not go out to eat at all.

Management Techniques

1. Try as much as possible to include the head injured individual in your outings.
2. Do not seriously alter your lifestyle because you think that you have to stay home and take care of your loved one.
3. Allow extra time to get ready when you go anywhere with the individual. This way, you will not continually feel harassed and running late.
4. Do not give in to what is easier by having therapists come to you if the person is capable of going to them.
5. Get follow-up feedback from therapists to help you determine how much protection is needed or not needed.
6. Assume that your loved one can do a task until he proves otherwise.

The Daily Schedule Reaction to Change

There was a fairly consistent schedule in the rehabilitation facility. It was also quite busy and somewhat inflexible in terms of what the patient could choose to do or not do. Head injured individuals need this structure to assist them with organization and memory deficits. It will make your life easier and the transition smoother if you, too, have a definite schedule determined before the loved one is discharged.

People with head injuries have difficulty with change, and there is no way to completely avoid this on discharge. However, as mentioned earlier, do not allow the person 3 or 4 weeks of relaxation (inactivity) because you think, or he says, he needs a rest. You will be asking for trouble if you have to get him geared up again for a regimented schedule after weeks of "vacation." Find out exactly what he did each day in the center, and try to be as organized in his home schedule.

Anniversary Reaction Syndrome

If it has not yet been a year since your loved one's injury, it is important for you to be aware of the

possible anniversary reaction syndrome. As you well know, people react differently to the same situation, but there are some similarities in the thoughts that families have as the 1-year or 2-year mark approaches.

The first-year anniversary is often filled with the memories of where you were when you were informed of the injury and all of the emotional reactions and thoughts that filled your mind at that time. You may have thought that you had worked through all those fears and anxieties, but they can sometimes return on the anniversary date. Another thing that can occur is that you may have had hopes that your loved one would have progressed much further by a year's time. Realizing that an entire year has passed without reaching a number of your goals may lead to a depressive reaction.

Many people refer to the magic "2-year mark" as the time when a person will have experienced most of the recovery that is to occur. It is true that a large part of the recovery takes place in the first 2 years, but recent research on long-term head injury care has shown that changes can and do take place after the 2-year mark. These changes do not necessarily show up as better test scores, but they can certainly involve changes in social and behavioral skills. Thus, do not look on the 2-year mark as an end to the recovery period. See Figure 4-1.

The Question of Driving

If your loved one is able to walk independently, he is going to think that he is able to drive. How are you going to know when or if he is ready, and how are you going to convince him that he needs more time to recover? This is a very difficult issue, particularly for those of you who are experiencing some of the remaining behaviors described in Chapter 10. One thing that most upsets a head injury individual is that he has to depend on other people too much if he cannot drive. Some of the most violent outbursts can occur over this issue. See Figure 4-2.

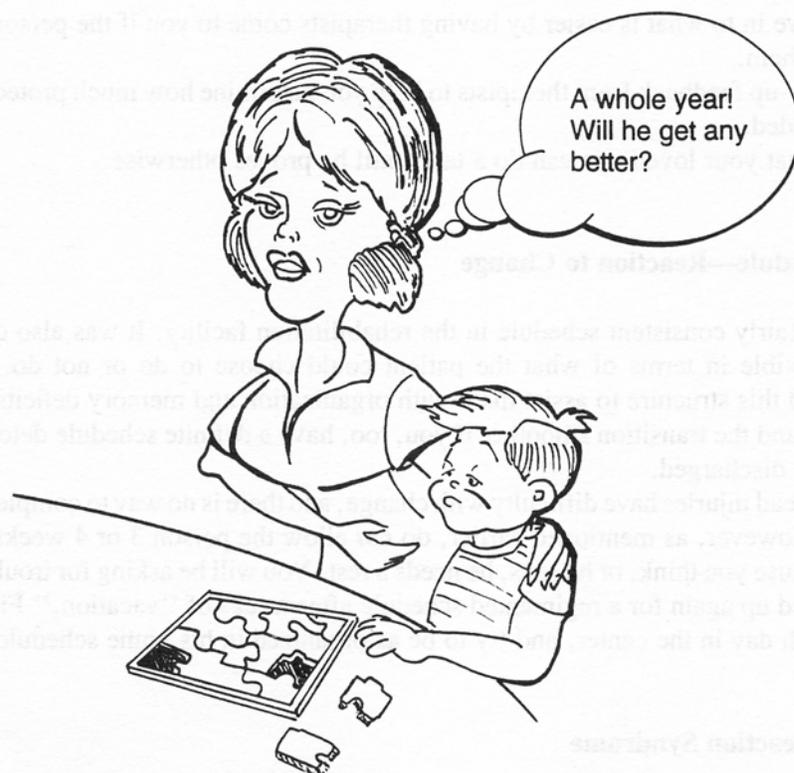


Figure 4-1 The Anniversary Reaction Syndrome**Figure 4-2** The Question of Driving

There are two main considerations in answering this question physical and mental. From the physical standpoint, you need to know about strength, reflexes, and reaction times. These can be evaluated by an occupational therapist and/or recreational therapist using a specially adapted automobile. Visual acuity can be affected by the presence of double vision, which may last for a few months or may linger for many years. Some people will cover one eye to eliminate the double image. This, of course, is not an adequate solution for driving because it eliminates depth perception which is very important for safe driving (see Chapter 13 on Diplopia). An additional physical deterrent is that of seizures. Most states have rules regarding the length of time that an individual must be seizure-free before he can drive. Be sure and check with your state's motor vehicle department for this information. The average is anywhere from 1 to 2 years.

From a mental standpoint, it is important for your loved one to possess the cognitive (thinking) skills and judgment necessary for operating a vehicle. If your loved one has been declared incompetent by the court, he is not considered eligible to drive or to take a test to renew his driver's license. Thus, if you believe that he is mentally capable of driving and his physician agrees, you will have to go to court and have him declared competent (refer back to Legal Issues in this chapter).

However, being competent does not necessarily mean that one is capable of driving. Being mentally capable of driving is difficult to assess, and there is little standardization regarding the adequate level of cognitive ability necessary for this complex task. Various rehabilitation centers across the nation are in the process of developing and refining numerous cognitive tests that will assist in determining whether or not a head injured individual is ready to drive. Some of the skills

measured are visual discrimination abilities (Does he see what you and I see?), distractibility (Is he easily distracted by minor visual or auditory occurrences that may affect his concentration?), right-left orientation (Is he easily confused by right-left directions?), visual organization (Does he find himself lost, although he has passed the same McDonald's three times?), problem solving (Can he choose an appropriate alternative to hitting the cat that crosses in front of him?), and visual perception (Is the car he thinks is 3 feet away from his car actually 3 inches away?).

The most difficult task that you will have is convincing your head injured family member that he must go through these tests before he can drive on the road. Many individuals feel that because their driver's license is still valid nothing else is necessary. Even more difficult than this is the situation in which you know that your loved one can never drive again. Sometimes it is easier to convince him to have the driving evaluation, and let someone other than a family member be the one to tell him he cannot drive.

Management Techniques

1. Ask your physician to tell the individual when he can drive again. If he believes that it is necessary for the doctor to release him, he will not put the burden on you.
2. If you know that driving is out of the question forever, try to sell or otherwise dispose of the individual's car so that it will not be sitting in the driveway as a reminder or tempting him to drive.
3. Once you believe in his capability or are told he should be tested for driving, consult the rehabilitation centers in your area to determine where you can go for the evaluation.
4. If he is allowed to drive, he must never drink.

Developing a Behavioral Management Program

It is almost never ideal for a family member to act as a therapist or behavior modifier; however, there are many situations in which it is helpful for all family members to understand the principles underlying a behavior-management program. Also, because of the lack of funding or therapist availability, you may find that you are the one who must come up with a workable program or, at the least, know how to monitor an existing plan.

Management programs can apply to all levels of head injury patients. We will try to give examples that apply to mild, moderate, and severe traumas. You may think that your loved one will be offended by what appears to be a child-oriented approach. It is very true that the procedures resemble techniques used with children with behavior problems. However, you can remind your loved one that life is based on contracts, and that this is what is being set up a behavior contract. When people accept jobs and sign contracts to work, they are agreeing to perform certain functions in return for paychecks. Your behavior plan is just another form of contract that sets out to manage your loved one's work behaviors. If he can understand that this is necessary to get him ready for the real world, he should more readily agree to follow-through. Do not forget that your perception is also very important. If you give him the idea that you think the plan is childish, you will not be able to obtain effective cooperation. Think of this as a stepping stone to help your loved one enter or reenter the adult world.

What Are the Problem Areas?

To take an organized approach to behavioral change, you must first determine the areas you want to address. Start by making a comprehensive list of all the problems. Divide this list into *Things I want him to stop doing and Things I want him to do*. It does not matter how long this list is at first. The important thing is to get down on paper all of the changes that you believe are appropriate. After listing everything, you might look back to see if some areas can be grouped together or if two changes are very similar in nature. If you are working in conjunction with a therapist, he can help you organize the issues.

Where Should We Begin?

This is a very important question, yet one that is not so simple to answer. Should you start with the behavior that drives you the craziest, the behavior that occurs most frequently, or the behavior that does not bother you so much but prevents him from being accepted socially? There is no set response here it really depends on your situation. If you are working with a specialist, he can guide you through the process of establishing priorities

If you must do this on your own, you will need to determine the most important deficits. This decision should be based on input from all significant others and, when appropriate, with your loved one participating. The behaviors chosen for change should be most pertinent to his general well being and/or adjustment to home and community.

You might start by choosing five areas that have been deemed absolutely necessary to change. You will need to take a frequency count over a week's time so that you can have objective information regarding the rate and intensity. In the therapy field, this is called baseline data because it gives you the rate of occurrence before you set up the program. This lets you compare frequency of events as you progress with the management program.

Collecting these data requires that you count the number of times a particular behavior occurs. Examples of recording data are as follows:

Example 1. Joe was a patient in a head injury unit for 5 months. During the last 2 months of his stay, the behavior management therapist had reduced his frequency of cigarette smoking to ½ pack a day. On returning home, Joe's parents noticed that he was up to more than a pack a day. His mother measured baseline data by recording the number of cigarettes smoked each day. The data sheet looked like that shown in Exhibit 4-1.

Example 2. Susan was walking through a doorway in her office building when a heavy wall clock dislodged and struck her on the head. She was not unconscious, but she reported "seeing stars" and she appeared disoriented to time and place for a period of 30 to 45 minutes. She was checked by the company physician and released. She came to work the next day, but blamed her grouchy mood and ineffectiveness on her severe headache. After 3 months time, she still had headaches, but they were less frequent and intense. Her co-workers found her to be much more quick tempered, yet still tolerable. Her family, however, asked the rehabilitation nurse for help. Susan was blowing up at home on a regular basis, and no one wanted to be around her. They found this behavior unbearable. In addition, she was refusing to go anywhere except work, and she was avoiding all social contacts. Her husband recorded the two sets of data found in Exhibit 4-2.

Name: Joe S.
 Observer: Mother
 Behavior observed: Number of cigarettes smoked

<i>Date</i>	<i>Frequency</i>		<i>Total Number</i>
	<i>AM</i>	<i>PM</i>	
March 4	8	26	34
March 5	5	19	24
March 6	3	20	23
March 7	11	24	35
March 8	13	12	25
March 9	4	17	21
March 10	4	22	26

Exhibit 4-1 Data Sheet for Joe S.

Name: Joe S.
 Observer: Mother
 Behavior observed: Number of cigarettes smoked

<i>Date</i>	<i>Frequency</i>		<i>Total Number</i>
	<i>AM</i>	<i>PM</i>	
March 4	8	26	34
March 5	5	19	24
March 6	3	20	23
March 7	11	24	35
March 8	13	12	25
March 9	4	17	21
March 10	4	22	26

Exhibit 4-2 Data Sheets for Susan D.

Name: Susan D.			
Observer: Husband (Mr. D.)			
Behavior observed: Number of temper outbursts at home			
<i>Date</i>	<i>Frequency</i>	<i>Total Number</i>	
June 1	XXXXX	5	
June 2	XXXX	4	
June 3	XXXXXX	6	
June 4	XX	2	
June 5	XX	2	
June 6	X	1	
June 7	XXX	3	
Name: Susan D.			
Observer: Husband (Mr. D.)			
Behavior observed: Number of outings other than work			
<i>Date</i>	<i>Frequency</i>	<i>Total</i>	<i>Comments</i>
June 1	X	1	drugstore
June 2	—	0	
June 3	—	0	
June 4	—	0	
June 5	X	1	7-Eleven
June 6	—	0	
June 7	—	0	

Mr. D. observed that Susan would get someone else to go out for her any time she could. On the two days she went out, to the drugstore and to the 7-Eleven, no one else was home and she had to get something that could not wait. The family realized that they had been catering to her because they thought the headaches kept her from being able to go out. In addition, they felt that she would be set off and have a temper outburst if they refused to run errands for her. In essence, they had all adjusted their behavior to center around Susan.

These examples provide you with a model for recording the data. Once you have done this for the pertinent areas of change, you are then ready to determine who should monitor the program and how he should go about it.

Who Should Carry Out the Program?

It is more practical for a home program to be monitored by the person who has the greatest contact with the individual. An obvious drawback to this is that it is difficult for family members to be objective and consistent in their approach. Lifelong family interactions can interfere with the head injured person's acceptance of the program based on how he feels about the person who is setting up the criteria.

You must make sure that the person doing the recording is willing to stick to the plan and enforce the program. Modifications can be made, but the head injured individual must not feel that he is in control of the plan. It is very important to carry through with whatever consequences have been set up. Thus, before you begin, make sure that there is someone in the family who is both capable and willing to follow through, even in the light of difficulties or setbacks.

What Basic Principles Do We Need to Know?

There are some basic terms that are necessary for you to know to enable you to design intervention programs that can modify minor behavior problems. Very difficult or severe behavior problems will require professional interventions. If you experience difficulty learning or applying these principles, you should consult a mental health professional. Do not expect to be able to set up an effective program immediately. It will take practice before you determine what works most effectively for your loved one. It is best to begin with just one behavior. This will prevent you from feeling overwhelmed and from being unable to determine what is causing your program to succeed or fail. The following terms are some that you will need to know and be able to apply to your family member.

Consequences. The first term you need to learn is consequences. Consequences are defined as events that follow behavior and either strengthen or weaken that behavior. Consequences that follow a behavior and result in an increase or strengthening of that behavior are called reinforcers. Consequences that follow a behavior and cause that behavior to decrease or weaken are called punishers. Here are some daily consequences that modify our behavior.

Consequences that increase or strengthen behavior include:

1. Paycheck—Receiving a paycheck is a consequence that strengthens the behavior of going to work each day.
2. Positive comments/compliments—Each time 12-year-old Chris washes the dishes, his mother says, "Chris, you did a great job." Mother's comment increases or strengthens Chris's behavior of washing the dishes.

3.

Consequences that decrease or weaken behaviors include:

1. Traffic tickets—Receiving a traffic ticket for speeding should decrease or weaken the behavior of driving too fast.
2. Missing a doctor's appointment—Each time you miss a doctor's appointment and do not call to cancel, you are charged for that appointment. The behavior of not calling is decreased.

Positive Reinforcement. Events or consequences that increase or strengthen desired behavior are referred to as positive reinforcers. Any behavior that is followed by reinforcing events is likely to reoccur. Positive reinforcement (reinforcing events) can strengthen both desired (appropriate) or undesired (inappropriate) behavior. The following examples clearly illustrate the power of positive reinforcement.

Example 1. Linda was discharged from the hospital and returned home where her parents planned to continue her rehabilitation program. Unfortunately, Linda's parents had no knowledge of behavior-management techniques. Linda had difficulty controlling her inappropriate language. Each time she cursed, either parent would respond by snickering, smiling, or touching her shoulder and saying, "Linda, you should not talk that way." It was noted that her swearing behavior increased in frequency. The increase in behavior was due to the manner in which her parents responded to the cursing. They looked astounded and surprised, which gave Linda the attention she was seeking. Their response reinforced her swearing and did not discourage it thus, she continued to swear.

Example 2. Joe's parents and older brother wanted him to continue his cognitive rehabilitation program in the home setting. However, it was difficult to get Joe to follow through with structured activities. A behavior management program was designed to increase Joe's level of follow-through. Joe's parents and brother divided his 2-hour program into eight 15-minute segments. For every 15 minutes of cooperating and participating in the program, Joe earned a poker chip accompanied by a positive, supportive comment from either one of his parents, his brother, or a friend. At the end of the day, Joe could exchange his poker chips for watching TV, renting a video, going to the mall, or various other activities that he enjoyed. Joe's time on cognitive tasks increased significantly as this plan was set forth and monitored.

These examples indicate the effectiveness of positive reinforcement in increasing behavior. In the example with Linda, reinforcement maintained inappropriate behavior. In Example 2, Joe's participation in his cognitive rehabilitation program was increased significantly through the use of positive reinforcement.

Types of Reinforcers. There are many different reinforcers that you can use in your program; however, there are two general categories with which you should be familiar: primary (unlearned) reinforcers and secondary (learned) reinforcers.

1. **Primary or unlearned reinforcers**—Primary or unlearned reinforcers include such things as food, drinks, toys, and pleasurable activities. They are called unlearned because they are naturally pleasurable and do not have to be followed by some other positive activity or event. When you give a child candy for cleaning his room, dessert for finishing his meal, or a toy for being good, you are delivering a primary or unlearned reinforcer.
2. **Secondary or learned reinforcers**—Secondary or learned reinforcers have no initial effect on increasing behavior until they are paired with a primary or unlearned reinforcer. Learned reinforcers can include such things as tokens, money, stars on a chart, praise, or grades in school. A child learns that when he brings home good grades, his parents will buy him something he has requested, such as a special toy. The good grades are the secondary or learned reinforcers for working hard in school. The good grades are paired with the primary or unlearned reinforcer of a desired toy.

Punishment. Punishment is not the best process for altering behavior. When at all possible, try to avoid the use of punishment in behavioral systems. However, with certain patients and under certain circumstances, punishment may be necessary. When it is deemed appropriate to punish, you should administer the punishment immediately following the inappropriate behavior. You should always provide a warning so that the family member understands the consequences. In addition, you should be consistent and never threaten to punish without following through.

The most effective type of punishment is the removal of a positive reinforcer. Using the case of Joe, who received tokens for his cognitive rehabilitation sessions, the parents found that they could not stop him from hitting his younger brother. Finally, they modified his behavioral program so that each time he was physically aggressive with his younger brother, he lost a token he had earned for cognitive work. This procedure was successful in reducing this hitting because Joe found that he wanted his tokens to trade for special activities with his older brother and his friends.

How Do We Set Up the Behavior Program?

If your loved one is being discharged from an inpatient program that already had an existing behavioral plan, ask a therapist to help you modify it for the home. If this is not the case, then you must begin to use some of the principles we have discussed throughout this chapter. In general, you can follow these steps:

1. Put priorities on the behaviors you want to change.
2. Initially, address only one or two behaviors.
3. Collect baseline data with which you will know if you are making progress.
4. Determine the reinforcers. Use primary or unlearned reinforcers at first, and then graduate to tokens or points that can be traded for primary reinforcers.
5. Maintain a chart so that everyone can see exactly what is going on both you and the head injured loved one.
6. Be consistent and follow through with the plan. If the behavior is not reinforced each time, learning will be very slow.
7. Make sure that you deliver the reinforcement immediately after the desired behavior, and make sure that the family member understands the connection between his behavior and the reinforcement.
8. Learn to recognize signs that indicate you need to modify the program. You may need to increase the amount of reinforcement to obtain a change. You may need to add a different reinforcer if the head injured person does not appear motivated to receive this particular reward.

Chapter 5

Outpatient Options

To the health care professional:

Although in this chapter we discuss facility and treatment options, the family will need considerable guidance in these selections. Through intimate knowledge of the case and the family situation, you can help assure the best placement for the head injured family member.

Chapter 5

Outpatient Options

TYPES OF FACILITIES

As a family member, there are a number of options that are available to you for outpatient facilities. The picture has changed in the past 10 years. At one time there were few free-standing or private facilities offering this specialized care. However, there are alternatives today, in both the public and private sectors, for your family member's head injury rehabilitation.

There are several considerations that you, as the primary caretaker, need to take into account when choosing a rehabilitation program. The first consideration is the comprehensiveness of the program. You will want to be able to receive all the services at a single location, rather than going to one location for occupational therapy, another for physical therapy and speech therapy, and to another for the psychological services and cognitive therapy. A comprehensive program will have a systematic and organized approach to your family member's rehabilitation. It will provide for interdisciplinary management, continual feedback to you, as a family member, in the form of family meetings or staffings, and communication between those providing medical, physical, cognitive, and psychosocial therapy for your family member.

A second consideration is how comfortable you are with the staff at the facility. You will be developing a long-term relationship with the therapists and the director. Consequently, it is imperative that you feel that you are a major part of the "team process" and are free to, and encouraged to, ask questions regarding progress and prognosis.

A third consideration is convenience. You may be involved in transporting your family member to a facility over an extended period of time. Therefore, you may need to discount a facility that is a long driving distance from your home.

As a final recommendation, it would be perfectly acceptable to speak with patients in the facilities you are considering and inquire into their satisfaction with that particular program. Although no one will ever be 100% satisfied with a program, it is wise to do some investigating into the reputation of the facility regarding both patient care and its philosophy of rehabilitative care. You will need to be mindful that you will have to interpret this information objectively. Consequently, the more information you collect, the more comprehensive you can be when you make your decision. In this case, you are the consumer, and it is important to remember that you are buying rehabilitation services, not unlike you would purchase other services. You are spending a great deal of money on this particular service. It is wise to consider all the alternatives before you choose a facility. You may want to enlist the aid of professionals, possibly a social worker,

discharge planner, therapist, or psychologist with whom you feel particularly confident. Ask your friends and other family members for support in helping you make this decision.

When you consider the options available, which range from private practice settings to long-term care facilities, please keep in mind that you may have to make decisions on an ongoing basis. The choice you make for a facility at the present time may not be appropriate 6 months or a year from now, because the needs of your family member may change. For example, the rehabilitation center that your family member is leaving as an inpatient may provide the most comprehensive services, but may be quite a distance for you to drive. You may want to use that facility for the present time. When your family member's needs change and require a less comprehensive program with fewer therapies, you may want to explore a comprehensive outpatient rehabilitation facility (CORF) or a private practice setting closer to your home for the sake of convenience.

The National Head Injury Foundation lists over 800 facilities in their resource directory that provide head injury services. These services range from private practice settings to extended care facilities. In this chapter, we will explore the options available to you if your family member is an outpatient, which means he lives at home and travels to one of the facilities for therapy.

Rehabilitation Center

Rehabilitation centers, either free-standing or within a hospital setting, can provide services for your family member. A rehabilitation center may be either public or private, for profit or nonprofit. These designations should not interfere with the therapy provided.

In a rehabilitation center, the physician is most likely the director of the treatment team, and therapies are administered under the physician's prescriptions with input from the interdisciplinary team members who treat the patient. One of the major advantages of a rehabilitation center is that it provides a comprehensive interdisciplinary therapy program. All therapy areas are available on a daily basis. Your family member will benefit from occupational therapy, speech/language therapy, physical therapy, cognitive rehabilitation therapy, psychological therapy, therapeutic recreation, and vocational and educational services, all within one facility. The team members will meet with you on a consistent basis throughout the outpatient period. Formalized staffings and family care conferences are integral parts of a rehabilitation-center operation. A physician is always present in the rehabilitation facility for consultation with the therapists and family. The physician directs the rehabilitation process. This may be a comfortable setting for you, especially if it is a continuation of the inpatient program from which your family member was discharged.

Some rehabilitation centers focus on acute rehabilitation and do not offer long-term programs or provide for the community reentry processes. However, many rehabilitation centers are beginning to focus on the development of long-term head injury programs through continued individual, group, and day treatment programs. They are also including vocational services as a part of the rehabilitation program, focusing on the community reentry process. Rehabilitation centers specializing in head injury rehabilitation will offer this type of continuing care.

When you are making a decision relative to placement in a rehabilitation center, inquire as to the comprehensiveness of the program from particular therapies offered, amount of medical directions, and your role as a family member. Inquire as to how cognitive rehabilitation is handled in the facility, how intensive is that program, and how intensive is the vocational reentry program. You may also want to inquire about how the treatment approach differs between individual, group, and day treatment. If you have had contact with the staff, evaluate your interactions and perceptions regarding the staff and how they relate to both you and your family member. Remember, you are entering a long-term partnership, and it is important that you feel comfortable.

Last, you need to consider the convenience of the rehabilitation center in terms of location and travel.

Comprehensive Outpatient Rehabilitation Facility

A comprehensive outpatient rehabilitation facility (CORF) provides comprehensive outpatient therapies. A CORF is operated under the direction of a medical director and an administrator. CORFs provide outpatient therapies through an integrated treatment plan. As in a rehabilitation center, the physician is responsible for establishing the treatment plan, administers the medical treatment, and directs the therapy. Your family member should receive as intensive a program in a CORF as in a rehabilitation center. Although the staff of a CORF is much smaller than in a rehabilitation center, all therapy areas are represented and should be involved in your family member's case on a consistent basis. Patient care will be handled through formal medical staffing and family conferences, on both a formal and an informal basis. A CORF will address outpatient therapies through either individual or group treatments. Many CORFs focus on the treatment program and vocational-community reentry and are excellent resources for this level of therapy.

One of the advantages of a CORF may be that it does not resemble a hospital. Your family member may feel as if he has recovered and no longer needs to be in a hospital or needs to return to the rehabilitation center where he was an inpatient. In that case, a CORF is a good alternative. If you are considering a CORF, it would be to your benefit to find one with head injury specialization. Some CORFs serve a general rehabilitation population and may not have a comprehensive program adapted toward head injury. However, other CORFs have developed a specialty in head injury. As a family member, you should inquire about this specialization and the comprehensiveness of the program, particularly relative to cognitive rehabilitation, day treatment, and community reentry programs.

As in choosing any facility, you need to meet with the physician and therapists to determine how you will feel as a member of their treatment team. Together with these factors, of course, you need to determine the convenience for you in relation to location and travel.

Private Practice

Therapy services that are available in a rehabilitation center or CORF are also available in private practice. Occupational, physical, and speech/language therapy are available through private practitioners who serve clients who have many disorders, including head injury. Speech/language pathologists provide cognitive rehabilitation therapy on both an individual and a group basis.

Neuropsychologists and psychologists provide intensive programs in the area of head injury rehabilitation. As well as providing an intensive evaluation, many provide cognitive rehabilitation programs, psychological counseling, family support, behavior management, group therapy, and community reentry programs for their clients.

One of the most important issues to be examined if you are using private practitioners is case management. Someone needs to assume responsibility for the coordination of therapies, family conferences or staffings, and direct communication with the physician. Many times this case management is provided by insurance companies, workers' compensation, or private case-management firms. If this is not the case and more than one therapy area is involved, one therapy (preferably the one with the most contact with your family member) should assume the case management role. If only one area is involved, you and that therapist can determine an effective communication format.

When assessing the private practice sector, you need to consider again the comprehensiveness of the program as it relates to your family member's recovery process. It may well be that he needs a very comprehensive cognitive rehabilitation, counseling, family support, and group therapy program that can best be found in a private neuropsychologist's practice rather than in a rehabilitation center or a CORF.

Again, it is important to interact with staff members to determine your role in the treatment process. Determine how comfortable you are with this interaction and weigh those issues relative to your convenience regarding location and travel.

When you deal with the private sector, you have the added responsibility of determining that therapists have had experience in the area of head injury. The National Head Injury Foundation provides information in this regard and is an excellent resource. If you are fortunate enough to have been assigned a case manager from the insurance company, he can also provide this information.

When exploring your outpatient options, you may want to keep in mind the aspects discussed at the beginning of this chapter, those being that different types of rehabilitation may be appropriate at different points in the rehabilitation process. The programs discussed thus far fall under the category of outpatient programs, meaning your family member lives at home and you arrange for transportation to and from the therapy program. In some cases, other alternatives may be necessary, and your family member will require a residential place on either a short- or long-term basis.

TYPES OF TREATMENTS

Individual versus Group Treatment

Your family member's therapy may be on an individual, group, or combination basis. With consideration for your input, this will be determined by the interdisciplinary team. Early in the rehabilitation process, all therapies may be individual. As your family member's attention and concentration improve, group therapies will be added to his schedule. The group therapies will be based on his individual needs. He may be involved in groups that work on attention, concentration, memory, or problem solving. These groups will help your family member carry over skills learned in individual sessions. Behavioral problems discussed in Chapter 11 may be the focus of psychosocial groups. Psychosocial groups will also address adjustment and lifestyle issues such as change of life goals, drug and alcohol abuse, and sexuality issues. Some therapy areas may use a combination of both individual and group therapy. For example, your family member may become involved in group activities in occupational therapy, such as meal preparation, shopping, or community reentry, and also be involved in individual therapy for increasing strength and range of motion in his arms.

As your family member improves, the program will contain less individual therapy and more group therapy. A major focus of therapy will be to assist your family member in participation in group situations. As he continues in his rehabilitation program, the focus is directed toward a day treatment program with a full-day schedule.

Day Treatment Program

The purpose of a day treatment program is to provide a full-day schedule for your family member. A day treatment program addresses the carry-over of skills acquired in individual and group sessions into a more functional and true-to-life environment. Day treatment programs are

often housed in locations other than rehabilitation centers. You may find this type of program in a simulated home or office setting. Even if the program is housed within a rehabilitation center, a homelike atmosphere is created. If your family member is involved in a day treatment program, he will most likely be involved in the program for 3 to 4 days a week. His treatment program will include both individual and group therapy.

Individual therapies will be gradually minimized, and your family member will become part of the day treatment group. The group will be like a family, and will deal with cognitive issues, discussed in Chapter 10, and behavioral issues, discussed in Chapter 11. These issues are addressed through group interaction with other day treatment members. Methods of compensating for deficits are discussed, and resolutions are attempted for behavioral issues. For example, the group may discuss how to deal with a particular member's inability to remember people's names. They may suggest he use cues and mnemonics (memory words) to remember these names. The group may also discuss the frustration involved in not being able to recall the names of co-workers. Suggestions may stem from the group on how to handle this frustration.

In the day treatment setting, individual work will be more self-directed. Your family member may be involved in more paper-and-pencil activities. He may have more homework assignments that will need your assistance and monitoring.

One of the goals of a day treatment program is to prepare your family member for community and work reentry. He may spend time on community-based outings (trips to the mall or recreational facilities) or in simulated work situations set up in the day treatment program (for instance, maintaining the plants in the building).

The staff in a day treatment program will vary with the setting. In some settings, a complete interdisciplinary team (physical therapy, occupational therapy, speech/language pathology, psychological services, education, therapeutic recreation, and vocational services) is responsible for the day treatment program. Other day treatment programs may be staffed by only two or three therapy areas (such as psychology, speech/language pathology, or occupational therapy). In either case, the program focuses on the rehabilitation of functional, prevocational, compensatory, cognitive, and behavioral issues in an extended environment.

Community Reentry

The purpose of a day treatment program is to establish the community and vocational reentry process. This process is two-faceted. One facet is the reentry to the recreational (leisure) community, and the other facet is the reentry to the vocational (work) community. Of the two facets, the leisure community is the most overlooked. It is important for the treatment team to determine what your family member's leisure interests were before the traumatic brain injury and how many of them he can still pursue. He should be participating in these leisure activities and be in contact with the community while he is in the day treatment program.

Prior to going home, the home situation needs to be explored in terms of independent activities that your family member can do during the day. For example, if he enjoyed chess, board games, or the computer before his injury, these should be added to his daytime schedule of activities. If your family member had been an outdoor person, then opportunities for activities such as fishing, gardening, walking, or swimming should be explored as daytime leisure activities. Prior to discharge, the treatment team or therapeutic recreation specialist will assess community resources available for leisure activities, including locations of parks, swimming pools, miniature-golf courses, shopping malls, tourist attractions, museums, nature trails, community recreation facilities, or any other source that may provide an outlet for your family member.

You play a vital role in making this program a success. During his stay in a rehabilitation setting, gain an understanding of what his leisure interests are you may even want to accompany him on an outing. Once he is home, the primary support role is yours. Encourage your family member to check the newspaper often for cultural and community events of particular interest to him. Then, if possible, provide the opportunity for him to go.

Transportation can become an issue affecting this process. If you cannot provide transportation to and from activities, other arrangements will need to be made. Some community centers have their own transportation systems. Some churches provide transportation to and from community events. Taxis and limos will take you where you are going, but are relatively expensive. Your best option may be to explore the public transportation system. If you are fortunate, this was already accomplished through the rehabilitation treatment team in the day program. They should be able to determine if your family member has the cognitive and behavior skills needed to use the transportation system. If appropriate, your family member can be taught to use public transportation through a series of practice sessions. This will allow him to enjoy more community activities.

Vocational Reentry

The purpose of a day treatment program is also to establish the vocational reentry (return to work) process. A day treatment program may provide these services through its own staff or through another facility that specializes in vocational reentry.

The vocational evaluation is usually the first step in determining the best reentry for your family member. A vocational evaluation for someone suffering from traumatic brain injury tends to be more comprehensive than vocational evaluations of those with other types of injuries (such as spinal cord injuries or amputees).

A vocational evaluation may be a 3- to 5-day process. During this time, the evaluation specifically explores (1) physical strength and flexibility, (2) intellectual capacity, (3) personal and social aspects of personality, (4) interests and attitude, (5) knowledge of occupational information, (6) aptitudes, (7) achievements, (8) work skills and habits, (9) job objectives, and (10) ability to benefit from further services. This information is obtained through both standardized tests and observing your family member in the evaluation setting. In the case of the traumatic brain injured client, the vocational evaluator correlates information from the neuropsychological evaluation with his own evaluation to assist in placement decisions. He looks particularly at neuropsychological information regarding the cognitive issues of memory, problem solving, attention, and organization, and the behavioral issues of denial, depression, agitation, and perseveration. For instance, if your family member is having difficulty remembering facts and information about his daily schedule, but denies or is not aware of the memory difficulties, the vocational evaluator or rehabilitation specialist will need to consider those factors when deciding on the next step in the vocational reentry process. A vocational evaluator will also use information from the rest of the team (particularly the OT and PT) to determine your family member's physical strength and flexibility, and will then relate that information to information regarding physical requirements of particular jobs your family member may pursue.

After the vocational evaluator completes your family member's evaluation, a number of recommendations additional skills training. This additional skills training should occur under the direction of a rehabilitation professional. The type of training will depend on your family member's work history and future vocational goals. It may consist of a refresher course in your family member's field (for example, a refresher on word processing, or update on a mechanical

procedure), or it may include learning a new technological skill in medical, mechanical, business, or services fields. For example, your family member may be enrolled in computer-assisted drafting to learn a new field that is in great demand in the job market.

Decisions relative to skills training are based on prior training, aptitude, attitude, achievements, interests, and physical capabilities to meet the demands of the job. Prior to being placed in any job, your family member may be placed in a work-hardening program. Work-hardening programs are designed to get people in shape for work from a physical, mental, emotional, and social perspective. A team approach to work hardening is often the most effective. Specific job-related activities are practiced within the rehabilitation facility with increasing frequency and duration. At the same time, the OT and PT address overall physical conditioning of your family member. Psychological and family services will assist your family member with social and emotional changes associated with return to work. In this way, work hardening is a systematic way of conditioning your family member for the work environment.

Supported Employment

Your family member may be placed into a work setting without any work-skills training or he may be placed in a work setting during or immediately following training. In any case, the rehabilitation professionals will provide a supported work environment for your family member. A supported work environment simply means that changes have been made in the work site in terms of environment, hours, job expectations, and additional personnel so that your family member will be able to perform his job responsibilities. In many cases, a job coach will work alongside your family member and coach him through aspects of his job that may be confusing for him. A job coach may be either a rehabilitation professional or someone who has the job skills your family member is trying to regain. A job coach may remain at the work environment from a few weeks to an extended period of time. Supported employment in the form of a job coach, adapted schedule, or physical modification made to the job environment will be continued as long as necessary for your family member.

Your family member may be followed for a considerable amount of time by the vocational counselor or other rehabilitation professional after he has secured his vocational placement. This follow along is a very important part of vocational reentry. Research in traumatic brain injury rehabilitation indicates that, even though persons who have suffered a traumatic brain injury may be able to find a job, they may not be able to keep that job. For that reason, follow along is important for your family member. During this process, the rehabilitation specialist should check in with both the employer and your family member on a weekly or biweekly basis. This follow along could continue for 6 months to a year past the time your family member was hired. This process will help make sure that your family member will be able to keep the job he secures.

One of the most ideal placements for your family member may be to return to the job he had before his injury. If he had a good work history and has a desire to return to his former job, the company may be very willing to have him return. They may also be very willing to structure the job situation so that your family member may return on a part-time basis with support (job coaching or other structuring) and work into a full-time role. If he is unable to return to his former position, the former employer may be willing to find other positions within the company that your family member can work into. This could be beneficial in securing the longevity of your family member's vocational placement.

Your treatment team will help you contact agencies that can assist in the long-term roller coaster that may be in store for you in dealing with employment ups and downs. Agencies such as

vocational rehabilitation, workers' compensation, SSI, SSDI, and unemployment compensation may be helpful to you in long-range vocational planning for your family member.

Chapter 6

Mild-to-Moderate Head Trauma

To the health care professional:

In the earlier chapters, we concentrated on aspects of severe head injury. It may be difficult for families to understand that mild head injuries can also be devastating and that no two head injuries are alike, particularly in behavior patterns that may develop.

Chapter 6

Mild-to-Moderate Head Trauma

MILD VERSUS MODERATE

The categories of mild, moderate, and severe are typically used when describing head injuries. Unfortunately, not everyone uses the same measures to determine these categories, so there is no complete consistency in the professional literature. In Chapter 2, we indicated that the Glasgow Coma Scale was used for classification. A score of 15-13 indicates a mild head injury, 12-9 is considered moderate, and 8 or less is severe.

Others use length of coma as the most important factor. A period of unconsciousness from 0 to 30 minutes is considered a mild or minor head trauma by some, and others classify coma of 24 hours or less as minor. Moderate head injuries are generally from 1 day to 1 week of coma. If your loved one has been unconscious for more than a week, then he would be classified as having a severe head injury.

The material in previous chapters focused primarily on the severe category. The most serious cases are concerned with most of the medical issues addressed in Chapter 2 and with all the aspects of inpatient rehabilitation as set forth in Chapter 3. However, there are many head injury cases that are considered less severe by the medical community. These mild-to-moderate head injury cases are discussed in this chapter.

INCIDENCE

The National Head Injury Foundation reports that we are approaching the 700,000 mark in head injuries in the United States each year, and one half of these are classified as mild or minor. The amount of time spent in the hospital ranges from a brief stay in the emergency room to upwards of 1 week. More often than not, the hospital stay is related to bodily injuries other than the blow to the head. Accurate statistics are difficult to obtain because many people are sent home after emergency room treatment and some never get to the emergency room at all. It is not until these individuals develop continuing problems that they are categorized as head injured.

RESIDUAL EFFECTS

The effects of mild head injuries have been documented throughout history, yet there have been periods of time when these effects were minimized. Until just recently, there was a tendency to think that people with mild bumps on the head were malingering or faking if they continued to have problems after a few months. In essence, it was believed that the remaining deficits were more emotional in nature.

More recently, research has revealed that approximately one third of those who have received a mild head injury continue to have problems longer than 3 months after the original injury. In addition, one third of those who were employed prior to the accident are no longer employed after 3 months. None of the subjects in this study were involved in lawsuits, so that the factor of having a monetary motivation to keep the problems was eliminated.

After a mild head injury, or postconcussion, patients often display symptoms that include headache, dizziness, fatigue, decreased concentration, memory impairment, irritability, depression, anxiety, insomnia, hypersensitivity to noise, photophobia (sensitivity to light), and ringing in the ears. If your loved one is continuing to experience some of these symptoms, it is likely that they are true and legitimate problems. Some health professionals may not agree and may tell you that the patient is feeding his difficulties and not trying. Be very careful in your skepticism. People with mild head injuries can have more than minor effects.

DOCUMENTATION

One of the most enlightening discoveries about mild head injury is that there is documented evidence of physical damage to the brain. Researchers, performing autopsies in cases with a known 'mild blow to the head, have found considerable damage to the core of nerve fibers at a microscopic level. These microscopic tears in the brain are known as shearing. This results from the twisting movement of the brain inside the skull caused by the blow. The harder the blow, the greater the number of injured fibers. In addition, there is evidence that the effects of multiple mild head injuries are cumulative, so that recovery of skills from a second mild head trauma is slower than it is from the previous injury.

There are two separate procedures that help verify mild head injury deficits. From a physical standpoint, magnetic resonance imaging (MRI) provides a very detailed picture of the brain. This procedure can reveal traumatic injury in the cerebral white matter that is undetected by the CT-scan procedure.

Second, the neuropsychological evaluations help identify some of the remaining emotional and cognitive (thinking) problems. Problems that are less severe, but still devastating, include decreased concentration, difficulty dealing with distraction, problems with controlling responses, slowed motor speed, and distorted visual organization. These problems can all be picked up with this testing. The neuropsychological evaluation provides a detailed analysis of how the brain is functioning in terms of intellect, memory, perception, language, problem solving, and emotional stability.

COMPOUNDING FACTORS

No two head injuries are exactly alike in how they affect an individual. Some characteristics, however, that are typically seen with this condition are described in Chapters 10 (cognitive), 11 (behavioral), and 14 (psychosocial). Your family member is not expected to show all of these effects, but there is enough similarity in injuries of this type for a knowledgeable professional to say that a characteristic "is a typical head injured-type behavior." Moreover, each person experiencing this injury had an already existing personality. This can range anywhere from a passive, meek style to an aggressive, hard approach.

As you read further in this book, you will note that typical head injury behaviors tend to cluster around temper outbursts, being insensitive, being self-centered, and other traits that are generally not classified as positive. If your loved one had a mild or mellow personality prior to the injury, you will probably notice changes that are obviously related to the incident. However, if

your family member had strong behavior problems prior to the head injury, it may be difficult for you to separate out what is called his premorbid personality (meaning before the injury) from what people may now tell you are typical head injury behaviors. Families often relate such things as, "He was always stubborn," "He was never any good in math," and "He had a short fuse before.

In most cases, families will recognize these premorbid characteristics, but frequently they become exaggerated after the injury. Thus, if your loved one lost his temper once or twice a week before, he may now fly off the handle once or twice a day. He may not have been sure about what he would and would not do, and now he simply refuses to participate in any therapies, saying he does not need them. In essence, the same person is underneath, but additional behaviors or stronger behaviors are now part of his personality.

In a few cases, although the injury may be only mild to moderate in nature, the change in behavior goes from negative to positive. In this individual, there may have been an aggressive personality that has now been mellowed out. In other cases, your loved one may have been shy and withdrawn, and now he opens up and talks freely, even to strangers.

Generally, people are willing to recognize significant personality changes when a head injury is severe. However, it becomes a somewhat more complicated issue when the classification is mild to moderate and the individual possessed strong head injury-like behaviors before the injury. It becomes important for you as a family member to understand the origin of these behaviors, and to receive assistance in how to change or manage your own interactions. Please seek assistance from psychologists, social workers, and counselors on how to best approach these behavioral issues. You must remember that, even though the injury is considered mild in nature, the effects may not be minor in reference to changes that are taking place in his life, as well as your life.

TREATMENT OPTIONS

A patient with a mild head injury often is not admitted to the hospital. In the emergency room, he may have been warned about physical problems that remain or that he may develop, such as headaches or excessive sleeping. However, rarely does anyone say to the person, "You may find that you forget easily," "You may feel like your get up and go just got up and went," or "You may feel constantly on edge." In general, the expectation is that your loved one will be himself again in a few days and there is no need to have him anticipate problems that may never arise. This may be an adequate approach for those who fair well, but approximately one third of the mildly injured cases continue to have problems. If you have not been presented with this possibility, you may think that your loved one is faking, playing it up for sympathy, or just plain lazy. He will be equally confused, but he will think he is too stressed, falling apart, or just plain crazy.

These same issues can apply to the moderate head injury, particularly when there has been a miraculous physical recovery. Your loved one will be cared for in the acute care facility, but he may never go to an inpatient rehabilitation center. In these cases, the neurologist or attending physician will call in a physiatrist (physician specializing in physical medicine) who will recommend follow-up inpatient services that include at least a neuropsychological evaluation. If this process did not occur, contact your local head injury support groups for recommendations.

Treatment options for mild-to-moderate head injury are generally provided on an outpatient basis. Moderate head injuries may be in an inpatient facility for a few weeks, but are typically discharged as soon as they become ambulatory (can walk around easily). Evaluations by physical therapists, occupational therapists, and speech/language pathologists may be needed to rule out the necessity for treatment. Psychological services, together with vocational services, generally make

up the majority of the outpatient intervention. In Chapter 5, we discuss the various types of facilities and therapies that are available on an outpatient basis.

In general, the main goal of successful treatment is to assist your loved one in reentering the community. If he has a mild-to-moderate head trauma, he has good potential for this reentry, because he typically does not have to deal with the wealth of physical issues that are characteristic of the severe injury. This positive quality, however, can be a double-edged sword. He will very likely look completely normal or "fixed," but you and I recognize that he is not the same. Does the employer realize these differences? Do his friends see the change? And more importantly, does he admit to changes or deficiencies? If not, he will think he can do much more than is feasible, and he will not understand why he is failing. In these cases, it is important for treatment to focus on determining his strengths, evaluating his capabilities, and pairing these with an appropriate school or job setting.

Chapter 7

Funding Sources

To the health care professional:

Although the medical and rehabilitation issues are complex, funding issues can be very traumatic for families. A counselor or social worker trained in this area should be involved as early as possible in the recovery process.

Chapter 7

Funding Sources

In Chapter 5, we addressed the options that are available to you as a family member in terms of outpatient programs and long-term placement. Today we are quite fortunate that there are a number of choices for the rehabilitation of your family member; however, you must remember that your choices are greatly limited by the cost of the sources that may be available to you and your ability to pay for the rehabilitation. If there is one consistent factor concerning the head injured person, it is that he is usually not insured or he is underinsured. In many cases, funding may be available for acute care or acute rehabilitation, but not for long-term rehabilitation or lifelong care. Let us examine the funding options that may be available for your family member.

INSURANCE

Insurance coverage varies greatly from state to state. It would be beneficial to you to investigate insurance laws in your particular state and only use the information in the following section as a guide. At the same time, you will want to investigate the limits of your insurance policy and acquaint yourself with the medical and rehabilitation coverage provided therein.

If your family member was injured in an automobile accident, his initial medical bills will likely be covered by the automobile insurance. Limits on these policies vary greatly from state to state and policy to policy. In some states, the limits of the policies are \$10,000, and we all know that \$10,000 does not cover much in the way of rehabilitation. Residents of other states, such as Michigan, Pennsylvania, and New Jersey, are more fortunate because general catastrophic funds are used to help provide rehabilitation needs for those injured in automobile accidents. In some states, the insurers set limits on the amount of funds that are available for rehabilitation purposes. Sometimes, a secondary insurance policy may provide coverage for rehabilitation expenses. The secondary policy is often a major medical insurance policy. Major medical policies will provide for acute care and inpatient rehabilitation, but many do not provide for any form of outpatient rehabilitation or long-term care. In addition, there are often limits placed on the amount of actual dollars that will be paid for therapies or the percentage of the total bill that will be paid for a particular therapy. For example, many traditional policies allow for payment of 50 of charges for psychological services. Because psychological services are such an important factor in head injury rehabilitation and because these services should be ongoing over an extended period of time, additional funds may be required on your part to provide your family member with the services needed. In addition, some major medical policies provide for only a limited number of physical therapy and occupational therapy visits or put a cap on the amount of money that can be spent in these areas. Speech therapy services may also be limited by the maximum reimbursement system

of some policies. Policies administered by health maintenance organizations (HMOs) and preferred provider organizations (PPOs) often have only limited coverage for outpatient services. It is important to know the limits of your policy, especially in an outpatient setting, because you want to be totally aware of the expenses for which you are responsible.

Unfortunately, the therapies most necessary to your family member's recovery may not be covered by your policy. Traumatic brain injury (TBI) rehabilitation is more complex than stroke, spinal cord, or orthopedic rehabilitation and requires a systematic, structured community reentry program. In a rehabilitation setting, this can be accomplished through therapeutic recreation provided by certified therapeutic recreation specialists. Your rehabilitation provider may have to request "out-of-contract" payment for these services. These services are necessary, so request assistance from the rehabilitation setting (case manager) in obtaining the most comprehensive program for your family member.

Policies may also be limited in the area of vocational services that provide for work evaluation, supportive employment, or job coaching. This important aspect of TBI rehabilitation may also need to be negotiated with the insurance carrier. Frequently, if medical necessity can be determined by physician's orders, you will be more successful in receiving reimbursement. Again, enlist the assistance of the staff at the rehabilitation facility in securing these much-needed vocational services.

Understanding the amount and type of coverage provided by your policy can be confusing. Unfortunately, most of us do not know the limits of our policies until we need to use the insurance. At this point, it is important that you are aware of all the limits and conditions of your family member's coverage. You may need legal assistance in determining coverage levels. It is also important to remember that if you feel your policy has been misrepresented, you can appeal to your state insurance commissioner for assistance.

STATE VOCATIONAL REHABILITATION

Vocational rehabilitation services are those provided through the department of health and rehabilitative services and administered in each state through the vocational rehabilitation administration (VRA). Funding requirements and overall involvement with the head injured person vary greatly from state to state. Funds are provided by this department through large grants for special projects and through funding for evaluation and treatment of individual patients. To understand why some clients are funded and others are not, it is important to understand that the role of vocational rehabilitation is to return people to the work force. Therefore, in individual funding cases, those who are determined as having a "return-to-work" potential will be considered for funding. This funding provides for the therapies needed by that person, including physical, occupational, speech/ language, psychological, and cognitive rehabilitation therapy. Vocational rehabilitation will also provide for ongoing vocational assessments, work hardening, and job placement services.

In many states, the funding provided for vocational rehabilitation for the head injured person is limited. These funds have to be spent cautiously. In some states, vocational rehabilitation has been used to administer special state funds for brain and spinal cord injuries. The state of Florida is an excellent example. A portion of state fines collected for driving under the influence (DUI) and speeding tickets is set aside through the Impaired Drivers and Speeders Trust Fund for care and rehabilitation of TBI cases that may not have other funding sources. These funds are administered through the vocational rehabilitation system. However, as with catastrophic-care funds in other states, there are more potential clients than funding resources, and they must be

administered judiciously. As a family member, you should investigate any set-aside funds that may be available in your state. The Vocational Rehabilitation Administration is a good place to begin this search.

WORKERS' COMPENSATION

Someone once said that if you are going to get hurt, get hurt on the job. In the case of head injury, this certainly holds true. Possibly the best coverage provided for head injured patients on a long-term basis comes from compensation to an injured worker. Workers' compensation is an insurance plan provided through employers that protects those who are injured on the job. It not only provides for the care and rehabilitation needed, but also provides a percentage of wages lost (as determined by each state) while in rehabilitation. Workers' compensation involvement in a head injury case will be long-term. It will continue to provide services for your family member until he either returns to work, reaches maximum medical improvement, or a settlement is made in the case.

Workers' compensation requires the insurance carrier to provide a case manager for your family member throughout the time the case is open. This person should be an expert in the area of head injury and, with your input, should be able to provide for the appropriate rehabilitation programs for your family member.

Items are often reimbursable under workers' compensation that may not be under other insurance systems, such as mileage, medications, or housing during therapy programs away from your family member's home. All aspects of a workers' compensation case must be heavily documented and explored for alternative ways of obtaining evaluations and therapy services. This can be a time-consuming process, but the comprehensiveness of the care is well worth the inconvenience of the wait.

PUBLIC ASSISTANCE

Public assistance varies greatly from state to state, county to county, and city to city. Funds are usually administered through a governing board. In the case of head injury, funds for catastrophic injuries are administered in this manner. Meeting the criteria for public assistance also varies with the location. Participants must meet strict standards regarding income, personal property, and documentation of need. In most cases, public assistance is reserved for those services that are required for a life-threatening situation. In other words, funds may be provided for an acute hospital stay, but not be available for the rehabilitation needs of the patient. There are also community service agencies, such as Easter Seals, or federally funded programs that will provide these services at a reduced rate, depending on your income and assets. You will need to explore the services offered by federally funded agencies and civic groups for needed therapies. Under particular sets of circumstances, assistance may be available through Shriners, Elks, Rotary, Sertoma, or other service clubs.

The public assistance agency will connect you with agencies in the community that will provide you with services on a sliding scale of payment. If your family member does not have insurance or is not covered by workers' compensation or vocational rehabilitation, except for life-threatening situations, there is little chance that public assistance will provide sufficient coverage for your family member's rehabilitation.

CHILDREN'S MEDICAL SERVICE

Children's medical service (CMS) is an agency regulated by state health and rehabilitative services that provides medical care for children who are hospitalized. As a parent, you must meet the financial guidelines to receive coverage under this program. In the area of rehabilitation, CMS aids in providing for comprehensive inpatient programs. Coverage in outpatient programs is not as comprehensive because psychological and speech/language therapy services are often not covered. MS is involved in a strong network of community-related programs that also offer needed outpatient therapies. If you have a head injured child, even if you think you may not meet the financial requirements, you should take the time to learn about the services offered by CMS.

Last, in the case of the school child, an early contact is often made with the school system to provide the needed educational program and therapies within that setting. Public Law 94-142 requires that appropriate education must be provided for these children within the public-school setting. As a parent of a head injured child, it is partially your responsibility to ascertain that this education is provided. For more information on this process, see the section in Chapter 20 on Back to School.

FUNDING THROUGH LITIGATION

In some circumstances, you may be involved in a legal situation. Your attorney may provide a "letter of protection" to the facility in which your family member is receiving therapy. The letter of protection guarantees that rehabilitation costs will be paid when the court reaches a final decision in your case. If the case is not settled favorably, however, a rehabilitation facility runs the risk of not being paid for their services. For this reason, some facilities will not accept a letter of protection. In many cases, it may take a considerable amount of time before a suit is settled. Facilities often are not able or willing to accumulate large rehabilitation bills and will refuse a letter of protection. If you have litigation pending, you need to be acutely aware that costs for all therapies, approved services, equipment, and specialized requests will be taken out of the final settlement.

Another form of funding as a result of litigation comes from the settlement. Many times, court settlements set aside a portion of the money for continued rehabilitation. Your family member's rehabilitation expenses may be paid from this fund. Monies awarded as a result of litigation vary in amount, restrictions, and allotment. You need to be acutely aware of all of the issues when arranging for the services to your family member. Make certain your attorney explains all of these aspects to you. Do not be afraid to keep in continual contact with your attorney so he can discuss these issues with you.

MEDICAID

A limited amount of funding is available for head injury rehabilitation through Medicaid. Medicaid funding also varies considerably from state to state. Coverage varies greatly between services offered in a hospital, a rehabilitation center, a skilled nursing facility, and in outpatient programs. In many states, Medicaid funding is limited to life-threatening situations, and a limited amount of money is available for rehabilitation.

To qualify for this medical coverage, one must meet restrictive requirements regarding income and assets. When your family member is hospitalized in an acute care setting, the hospital social worker will assume the responsibility for assisting you with preparing the necessary paperwork for initiating this process. In rehabilitation settings, social workers or case managers will assist you with that procedure.

MEDICARE

Another federally funded program that may be available to your family member is Medicare. There are requirements for this type of funding either in age (over 65) or in the amount of time since someone has been injured. Patients receive Medicare coverage under Medicare Part A and Medicare Part B. Therapy services are provided under Medicare Part B. A limited number of therapy days and predetermined therapy services are offered under this coverage. The case manager or social worker in your rehabilitation facility will be able to assist you in interpreting Medicare coverage and how it applies to your family member's case.

Chapter 8
How To Choose an Appropriate Treatment Facility

To the health care professional:

As you pragmatically address the subject, specific counsel and guidance, as presented in Chapter 5, will be important early in discharge planning.

Chapter 8

How To Choose an Appropriate Treatment Facility

As your family member recovers from his head injury, many decisions will need to be made regarding his placement and level of care. The continuing care in head injury rehabilitation is defined by both the setting (hospital, inpatient rehabilitation center, outpatient rehabilitation center, group homes, or long-term residential centers) and the intensity of the rehabilitation (acute medical care, intensive inpatient and outpatient rehabilitation, day treatment, single therapies, community reentry, and vocational reentry programs). The settings and programs are discussed in detail in Chapters 3 and 5. At many points in your family member's recovery, you will need to make decisions as to the appropriateness of these particular programs for your family member's needs.

REVIEW OF CHOICES

In some cases, you may not be the decision maker. The insurance provider may assume that responsibility; however, your input will be invaluable in making the final decision. What, then, are the guidelines that should be used to judge the appropriateness of a rehabilitation facility for your family member's needs? In making this determination, three major aspects need to be considered: (1) program issues, (2) family issues, and (3) cost issues.

Program Issues

First and foremost in your choice of a rehabilitation facility must be the comprehensiveness of the program. You will be involved in a long-term commitment with this facility and will need to feel comfortable with the program. A publication from the National Head Injury Foundation (NHIF) serves as an excellent guide for assisting you in evaluating the comprehensiveness of a facility. Copies can be obtained by contacting your state NHIF Association or writing NHIF, 333 Turnpike Road, Southborough, MA 01772. The publication is entitled *What To Look for When Selecting a Rehabilitation Facility: A Working Guide*. The working guide helps you ask the right questions when you visit a traumatic brain injury rehabilitation setting.

As a family member, you can evaluate the comprehensiveness of a program by investigating a number of characteristics of the facility or program. The treatment history of the facility should be explored. A traumatic brain injury rehabilitation center should specialize in treatment of the traumatic brain injured. This means the facility will have been in business for 3 to 5 years and will

have treated at least 30 cases a year. The facility you are evaluating should also have an experienced staff. The staff should have 2 to 3 years of experience in the treatment of the traumatic brain injured. Clinical managers or department heads should boast an even greater level of expertise.

The comprehensiveness of the program can also be measured by the composition of the team and coordination of the therapy. The treatment team will vary, depending on the extent of the program and type of facility (inpatient, outpatient, day treatment, community reentry, or long-term care facility). However, at a minimum, any program should have direct or consultative services from occupational therapy, physical therapy, speech/language pathology, psychology, vocational services, therapeutic recreation, neuropsychology, education, family services/case management, and nursing. The comprehensive team should be managed by a physician (usually a physiatrist) who is responsible for your family member's care. In an outpatient, day treatment, community-vocational reentry, or long-term care setting, representatives from all therapy areas may not work with your family member; however, all services should be available to the treatment team through consultation or written reports.

Psychological and vocational services play a major role in the rehabilitation of your family member, particularly in the outpatient setting. You may want to be sure that there is a neuropsychologist on the team to assist in programming for cognitive and behavioral issues and that strong psychological support is available for both you and your family member. It is important that your vocational (return-to-work) specialist be well trained in traumatic brain injury rehabilitation. For a successful vocational placement, many modifications need to be made in the evaluative, treatment, and job setting. These modifications need to be made specifically concerning your family member's cognitive and behavioral deficits. Much creativity in vocational placement is needed. Consequently, it is very important that vocational services be a vital part of your family member's rehabilitation, including the day treatment and community reentry portions of the program.

A final question to ask when you look at the composition of the team is whether or not there is a special contact person for you. In the team process, either the social worker, family services representative, or case manager should assume the role of contact between you, the team, the physicians, and the insurance carrier. This role is critical in keeping lines of communication open throughout the treatment process.

The contact person may also be instrumental in coordinating the overall team process and therapy. In addition to medical or physical issues, the treatment team should address behavioral, cognitive, family, psychological, and vocational issues. In the behavioral area, you may want a representative to explain to you the facility's approach to behavior management. In particular, you may want to ask about medications or restraints that may be used. You may also want to ask what your role will be in managing your family member's behavior. All levels of traumatic brain injured programs should have a behavior management component. The approach should be structured, consistent, and repetitious. The program should be managed by the entire treatment team and reinforced by the family.

You may want a member of the facility to explain how the cognitive (thinking) issues, as described in Chapter 10, are addressed in the treatment facility. Have them discuss the role of the neuropsychologist in the treatment team. Ask them to discuss in particular how they treat memory deficits. Do they try to increase memory or do they use compensatory techniques? Investigate if the cognitive activities are "real life." For instance, is time for cognitive activities spent in structured settings (therapy, work, home) or in front of a computer in nonfunctional activities?

Your family member will benefit more from functional, structured activities than from activities not related to everyday life.

The comprehensiveness of a program can also be determined by your role as a family member on the team. You should be an active team member in making decisions about your family member's rehabilitation program. You should receive written reports on a regular basis. Family-care conferences should be scheduled on a regular basis. Family support and counseling should be offered to you as an integral part of the rehabilitation program.

In addition to program components and coordination, the process and organization of the program are critical to the success of your family member's rehabilitation progress. What are the facility's admission criteria and procedures? What is involved in the initial evaluation? How often are patients involved in therapy? Is the therapy provided in groups or individually? How are goals established and reviewed? Who makes the final decisions as to frequency and duration of therapy? How is equipment ordered? How are discharge plans made? How is the team organized? Is there a program evaluation system that monitors the quality of the rehabilitative care? A representative from the rehabilitation facility should be able to explain the admission, evaluation, and monitoring process within the rehabilitation facility in a clear, concise manner. The team process should also be explained so you are comfortable with your level of understanding. You should get a sense that the program is comprehensive, well staffed, well organized, and well monitored.

Factors To Consider

How do you, as a family member, obtain all this information? The best way is to tour a facility with these questions and the NHIF book, *What To Look for When Selecting a Rehabilitation Facility: A Working Guide*, in hand. Ask numerous questions and get an overall feeling of the facility. When you tour, ask about the accreditations of the program, such as ratings from Health and Rehabilitation Services (HRS), Commission on Accreditation of Rehabilitation Facilities (CARF), and Joint Commission on Accreditation of Healthcare Organizations (JCAHO). These three organizations have established strict guidelines for the quality of care within an institution, and they rate organizations on their level of compliance. Particularly look for CARF accreditation for brain injury. Talk to other people whose family members were in the facility, and get a sense of their feelings about the comprehensiveness, staffing, organization, and monitoring of the facility.

Financial Aspects

A number of financial considerations will come into play when you evaluate rehabilitation programs. Unfortunately, many of these financial considerations are out of your control. Your family member's insurance coverage will determine what will and will not be covered in the rehabilitation program. Managing these financial aspects will be an ongoing issue as long as your family member is involved in rehabilitation (see Chapter 7).

There are several aspects you need to consider when assisting your family member in managing his financial resources. The goal is to get the greatest amount of rehabilitation for the least amount of resources. To achieve this goal, you must understand the limits of your family member's policy. The limits will help you determine what your family member's remaining financial responsibility may be after insurance has paid its portion of the bill.

Some facilities may be willing to accept contractual agreements (a lower rate) for your family member's rehabilitation. They may also be willing to accept insurance coverage without co-payment by you. Facilities that offer these financial arrangements may allow you to conserve

resources. In this way, your loved one may be able to be involved in a more intensive program for a longer time period. Ask questions about these issues when you visit facilities.

In making long-range plans, you need to be well aware of what the lifetime cost will be for your family member. In light of those numbers, you will be able to determine the therapies, their intensity, and the length of time your family member can afford. Given those numbers, you may have to determine which programs are affordable and which may require you to consider alternative funding. These numbers will also clarify long-term placement options for your family member (residential or home care). A later section of this chapter gives you some general numbers as to lifetime costs for traumatic brain injured victims. Hopefully, these numbers will be helpful to you in your long-range planning.

A case manager, either as a representative of the insurance company or as a staff member in the rehabilitation program, will be able to assist you regarding the financial considerations when choosing a facility. To be clear on these financial issues from the beginning, it is best to establish early contact with a case manager to eliminate any confusion or undue stress.

Family Issues

The focus of this chapter has been on making the appropriate choice on the basis of your family member's needs and his resources. To some extent, the choices you make also need to be made on the basis of your needs and resources.

Your needs should be met in that you feel comfortable with the placement. To the best of your knowledge, you have chosen and financially appropriate setting for your family member. Realizing that you may not always achieve the optimum, you should have a sense that this was your best choice, considering all the circumstances. You should then become an active member in that treatment team and take advantage of the services offered to you, such as support, counseling, and treatment planning.

Another fact you need to consider in choosing a treatment facility is that of your resources: resources in the form of your time, energy, and money. During this rehabilitation process, you have spent a considerable amount of time with your family member. This may mean that you have taken a leave of absence from work, cut your working hours, or resigned from your position altogether. In most instances, you will have to return to some level of work before the rehabilitation process is complete. For that reason, the location of the facility may strongly influence your choice. If you are not able to provide transportation, a facility that assists with or provides transportation may need to be given more weight in your decision. If one facility is near you and another is an hour away, you may want to choose the facility that is closer.

Another resource you need to consider is your energy. Traumatic brain injury rehabilitation is a lifelong process. The ongoing need for care can drain you. At times, you may not have the energy to deal with the day-to-day issues. That may be the time to choose an inpatient setting rather than an outpatient setting for a period of time. In that way, you can recharge for the next stage of your family member's progress. It may be at that point you decide to explore long-term care or structured community reentry programs for your family member. If your family member is in a program that requires a great deal of your time, such as transportation to daily therapies, and your energies are drained, you may decide to cancel therapy for a few weeks and take a vacation to recharge. Check with your family member's physician, but in most cases he will probably agree to give you the much-needed rest.

Cost Issues

You need to consider your financial resources when making decisions regarding your family member's placement. You may be drained financially because of medical bills, loss of work, transportation costs, medications, equipment, and incidentals not covered by your family member's insurance. Paying one more bill may put you over the edge. For that reason, you may want to strongly consider the inpatient program that accepts contracts without co-payments. On the other hand, you may want to choose the outpatient program that will provide the transportation so that you can conserve your resources for the supplies, equipment, and so forth that may be needed in the future.

Ideally, you would like your family member to be involved in the most comprehensive programs that can be provided for him. You want him to be involved in therapy until he is able to return to his community or a long-term residential placement. However, it may be difficult to find the best placement situation in light of your time, energy, and financial resources. Nevertheless, in making these ongoing decisions about your family member's placement, it is important to remember that practical reasons may determine the ideal placement decision, given equal or near-equal program effectiveness.

LIFETIME COSTS

The cost of traumatic brain injury rehabilitation varies from case to case; however, some estimates have been made that have established a range used by insurance carriers for yearly costs of the traumatic brain injured. William Davis and Louis A. Papastart present reliable numbers for rehabilitation costs according to the severity of the injury. Their information can be summarized as follows:

For moderate traumatic brain injury (unconscious 1-24 hours*), the acute care phase costs approximately \$174,000. This includes physicians' costs, therapies, and hospital costs. Annual medical costs after the acute care phase range from \$650 to \$10,650. Given these figures and a normal life expectancy, lifetime costs for a person with a moderate traumatic brain injury may range from \$160,700 to \$687,800 for medical costs.

The cost for a person who has suffered a severe traumatic brain injury (defined as comatose more than 24 hours) is approximately \$435,950 for the acute care phase. This cost reflects physicians' charges, hospital costs, therapies, equipment, and home alterations. Annual medical costs after the acute care phase run between \$12,550 to \$46,350.

The cost for a traumatic brain injured patient who is in a persistent vegetative state is approximately \$149,200 for the acute care phase, including physicians' and hospital costs. The annual cost for a patient in the persistent vegetative state is \$182,500. This number is based on yearly nursing home cost.

The above numbers were presented to give you an idea of how astronomical the costs are for traumatic brain injury rehabilitation. Although costs for your family member may vary, it is helpful to understand these parameters when making decisions regarding lifetime care for your loved one.

*Footnote Note that in Chapter 1 this is classified as a moderate head injury.

Chapter 9

Long-Term Placement Considerations

To the health care professional:

The decision to place a loved one in some facility away from home is very difficult; however, if the family considers home placement, they must fully understand the implications of the demands that will be placed on them hour after hour, day after day so that they can determine the best answer for them.

Chapter 9

Long-Term Placement Considerations

When long-term placement is an issue, you will need to consider whether your family member will stay in your home, require placement in a residential head trauma program, or be cared for in an extended care facility. Extended care facilities include group homes, nursing homes, or transitional living facilities. All are possible considerations, depending on the severity of your loved one's deficits and locating funding resources (see Chapter 7). As the primary caretaker, it will eventually become your responsibility to determine the nature of his long-term care. You may have various placement options at different points in your family member's rehabilitation that are based on both your needs and your family member's needs. It will help you if you are acquainted with all of the possibilities.

RESIDENTIAL HEAD TRAUMA PROGRAM

As the name implies, a residential treatment facility means that the head injured person lives at the treatment site. There are a number of reasons why you would choose this particular type of facility. If your family member is in need of a strict behavior management program, he may best be served in a residential facility in which a strong program can be in effect 24 hours a day. In this way, virtually everything in your family member's environment can be controlled. It is extremely difficult to establish this type of program in an outpatient rehabilitation setting or in the home. As a family member, you can be trained in these techniques; however, if your family member exhibits extreme behavioral problems and these behaviors are disrupting the entire home situation, you may want to consider a residential placement on a temporary basis. The residential placement program can establish behavioral controls. It should be noted that in some extreme cases, a head injured person will need to remain in a residential treatment facility indefinitely to maintain any control for daily living skills.

Second, a residential treatment facility can offer the most intensive program for rehabilitation after acute head injury. Patients are involved in the rehabilitation process on a 24-hour basis. The ratio of staff to patients is extremely high to accomplish this purpose. Many head injured people need this intensive program after discharge from the acute care hospital or acute rehabilitation center. A head injured person can enter the residential treatment facility from both an acute care hospital or an acute rehabilitation center or even following attempts at outpatient rehabilitation programs.

A residential placement may also be appropriate for a person who is quite some length of time past injury. For example, his recovery may have leveled off for a period of time and then he began to improve again, which suggests he would now respond favorably to treatment.

Although you may not be in close proximity to your family member, you are still considered an important part of that treatment team. During discharge planning from a residential treatment center, you will become a major team player in determining discharge goals. Usually, a representative from the facility will meet with you at length to make certain that the transition is smooth.

The treatment goal at some facilities is community reentry. In this case, a head injured person will remain at the residential facility to obtain the vocational, self-help, and everyday-living skills that are needed to succeed in the community. The person will then be systematically moved to a less restrictive environment, such as a supervised apartment, and gradually transferred into a vocational environment that offers supervision. At that point, he may be ready for a return to the home situation and employment in that area. Discharge planners make sure that all these mechanisms are in place before the head injured person goes home.

One question you may have, as a family member, is, "How long will my family member remain in this type of facility?" That is an extremely difficult question to answer because each situation is unique. It appears from the information available that most residential treatment centers request at least 6 to 9 months at their facility. In some cases, the stay may be much longer, and the head injured person may be transferred to one of the extended care facilities that are available in conjunction with residential treatment centers.

EXTENDED CARE LIVING FACILITY

At some point in the rehabilitation cycle, it may be determined that your family member is not benefiting from ongoing intensively based therapies and needs to be in an extended care facility. One of your choices may well be a nursing home. As you explore this option, you will note that there are nursing homes that have special wings for younger patients. Some head injury facilities also offer this form of extended care for those who no longer benefit from the intensive therapy program. The best way of making a decision regarding this type of placement is to determine your family member's needs for physical care and supervision and your ability to provide for those needs on a consistent basis. You need to determine how to balance the two areas within your family structure. A decision to put your family member in a nursing home is never an easy one, no matter what the circumstances, but it is the one best decision in certain circumstances.

Another type of extended care facility is the group home. In a group home setting, your family member will become a part of another family that will be responsible for his daily care and needs. He will be supervised 24 hours a day and involved in a needed therapy program. As he demonstrates progress, he will assume more responsibility with less structure, and different rules will be imposed on him. The entire focus is to aid the head injured person in becoming independent. In some situations, this may be only a short-term placement for your family member in which to learn these skills before coming home. In other situations, a head injured person may be unable to accomplish these skills and will always need to be supervised. If this is the case, a group home on a long-term basis is a reasonable alternative.

As soon as your loved one has established functional skills and a relative amount of independence, he will be transferred out of a group home model into a supervised apartment. He may remain at this level on a long-term basis. Supervised apartments provide the most homelike atmosphere for the head injured person.

HOME

If you and your family member decide that he should be at home for an extended period, it is very important that you consider all the aspects of this type of commitment. Some head injured family members go home with no problems, return for outpatient therapies, become involved in vocational rehabilitation, and later find jobs that are suitable for them. In other cases, your family member may need constant care or supervision, and this requires a substantial commitment on your part. You may think you are ready to handle all of this, but make certain you have all the facts before you embark on any type of full-time responsibility.

If you intend to keep your family member at home, two important factors must be considered. First, your family member's therapy should continue at the nearest quality rehabilitation facility. Second, it is extremely important that you devise and adhere to a daily schedule that fits the needs of both of you, then do not deviate from that schedule. Allow for a significant amount of time to be spent out of the house involved in either planned activities or therapies.

Along that same line, you will need to protect yourself from burnout by getting relief in the care of your family member. You must take time away from him, so that you will be able to recharge your battery. You will be able to find reliable people who can care for him for a few days, allowing you to take a break. Please take advantage of that situation so you can be a continual support for your family member.

A final issue that needs to be addressed in the extended care arrangements for your loved one is that he may outlive you. A concern of yours may well be how to provide for him or see that he is well cared for when you are no longer there to be the primary caretaker. You may want to obtain legal advice to set forth your wishes for his future care.

Chapter 10

Cognitive Problems and How To Manage Them

To the health care professional:

As discussed in Chapter 2, some families will have difficulty comprehending what cognitive deficit means and why it cannot be "fixed" like a broken bone. It will be helpful to discuss why such deficits are the last to resolve and may last a lifetime, as well as to go over all pertinent deficits their description, some examples, and management techniques.

Chapter 10

Cognitive Problems and How To Manage Them

Cognitive problems refer to difficulties in using the thinking skills that are important in the learning process. More simply stated, our cognitive skills memory, problem-solving, attention/concentration, understanding information, expressing language, and putting things in the right order help us live day-to-day without getting into a lot of trouble. Cognitive skills are what professionals call brain-related processes, which simply means they are controlled by the brain.

In a traumatic brain injury (TBI), the cognitive problems are the last to get resolved and, in many cases, are lifelong. In the course of your family member's recovery, the treatment team will refer to cognitive deficits (problems). In this chapter, we will help you to better understand those deficits. These ideas originally appeared in *Life after Head Injury: Who Am I?* and *Patient/Family Handbook* (see Bibliography). For your convenience, each section is divided into an explanation of the cognitive problem, some examples of the problem, and management techniques.

MEMORY DIFFICULTIES

Your family member's memory problems may be confusing to you. Initially, he may not be able to recall any day-to-day information. As he recovers, he becomes more oriented. Day-to-day memory difficulties seem to resolve. He still may not be able to recall names of therapists, therapy schedules, or recent activities (such as eating, shaving, or talking with you), but he may recall past events, names, and facts with a great deal of accuracy (such as names of high school friends or the great time he had prom night). As he continues to recover, he may be able to recall immediate events and faces and names that occur on a consistent basis (such as therapists and nurses), but memory for incidental information (from surrounding environment) and specific detail (names, dates, times) may remain impaired for a considerable length of time or may never resolve. This inconsistency in memory functioning may be somewhat confusing to you as a family member, but it occurs frequently as one recovers from a head injury. In fact, it has been dubbed the "swiss cheese" memory by professionals, because some information "falls through the holes" and other information is retained.

One of the most devastating effects on your family member is the long-term memory difficulty. This difficulty affects his ability to learn new information, such as may be needed in his job.

Examples

The following are examples of memory difficulties you may observe:

Your family member may not recall names, addresses, or phone numbers.

You may hear your family member using statements such as, "Hey, you!" or "Hey, nurse!" or "the speech person." This may happen because he is not able to recall names of new acquaintances. As therapy schedules continue, he will improve in his recall of names.

Your family member may not remember the specifics of a meeting he has attended. In fact, he may not even remember the meeting.

Learning new job skills may be particularly difficult for him. For that reason, a return to his previous job may be the best alternative.

Your family member may become frustrated when he cannot remember where he has put things in the house.

Management Techniques

Memory deficits usually do not become resolved. Instead, your family member will need to learn compensatory techniques to function in the home and work environment.

Insist that your family member use a notebook as a memory aid. Encourage him to carry his memory "with him at all times. A commercial calendar such as a Day Timer or Day Runner will be most helpful. Assist your family member in organizing the Day Timer and recording the pertinent information.

Keep a record or map of where important items are kept in your home. In that manner, if your family member loses something, he can go to his notebook to find the location.

Encourage your family member to use his notebook. When he meets a new acquaintance, have him write the name and a cue, either a drawing or a description, to help him recall the person.

Use a cuing system, such as a watch with an alarm, to cue your family member as to when to use the notebook. Use the cuing system in conjunction with a set of written instructions, so he can always use them as a reference.

The difficulties your family member has in the work setting will be frustrating for him. Be as supportive as possible. Maintain contact with the rehabilitation professional who is supervising the work reentry process. In that way, you will be aware of any difficulties in the work setting.

PERCEPTUAL PROBLEMS

Perceptual problems result from a difficulty in processing the information that comes either through ears, eyes, touch, or movement.

Auditorially, your family member's ability to hear sounds will probably be fine. However, he may not be able to understand what is said to him. This may happen because he does not perceive the different sounds in words. For example, he may misunderstand addresses, directions, or names because he mishears similar-sounding words.

Visually, your family member's ability may be intact (i.e., 20/20 vision); however, he may have difficulty recognizing shapes or following written directions because he does not lift the information correctly from the page. In the same manner, he may have difficulty with left/right, top/bottom orientation.

Your family member may not be able to obtain as much information through touch as he once did. This does not mean that he won't feel sensations as he once did, but his interpretation of what he feels may take longer (i.e., identifying coins placed in his hand). He may not be accurate at discriminating objects by touch.

Your family member may not move as quickly or precisely as he did before (this will be covered in depth in the section on slowed response time). He also will not receive as distinct or accurate feedback from his movements as he once did.

Examples

The following are examples of perceptual problems you may observe in your family member:

He may have difficulty understanding similar-sounding numbers and words, particularly new information such as room numbers and addresses. Often, 15 will be confused with 50, 30 for 13, Mike for bike.

2. It may seem as if your family member does not hear what you are saying. He may ask you to repeat it. It may seem as if he does not hear simply because it takes him longer to process information.

3. Your family member may have extreme difficulty finding new places. He may become lost easily, confuse north, south, east, and west, and therefore lose confidence in going places by himself.

4. It may take him longer to find keys, lock and unlock doors, and manipulate hand-held tools. He may also take longer to write or type words than prior to the TBI.

Management Techniques

Many perceptual difficulties improve with time; however, some remain. Your family member may always have difficulty following directions, either written, graphic, or verbal. Therefore, he may also always need to rely on writing down information.

Before giving your family member any directions, make certain that you first have his attention. Subtly structure directions so your family member knows when to pay attention.

2. Ask your family member to repeat numbers, letters and directions back to you. In that way you can be certain he heard it properly. Encourage him to write down important information so he can refer to it.

3. Walk your family member through new environments. Also, talk your way through them. Reinforce directions for a new environment with maps and written directions for easy reference.

4. Give your family member more time for tasks that require manual dexterity. Remember that activities he once enjoyed (such as doing home improvements) may now be frustrating for him. He may also experience difficulty with fine manipulation skills, such as opening envelopes, unscrewing lids, or working locks.

ATTENTION/CONCENTRATION PROBLEMS

To benefit from any rehabilitation program, the person must be able to concentrate on the therapy situation. Attention/concentration difficulties consistently occur when one suffers a head injury. This difficulty may take one of two forms. First, attention refers to the ability to respond to the relevant or most important information and to screen out irrelevant information. For example, it refers to the ability to listen to a conversation while a phone is ringing in the background. This

concept is referred to as *selective attention*. Second, attention also refers to how long one is able to focus on a task without reinforcement. This concept is often referred to as attention span or *focused attention*. Some professionals refer to this aspect of attention as the ability to concentrate.

As he recovers from head injury, your family member will demonstrate difficulties in both areas. It may be difficult for you to hold his attention when there are any other distractions in the room or hallway. These distractions may be visual (other people in the environment), auditory (noises or voices), or internal (you may not be able to tell exactly why you sometimes cannot hold your family member's attention). Attention difficulties of this nature tend to improve as a patient recovers.

Your family member's ability to focus or concentrate affects progress in therapy. Without this skill, he will not be able to benefit from therapy sessions, particularly those sessions that require him to be focused for more than 5 minutes. This ability improves as your family member recovers, but you may find that he will continue to be easily distracted and have a short attention span after the head injury.

Examples

1. 1. It may be very difficult for your family member to hold his attention on any task once he comes home. He may wander from the TV to yard work to attempting to assist you with housework, all in the course of 15 minutes. This will make it extremely difficult to keep him entertained all day long.
2. Your family member may no longer enjoy his previous hobbies. This is particularly true if they required concentration, such as reading, Grafting, or working with computers.
3. Your family member may have been one who could divide his attention between two things at one time. He may have been able to talk on the phone and watch TV at the same time. After a head injury, this will be very hard to do. He will have to concentrate on one thing at a time.
4. Your family member may have been one who was able to operate in an environment with a lot of clutter. He may not be able to do this any longer. Before he can start any new project, he will need to have his work area cleared of all visual and auditory distractions, including children.

Management Techniques

First and foremost, clear the environment. Remove anything that your family member does not absolutely need for his present activities. This should go as far as having children leave the room. He should be able to complete activities without distractions.

2. Make suggestions for new hobbies for your family member. If he no longer enjoys reading books, he may be able to enjoy reading magazine articles and short stories instead. Have a supply ready for him to read.

3. Structure your family member's environment so that it is organized. Everything should be kept in its place. Encourage him to use only what is needed for a particular project.

4. Designate space in your home in which your family member can work. Clear that work environment of extra clutter, both visual and auditory. Turn off radios and TVs. Close the doors so he can have the privacy he needs.

LACK OF INITIATIVE

Initially or early in the recovery process from injury to the brain, apathy or lack of initiative will often develop. Your family member is confused and unable to conceptualize and plan activities. All projects or goals, however small, are overwhelming, so it is less threatening and less anxiety provoking to just sit and do nothing. This lack of initiative is extremely frustrating to families. They are aware of the precious time that is taken away from rehabilitation efforts when the patient says, "I don't want to do anything."

Examples

1. Your family member may be content to spend most of the day in front of the TV set, watching either movies or soap operas. He says he doesn't want to do anything else.
2. He may plan the activities for the day in great detail. However, he may not get past the first activity on the list because it may take him all day to accomplish it.
3. Your family member may no longer be interested in his previous hobbies. He may have enjoyed his computer before his injury. Now you may not be able to perk his interest in any aspect of computer programming or game playing.
4. He may be improving in following his list for the day. However, when a friend called after he finished task two, he never got back to his list.

Management Techniques

1. 1. Help your family member make a daily schedule. Set up his schedule the evening before. Have him write time frames necessary for each activity. For example, if making phone calls should take 30 minutes, list "9:00-9:30—make phone calls."
2. 2. He may become easily distracted. For that reason, it is important for him to check off his activities as he completes them. If you are away, calling him periodically during the day to cue him will also keep him on his schedule. Perhaps other family members can take turns with daily phone calls.
3. 3. Give your family member time to develop new hobbies and interests. More active interests may hold his attention and keep him moving. He may now enjoy a fitness program more than something requiring concentration and problem solving. He may feel more of a sense of accomplishment with the physical activity.

COMPREHENSION/UNDERSTANDING DIFFICULTIES

Comprehension difficulties may inhibit your family member in correctly understanding what is happening in his environment. He may not appropriately interpret what he hears or sees, or he may be confused when he attempts to understand what he hears and sees. For example, he may have difficulty understanding classroom lectures, and he may become even more confused when the instructor uses audio-visual aids such as graphs and charts to reinforce the main points of the lecture.

Your family member's therapists may discuss auditory-comprehension difficulties. By this, they mean that he is having difficulty understanding what is said to him. He may have difficulties following specific directions, conversations, or major points of a lecture. He may also have difficulty picking up on humor in conversations. In particular, he may not understand puns and the other language subtleties that make up humor in conversation.

Visually, your family member may perceive information correctly (see section on visual perception) but not truly understand it. A good example of this is the ability to read words and

graphics but not truly understand sentences and paragraphs. If your family member once enjoyed reading, he may enjoy it much less now.

Examples

The following are examples of comprehension difficulties you may observe in your family member:

1. He may appear to be out of the realm of conversations. He may either not answer questions or respond with off-the-wall comments. His response makes it appear that he did not quite understand the question or the intent of the question.
2. Your family member may take phone messages during the day, and then have difficulty explaining these messages to you when you return home. In following up on the messages, you may find that specific details, such as numbers and street names, may not be accurate.
3. Models and kits that include both written directions and illustrations may be particularly difficult for him to follow. This may not be the time for you to buy a new outdoor barbecue for him to put together in his spare time.
4. When you discuss a newspaper article with your family member, you may discover that you have keen differences of opinion about the facts stated in the article. You soon discover that he misinterpreted much of the article. In the course of your conversation, he may also relate that he did not finish the whole article. He may have lost interest in the article because he was not comprehending the details or main points.

Management Techniques

1. Your family member will probably always have difficulty following conversations. You will have to learn to expect off-the-wall comments from him periodically. In social conversations among his associates and friends, inaccurate interpretation of information is only a mild annoyance. However, in the employment arena, it could cost him his job. Strongly encourage him to ask for clarification of questions he does not understand. On business-related issues, he should insist that discussions and decisions be made in his office in one-on-one conversations and not in informal conversations at social gatherings.
2. Encourage your family member to ask for the correct spellings of names and street names. In that way there will be less chance of a mistake. He may have to adjust to the fact that he should not be the one responsible for taking phone messages.
3. Underestimating the difficulty of a task can be a downfall when deciding what your family member can and cannot do. Many times, tasks that appear easy are a sequence of difficult small steps. Avoid new projects that appear to be something that could fill your family member's time. If the projects are supplied with written directions and diagrams, they may only be a source of frustration.
4. Among comprehensive skills reading is at the highest level. Expect your family member to have difficulty in this area. In discussions of current events and news, reiterate the important details for him indirectly through your conversation. In that way, he won't become defensive and will be aware of current political and social issues.

EXPRESSIVE DIFFICULTIES

One's ability to express himself is a reflection of the integration of concentration, comprehension, memory, and initiation. To express himself, a person must concentrate on what the other person is saying, understand it correctly, remember it, formulate the appropriate thought,

and initiate a verbal, gestural, or written response to the other person. We do this automatically every day as we talk, gesture, or write memos.

Your family member may have difficulty in one or all of these avenues of expression. Verbally, he may not be able to find the correct word or he may use inappropriate grammatical structures. One of two types of expressive difficulties is usually present after TBI: (1) either a person will talk much less than he did before the TBI, using a less sophisticated vocabulary and speaking in shorter sentences, or (2) he will talk more than he did before TBI, but say less. His speech will be characterized by much off-topic irrelevant information and repetition.

Nonverbal expressions (gestures, body language, eye contact, or facial expressions) are as important to the communication process as the words that are used. You may notice that your family member does not make good eye contact or that his face is not as expressive as it once was. In other words, when he is angry, his facial expressions do not indicate that he is angry. You may also notice that he stands too close to people when he talks with them. This can make your family member's friends and co-workers uncomfortable.

The most complicated level of expression is the written word. Putting thoughts on paper may be much more difficult for him than it was before. His writing may have more errors and take much longer for him to complete.

Examples

The following are examples of expressive difficulties your family member may exhibit:

1. You may note that he never seems to get to the point in conversations. He may start a conversation about work and end up telling you about one of the kid's problems at school. Not only is the conversation difficult to follow, but it puts you at a loss for information.
2. Your family member may have enjoyed lively arguments and discussions before the injury. Now, he is not able to keep up with you in conversations, hold his own in arguments, or give you a quick comeback for jokes.
3. Your family member never brought work home before the TBI. Now he brings his full briefcase home every night. When you ask him about it, he says he has a number of memos to write and then never gets them done.
4. You observe that your family member does not make eye contact when he speaks with you or others. He also has started an irritating nervous laugh that he resorts to during nearly every conversation.

Management Techniques

1. Set up a cuing system to let your family member know when he is getting off the topic. A hand signal or key word will help redirect him back to the subject. In private conversations, be direct and tell him when he has wandered off of the topic. You can also assist him by asking the *wh* questions to get him back on topic (who, what, when, where, why).
2. Discontinue your family discussions for a time. Your family member is no longer a match for you in verbal debates. The experience will only be frustrating for him.
3. Assist him in setting up a structure for his written memos. The *wh* questions are appropriate for memo writing (who, what, when, where, why). This could be set up in a computer format so your family member has only to fill in the blanks.

4. Direct instructions from you on eye contact and other communication skills will be most helpful. Privately discuss these issues with your family member so he can be aware of others' responses to his communications. If appropriate, set up a cuing system to help him monitor these responses.

SEQUENCING PROBLEMS

Sequencing, as it relates to TBI, refers to the ability to put the steps or processes associated with speech, movement, memory, or daily activities in the proper order. Sequencing difficulties that are related to speech and movements are usually referred to as apraxias. Sequencing difficulties in academics or activities of daily living are directly related to memory. In the cognitive sense, your family member may be able to recall words, letters, sentences, and numbers, but he may not recall them in the order presented. In his daily activities, he may no longer recall the sequence used for performing household tasks. Laundry, dishwashing, and meal preparation may be particularly difficult for your family member.

Examples

The following are examples of sequencing difficulties you may observe:

1. During your family member's inpatient stay, rehabilitation therapy is directed toward resolving apraxia (sequencing difficulties). This occurs particularly in the areas of speech and OT. Your family member may show signs of apraxia, in which his speech is confused and difficult to understand, or he may not be able to sequence the steps needed to comb his hair or brush his teeth.
2. Your family member may recall phone numbers or street addresses in the wrong order. He may not be reliable in taking phone messages.
3. Your family member may have difficulty completing household tasks. Very likely he will omit a step in the sequence. For example, he may forget to subtract the checks in the checkbook or forget to add the soap when he does the laundry. Either could have an adverse effect on the smooth operation of your household.
4. Your family member loved his computer. Now, however, he has a great deal of difficulty recalling the sequence of steps to call up the programs he needs.

Management Techniques

1. The apraxia (sequencing difficulty) you observe when your family member is in an inpatient facility will resolve to varying degrees with time and therapy. Nothing you can do will speed up that process. When you work with your family member, encourage him to talk and attempt personal-care activities, but do not push him. More therapy is not necessarily better in this case.
2. Sequencing difficulties can often be offset by compensatory methods. Encourage your family member to ask people to repeat numbers and addresses. Request that he write down all numbers, and that he recall numbers in chunks of two or three. For example, the phone number 6-8-4-2-3-2-0 becomes (684) (23) (20). In that way, he only needs to recall three series of two or three numbers instead of seven individual numbers.
3. Outline the steps in a task for your family member. Place the detailed outline by the activity. For example, put the outline for doing laundry in the laundry room. Keep the outline there as long as he needs it.

4. Set up the sequence for the use of the computer on a piece of paper next to the computer. Keep it there even when it is no longer needed. Use the most user-friendly software available. In particular, use software that contains a menu outlining the steps needed to run the program.

SLOWED RESPONSES

Your family member's ability to respond or react may be a great deal slower because of the TBI. There are two primary reasons for the slowed response: (1) damage to motor strip results in a generalized slowing of the physical response, and (2) responses that were automatic before the injury no longer are. Your family member needs more time to process, integrate, and respond than he did before the TBI.

The overall effects of slowed response for your family member will be (1) taking longer to perform most activities, which can cause significant problems in a job situation, and (2) taking too long to act in emergency situations.

Examples

The following are indications of slowed responses that you may observe:

1. It takes your family member longer than usual to coordinate two-handed activities with household objects (i.e., opening cans, opening packages, making coffee).
2. You are concerned about your family member's driving ability. No one has said he should not drive. However, you think it takes him too long to react to light changes. You are afraid of what might happen if a car suddenly stopped in front of him and he had to apply the brakes quickly.
3. Your family member is not doing well at work. He has not been able to complete his share of the workload. To do so, he would have to stay later; however, his employer does not want to pay overtime.
4. In social situations, your family member may not be as quick or witty as he once was. By the time he processes the information, the chance for the joke has probably already passed.

Management Techniques

1. Your family member's response time will decrease as he recovers. Many of the early difficulties are not permanent. In the meantime, give him the time he needs to complete household tasks. Task completion is more important than a quick response.
2. If you are concerned about your family member's driving ability, you probably have cause to be. Refer him to a rehabilitation center for a driver evaluation. During this evaluation, he should participate in both a clinical and behind-the-wheel evaluation.
3. Your family member may have difficulty in a job setting that measures performance by the quantity of work produced. The rehabilitation center should work with the employer to ease your family member back into his job. Support this effort. If you do not have the resources for the rehabilitation setting or another agency (such as state vocational rehabilitation) to interface with the employer, you may need to educate your family member yourself.
4. Although your family member may not be as witty as he once was, do not avoid social situations. If he enjoys old friends, see them as often as possible.

INFLEXIBILITY

Your family member may become quite inflexible in his thinking. Inflexibility is closely related to overall difficulty with problem solving. In the early stages of recovery, the inflexibility might be demonstrated by his unwillingness to accept any change in his routine or schedule. This rigidity reflects his need for consistency and structure.

As your family member improves, the inflexibility might be demonstrated by difficulty in problem solving. He may only be able to come up with one solution and will not see any alternatives. The more difficult it is for him to see alternatives, the more fixed and vocal he will become regarding his solution. He will also have a tendency to want everything done exactly the way he remembers it was done before his injury.

Examples

The following are aspects of inflexibility that you may observe:

1. The therapists have changed your family member's schedule. He becomes irritated because they have no right to ruin his day like that.
2. If you hear your family member say, "I won't do it that way because we used to do it *this way*" one more time, you may scream. He may use this statement whenever he is not comfortable with something new and does not want to change.
3. Your husband and son used to have a wonderful relationship. Now, after your husband's head injury, all they do is argue. You might expect your son to be somewhat tunnel visioned and inflexible; he is an adolescent. But you do not expect the same behavior from your husband.
4. Things are not going well at work. Procedures have changed since your family member left. He complains loudly that the business is not as effective as it once was. They have also updated the computer system. It is nothing but a "monster"—it saves no time.

Management Techniques

1. Be patient. Be prepared. Realize that changes should not be made in his schedule early in the recovery process. Insist on consistency and structure.
2. Because your family member will have a great deal of difficulty seeing alternatives, he will return to what is safe and comfortable. The "way he did it before" meets both of these criteria. Gently encourage him to try new ideas and procedures for completing home and work activities. If you have purchased new equipment or tools while he was in the hospital, teach him how to use them. Be patient as he learns a new skill. Remember, it will not help if you disagree with him or attempt to persuade him to change his mind. The best you can do is teach and encourage. If that does not work, give yourself a rest and then regroup to try again at a later date. Be patient with yourself and don't try to fix it all at once.
3. Be prepared for family blow-ups and conflicts. Talk with siblings and children about not confronting or arguing with your family member over insignificant happenings. Save your energies for the attempt to convince him that that he needs to consider a choice or his decisions about the *big* issues that affect all members of your family.
4. Be prepared for problems at work. You cannot handle them for your family member; however, you can be supportive when he brings the issues to you. Suggest that a fellow worker could be used as a coach to give him a comfort level for learning the new job skill. If this can be accomplished in small steps, he may be able to break through his inflexibility and remain on that job.

DISORGANIZATION

Organizational skills require the highest level of integration of the cognitive skills of concentration, memory, sequencing, and problem solving. If your family member has difficulties in any of these cognitive areas, he will most likely be disorganized.

Our ability to organize is an automatic function. In other words, we do not recognize that we are organizing information for daily home or work activities. Our brains automatically perform this function for us. However, when someone suffers a TBI, it becomes quite evident that this automatic process has been altered. Your family member's previously neat home or office may now be strewn with papers, books, and household items. He may become frustrated with the amount of time it now takes him to reorganize before he can start any projects.

Your family member's organizational difficulties will most likely never completely resolve. For that reason, an external organization may need to be used. Notebooks, checklists, and Day Timers can be quite helpful in organizing his home and work environment.

Examples

The following are examples of organizational difficulties you may observe:

1. Before the injury, your family member may have been able to remember times and details for meetings. He may have never missed an appointment or arrived at a meeting unprepared. He was naturally efficient. However, his life is now in chaos, and he is no longer ready for appointments, even though he spends a lot of time "organizing" his life.
2. Your family member may have difficulty finding things. He swears that he put his papers in his office, and they are nowhere to be found. He finally finds the papers filed in the wrong folder.
3. Your family member may master the art of note-taking. However, he can never find the notes when he needs to relocate them.
4. Your family member used to be excellent in verbal confrontations. He was always able to solve problems quickly. He is no longer able to think on his feet the way he did before. Consequently, he is not as successful in handling work-related problems.

Management Techniques

1. Establish an external organizational system for your family member. One of the commercial Day Timer calendars may be very useful. However, you can also accommodate this organization through use of a notebook and other types of calendars. Remember, the important point is to develop the external organizational system. For that system to work, he must use it daily.
2. Set up an organizational system for your family member's environment. Have a designated place for every file, pen, pencil, calculator, and envelope. Encourage him to always put items in the proper place. He will save much wasted time.
3. If you teach your family member only to take notes, you will solve only half the problem. The note-taking needs to be part of the whole system for organization (as described in Example 1, this section).

Encourage your family member not to engage in verbal confrontations or attempt to problem solve on his feet. He needs to be encouraged to make decisions after he has had the time to process, organize, and problem solve, using all the information.

PROBLEM-SOLVING DIFFICULTIES

To problem solve, one must be able to integrate the other cognitive processes that are outlined in this book. He must comprehend the basic factors to be considered, be able to recall these factors, organize them for analysis, and be flexible enough to make the appropriate choice from a number of alternatives.

Problem-solving difficulties vary greatly along the recovery process. While your family member was an inpatient, his problem-solving skills addressed the functional daily activities of dressing, bathing, walking, and expressing himself. As he recovers, his problem-solving skills will need to encompass work, home, and family issues.

People vary greatly in the level of problem solving needed for their work setting. Some occupations require daily verbal problem solving. Others require repetitive job tasks that do not need continual problem solving, unless there is a mechanical failure.

The goal of a rehabilitation program is to assist your family member in attaining a level of problem solving that allows him to succeed both at home and at work.

Examples

The following are examples of problem-solving difficulties you may observe:

1. Your family member may become extremely frustrated when he is not able to install a new garage-door opener. After all, it is a simple project, and he added one to his last garage.
2. He may lose patience with himself because he cannot figure out how to use his new computer program. He continues to get an error message. He is certain the program has a bug.
3. Your family member was once a card shark. He could easily keep track in his head of the cards played. It was difficult to beat him at any game. Now, however, he cannot keep track of the cards and makes poor decisions or bad plays. It is very difficult to get him to even play.
4. He may have problems at work because he appears somewhat stubborn. Reports indicate that he does not listen to all the information before he makes a decision.

Management Techniques

1. Difficulties with problem solving can stem from comprehension problems (see the section on comprehension in this chapter). Give your family member some time before you ask him to assemble household items. If he is not able to follow the directions explicitly, he may not be able to problem solve for an alternative.
2. This may not be the time to add new programs to the computer. This is particularly true if the program is not user-friendly.
3. Remember, activities that appear to be simple, often are not. Card playing is one of these activities. Encourage your family member to continue to play cards. It is a great exercise for improvement of problem-solving skills. However, you may want to ease the competitive nature of your games.

4. Exhibiting problem-solving difficulties at work can cause big problems for your family member. He may end up in a confrontation with co-workers. Encourage him to not make snap decisions, but to listen to all the alternatives.

NEW-LEARNING PROBLEMS

One of the most devastating effects of TBI may well be the memory difficulty associated with new learning. Your family member may have considerable difficulty learning new job skills, new procedures to be used at the job sites, and new routines in the home. Difficulties in memory, concentration, organization, sequencing, and problem solving will all slow the new-learning process. However, the memory difficulties are the biggest problems to this process. Your family member will not be able to increase his skills from day to day if he does not remember from day to day. To affect new learning of either a household task or job skill, your family member will need to repeat that particular task over and over again until it becomes automatic. For example, if you are teaching your family member to use a new system of balancing the checkbook, you will have to go over this system with him step by step, over and over again. At some point the system will be "automatic" for him, and the system will be his.

Examples

The following are examples of new-learning problems you may observe:

1. When your family member returns home, you give him the responsibility of taking the kids to their after-school appointments. He is not able to keep up with the schedule. The kids do not get where they need to be on time.
2. While your family member was gone, a new system of billing was developed at work. He complains, "the people at work have really screwed up this time . . . they have a system so complicated that no one can figure it out!"
3. Your family member was always a game player. Your friends found a new board game they want to teach him. He becomes very frustrated when he cannot follow the rules.
4. When he first returns to work he does very well. After 3 months, a new supervisor is hired, and procedures change. Your family member is not able to catch on to the new procedures and fears for his job.

Management Techniques

1. Work with your family member in setting up his own system for transporting the children from place to place. He is more likely to remember the pick-up points if he develops his own system rather than attempting to adjust to yours.
2. Work with your family member in helping him understand that he has to learn the new system. Ascertain whether there is a friend at the work site who could help him learn the new system.
3. Teach your family member new games and activities on a one-on-one basis. Once he has mastered the skills, then play these new games in social situations.
4. Be aware that TBI clients often lose their jobs when there is a change in a supervisor or in management staff. Enlist the assistance of rehabilitation professionals to help your family member in the transition between supervisors. This is a time when you will need to be very supportive to assist him through a particularly difficult time.

Chapter 11
***Behavioral Problems and How To Manage
Them***

To the health care professional:

Even more problematic to the family than cognitive issues are the behavioral issues. Furthermore, the family plays a vital role in handling behavioral problems. Counselors are advised to carefully discuss each issue that is pertinent to a specific case to encourage understanding and positive reactions.

Chapter 11

Behavioral Problems and How To Manage Them

A large majority of head injured individuals have behavioral changes, even when the blow to the head may have been minor in relation to the other physical injuries occurring in the accident. It is possible that your loved one will not have difficulty with all of the areas we are covering, but it is probable that he will experience at least some of them. If the injury is recent, you may not have seen any of these behaviors, but you may have observed some of them on the hospital floor or heard of them when talking to other families. If the injury happened more than 6 months ago, it is likely that you are only too familiar with the topics we are about to discuss.

In the previous chapter, we focused on the cognitive or thinking problems following head injury. People generally have an easy time remembering and understanding that these are caused by injury to the brain. However, the behavior problems associated with head injury are not as easy to identify or understand. It seems that there is much more emotion and confusion associated with the behavioral deficits than with cognitive deficits. Frequently, there is at least one person in the family who believes that the head injured person is just being mean, hateful, or revengeful when he acts the way he does. This is especially true if the relationship before the accident was not particularly positive.

Research in head injury shows that a personality characteristic that existed before the injury is often exaggerated after the injury. Thus, if your family member was aggressive and obstinate before the injury, then you are undoubtedly going to experience significant problems in this area now. There are a few exceptions to this, but they are definitely the exception rather than the rule. For example, if your loved one is extremely impaired by the injury, he may have such severe deficits that he is no longer able to assert himself.

On the other side of the coin, there are those who were extremely mellow prior to injury. They can take on an altogether different personality that includes impatience, verbal outbursts, physical threats, and all types of things that you never imagined would ever appear in this person. This is, of course, one of the most difficult changes to live with—a complete stranger is coming home to live with you.

Although all of these behaviors are brain related to begin with, the family's reactions over a period of time can also impact on which behaviors remain and which ones get better. Because this is such a new experience for you, it is difficult to know how to act and when to act. You can inadvertently contribute to your loved one's continuing inappropriate actions. We want to help you avoid this situation. To do this, we have briefly described a number of possible behavior

problems. Examples have been provided to help you identify and recognize these actions as they relate to the behavior of your head injured family member.

Following the description and examples, we mention some possible ways to assist with management of the problem. These are not meant to be clear-cut and fool-proof solutions. They are suggestions for you to try, modify, discard, and maybe try again later when your loved one is at a different stage of recovery. They are not meant to be a substitute for a rehabilitation counselor who would be able to refine or redefine the techniques for you. If your home life is being torn apart by these behaviors, please seek professional assistance.

The original ideas for many of these topics appeared in two patient-education manuals. One is *A "How To Handle" Manual for Families of the Head Injured*, and the other is *Coming Home: A Discharge Manual for Families of the Head Injured*. These manuals are listed in the Bibliography.

AGITATION

One of the first behaviors that you will notice (if your loved one is still in coma) or have already noticed (if your loved one is already involved in a rehabilitation program) is that of agitation. On awaking from unconsciousness the person will move excessively in a generally unpurposeful behavior. You and your family will be elated to see the person moving because movement is a sign of being alive. See Figure 11-1.

At times the family will mistake this step as "being out of the woods." In an effort to be helpful and realistic in this book, we must say that you are just entering the woods at this time. Those of you who have experienced this already are probably nodding your heads in agreement.



Figure 11-1 Agitation

From a neurological standpoint, what is happening is that the patient is reacting to the environment in an undifferentiated manner. That is to say, his agitated reactions are due to the fact that he cannot yet understand the difference between a nurse approaching him with a shot and a therapist approaching him to assist with range-of-motion therapy. He will gradually gain the ability to interpret significant differences, but will still have difficulty with subtle differences because of cognitive difficulties, described in a previous chapter.

As time goes by, you will gradually note a decrease in the agitation, particularly when things are going smoothly. However, when things are not going the way he would like, he may again engage in an agitated response. Over time you will see progress in this behavior; however, it is possible that he may always be much more easily aroused than he was prior to the accident.

Examples

1. He continuously pulls on his tracheostomy tube.
2. He becomes very upset each time the speech pathologist tries to get him to point to a picture.
3. He wakes up in the middle of the night and says that someone is trying to break into the house.
4. He does not allow the TV and radio to be playing at the same time.
5. He becomes aggressive and angry each time a particular therapist's name is mentioned.

Management Techniques

Remember that within the first 6 months after injury, agitation is a stage that must be worked through.

1. Do not take personally the agitated behavior that appears to be directed toward you.
2. Never allow yourself to become combative in reaction to his agitation—that will only lead to increased agitation.

DENIAL/OVEROPTIMISM

From the time that your head injured loved one began to talk again you have probably noticed that he is not always realistic about what he is capable of doing. This is a characteristic that, to some degree, often lasts a lifetime. In the field of rehabilitation, we call it denial. At first this denial of his limitations is beneficial because it keeps the individual motivated. However, as time goes on, it can lead to anger and depression. The anger develops because the individual is convinced that he should be able to go back to work and that people are unjustifiably keeping him from this. You may have heard your loved one enumerate a long list of people who are at fault for his lack of progress or his failure to return to the real world.

It is a delicate proposition to balance the protective quality of denial and the rehabilitative need for reality. It is not usually necessary to take away all hope of living independently, going back to work, getting married, and so forth. The best way to handle these issues on discharge is to indicate that there are a number of steps that the individual must go through before these goals are obtainable. For example, if you are getting bugged daily by your son who wants to live in his house that he owns, let him know that the steps are as follows:

1. Come to live with us until you can complete the following activities
2. Possibly live in a transition living facility where additional skills will be mastered.
3. Move to a supervised apartment until minimal supervision is needed.
4. Move back into your home with the support of family, friends, or a hired aide.

The reality may be that you and the therapists are thinking that the end goal is not feasible. However, keep focusing on the fact that he still has steps (1), (2), and (3) to work toward.

Examples

1. The man is convinced that his wife is waiting and ready to take care of him, even though she has filed for divorce.
2. The woman is sure that her boss at the law firm will take her back as a legal secretary.
3. The adolescent says that his dad has a new truck ready to replace the one he wrecked just as soon as he gets out of the wheelchair.
4. The parents refuse to talk about appropriate special education placement or assistance as they are sure their daughter will be able to return to her regular classroom.
5. The man does not see any need for a therapist to talk to his employer because he knows he can go back to work and do everything he did before the accident.

Management Techniques

1. Allow the individual to hold onto some denial to maintain his motivation to participate in rehabilitation.
2. Never out-and-out lie to your loved one, saying he will be able to do something that seems unlikely. Instead, point out the progress that is necessary to get to that particular goal.
3. If the head injured person insists he can do something and it would not be dangerous to him or anyone else, allow him to try the activity. This can often lead to a realization that he is not quite ready to complete this task on his own.
4. If your loved one tries to tell you that he is not getting anything out of occupational therapy because he is always doing the same things, do not be coerced into thinking that the therapist does not have anything else for him to do. The reason he is repeating tasks is that he has not completed them correctly or with the desired speed—he needs more practice.
5. It is important for you to know that those times when your loved one is obstinate and refuses to cooperate may be his way to avoid (deny) facing the fact that the activity is too difficult for him. He may see that it should be simple and he does not want to face the reality that he cannot do something that is simple.

Participation in a head injury support group is often a good place for the individual to hear other people talk about their difficulties and how they have dealt with them. This can make it a little easier for him to identify his own deficits and admit to them.

IMPATIENCE

If your loved one did not like to wait for people or events prior to the accident, you are, or will be soon, facing some pretty trying times. Your loved one may possibly lose most of the patience he had, and if he was low in that area to begin with, he may not want to wait for anything or anybody. This is a particularly difficult residual behavior as recovery from head injury can be extremely slow.

For some individuals, this may be worsened by the fact that their early stages of recovery are next to miraculous. The night of the accident the doctor may have given you little hope that he would live, and then 6 to 8 weeks later he is up walking, talking, and ready to be discharged. This phenomenal progress can lead to the expectation that each 6 to 8 weeks he will have improved an equivalent amount until all is normal again.

If you have done any reading prior to this book, or if you actually have lived with your injured loved one for some time, you are aware that the bulk of the recovery occurs in the first 6 months.

Although progress can continue for years and years, the rate of change is quite different from those early months. Both family and patient can have a difficult time understanding that they will need to increase their patience rather than hold on to the expectation that progress will proceed smoothly and expediently.

There are three additional factors that appear to explain the presence of impatience in the head injured individual's everyday routine. First, the areas of the brain that help him to control his emotions have, in all likelihood, been damaged, leaving him with little control over frustration and anger. Second, head injury often leads to self-continued behavior, which will be described in greater detail under Egocentrism. Because he tends to look at all happenings from only his point of view, he has a hard time understanding other individuals' reasons for being delayed or late in responding to his wants and wishes. Third, because of the cognitive difficulties described in Chapter 10 (such as decreased problem solving or a lack of abstract reasoning), he may misinterpret a situation or find himself very impatient for what other people think are unfounded reasons.

Examples

1. The head injured individual is not willing to go to a 3-month day treatment program; he wants to go back to his job now.
2. He calls his insurance company and asks for a new rehabilitation nurse because his present nurse does not return his phone calls on the same day that he calls.
3. The head injured individual says that he definitely does not need supervised help to go back to work.
4. He wants to get up and leave the doctor's office after waiting 30 minutes.
5. He has fired two attorneys for not moving on his case.
6. The head injured individual can no longer tolerate having the grandchildren spend the night—he cannot tolerate their bickering.
7. The individual calls his vocational rehabilitation counselor 2 or 3 times daily about an authorization for driver's training.

Management Techniques

1. Resign yourself to the fact that you will be living or interacting with a person whose patience may appear nonexistent.
2. Remind your loved one of the steps that are necessary before he can accomplish the event about which he is complaining.
3. Remind him that people in certain jobs are very busy. They have other cases that are just as important as his.
4. Do not let your loved one set arbitrary time frames for accomplishing a specific goal. He will only set himself up for disappointment and frustration.
5. Try to have the individual focus on the fact that recovery from head injury is a long process that cannot be speeded up through anything but hard work.
6. Teach other family members to recognize his impatience and to apologize to offended people when and if he is offensive.
7. Teach your loved one to discriminate and not blow off steam at innocent individuals.
8. If he is currently seeing a cognitive therapist or counselor, ask this professional to help you with modifying his impatience.
9. When he complains about things not occurring fast enough, remind him of all the positive accomplishments he has achieved.
10. Firing attorneys and other helping professionals can delay rehabilitation efforts—be sure that a change is for the best and not based solely on impatience or anger.

IRRITABILITY

One of the most prominent and universal personality changes after head injury is an increase in irritability. Even those who have only been dazed by a bump on the head will often display a change in mood. The once easy-going husband and father becomes someone with a short fuse. This can be disconcerting to families who are not used to living with such a grouchy individual.

At times, you may think that the person is acting this way because he wants to get back at you for something you did or did not do. Or you may think he is trying to be mean to get out of doing something asked of him. It is possible that the person is consciously being irritable to manipulate you, but it is not probable. Because of damage to the person's filtering system, he is not able to block out excessive noises. Because of cognitive (thinking) deficits, he cannot always figure out

why certain things are necessary. Because of memory problems, he may not remember that he just told you 30 minutes ago that he did not want Aunt Susan to come over. All of these issues are related to damage to the brain and lead to a short-tempered, irritable individual.

Examples

1. Nothing at home seems to please your loved one; he complains about everything.
2. His friends come around less and less; they tell you that they find him difficult to get along with.
3. He finds it difficult to allow others to listen to TV because the noise annoys him.
4. He always has critical things to say about your friends.
5. He becomes very anxious and agitated when he has to go see his physician.

Management Techniques

1. It is useless to ask, "Why are you so grouchy?" He probably does not understand or even realize the magnitude of his personality change.
2. If there are certain people that your loved one finds irritating, minimize the time that is spent with them if possible.
3. Provide whatever comfort is needed when the person becomes agitated; frequently, he just needs a reassuring remark or pat on the back to reduce the agitation.
4. Keep surprises and changes to a minimum—head injury individuals do not react positively to either of these.
5. Allow the person to talk through his problems—this can reduce his agitation if you can stand to listen to the same topic over and over and over.
6. Keep excessive noise to a minimum.
7. Develop methods for compromising. You should not give in entirely to the patient, but it may be necessary to make allowances.
8. Do not take the irritability personally—you are not the cause of the bad mood.
9. If you feel that your loved one has begun to use his irritability to get his own way, make sure that you do not allow this type of manipulation. You may need some assistance from a therapist or counselor to turn this habit around.

OUTBURSTS

When that short fuse causes an explosion, the person can display a multitude of physical and verbal outbursts. Excessive swearing is a common characteristic and can be most embarrassing to family members. Frequently, the head injured individual will blurt out something that he is admittedly sorry for later, yet he continues to do this with little change in his behavior no matter how badly he says he feels every time it happens.

Although it is common for head injured individuals to become physically abusive, this does not mean that you should have to live in terror of this abuse. There are head injury facilities that are specifically set up to deal with this type of serious behavior problem. Your loved one may need to go to one of these special centers to bring this behavior under control. If you find that the physical assaults become unmanageable, explore the possibility of a behavioral center. The reality is that you will need to make some allowances or concessions for the fact that this individual will often act before he thinks, not unlike the small child who has to be trained to take many things into consideration before he sets his mouth or body into motion.

Examples

1. You are shocked at the bad language. Prior to the accident you rarely heard your loved one swear. Now it is a daily occurrence.
2. Your husband has begun to get physically abusive, when he had never lifted a finger in your direction before the accident.
3. The head injured adolescent threatens to kill his teacher.
4. The head injured student becomes a significant behavior problem at school. Before the accident he had never been to the principal's office for discipline.
5. The once mild and complacent husband tells his mother-in-law to "butt out or go home."
6. Your husband pulls the phone out of the wall after your daughter's boyfriend calls for the third time that night.

Management Techniques

1. In reference to swearing, try to ignore this as much as possible. If he thinks it is terribly offensive to you, it could increase in frequency if he is trying to get your attention.
2. Let him know that verbal abuse or screaming is not the best way for him to get his needs met, by not meeting them when he acts this way. For example, "I will not listen to you when you scream at me," or "If you would like to ask that in another way, we can discuss it," or "I will not stay in the room when you talk to me that way."
3. Teach the individual the skill of stopping and thinking before he speaks. You can devise a signal whereby you hold up two fingers or crossed fingers, or whatever sign you want, to get the person to consider carefully what he is going to say. This silent signal is effective in public because it does not have to look like you are treating him like a child. Other signals could be as follows:
 - (a) squeezing your nose
 - (b) scratching your head
 - (c) winking
4. Talk to friends and neighbors and explain to them about these head injury behaviors. Do this before the individual comes home rather than after he has blown off steam at someone. Tell people not to take the verbiage personally or to react to physical threats. In most cases, these will be just that—threats.
5. Learn to build a thick coating around any sensitive feelings you have. Personal sensitivity is a trait that is counterproductive to living with a head injured individual.
6. Do not badger the person about past verbal or physical transgressions—it won't help.
7. Do not allow yourself to live with physical abuse—get professional help.
8. Be sure to recognize when outbursts decrease and reward this positive change. This can be accomplished by monitoring the frequency of outbursts, as discussed in Setting Up a Behavior Management Program in Chapter 4.

PERSEVERATION

The definition of perseveration is talking about something over and over or obsessing on an action or idea over and over. Head injury entails two main characteristics that lead to this type of behavior. First, difficulty with short-term memory causes the individual to have little or no recognition that this issue was discussed less than half an hour before. Moreover, the cognitive problems related to inadequate problem-solving skills lead the head injured individual into the

necessity of rehashing issues incessantly because they are never adequately resolved or solved by the person himself. See Figure 11-2.

As a result, you will more than likely have three to four themes or conversations that occur over and over and over again, until you will think you are going to scream, or until you do scream. It may be next to impossible to change this behavior entirely, but there are some ways you can learn to live with it and tolerate it.

Examples

1. Your head injured husband talks constantly about your daughter's terrible husband.
2. Our son speaks daily of getting his driver's license renewed.
3. Your wife continually writes letters to her vocational rehabilitation counselor telling him that he is not helping her.
4. The neighbor's dog is a continual subject of conversation each time there is evidence it has been in your yard.
5. Your loved one tells all of your friends a long drawn-out story about the accident even when the same people have heard it many times before.



Figure 11-2 Perseveration

Management Techniques

1. If there is some burning issue that the individual dwells on, set up a designated time each day for that particular discussion. Then do not participate in any conversation regarding that

issue except at the specific time. For instance, tell your loved one that the issue of his returning to his job will be discussed only from 5:30 to 6:00 P.M. each day.

2. If the issue is something that is definitely not feasible or is unsolvable at this time, you can refuse to engage in any type of conversation until it becomes a viable alternative. For example, tell your son that talking about him living on his own right now is nonproductive until he can demonstrate that he can care for himself in specific areas.
3. Be firm and say that you refuse to discuss the same topic anymore. If he continues, walk away. Do not feel bad about being up-front with the person. Sometimes, the social amenities we use with others are too subtle for the head injured individual to process.
4. Try to divert the conversation to another topic. Frequently, it is easy to lead him into another train of thought.
5. Continually talking about an area of concern is, of course, a sign of anxiety. In many ways the talking is therapeutic (to a point). Take what you can tolerate and then divert the individual.
6. Remember, you may think you are doing the loved one a favor by listening over and over; however, in the long run this may not be the case. When he is constantly talking about a worrisome issue, he is physically experiencing anxiety. We all know that stress and anxiety can have a negative effect on one's physical health. Thus, you are actually doing him a favor by minimizing the time he obsesses on the issues.
- 7.

FAMILY ABUSE

The behaviors previously addressed, as well as others yet to be covered, all have an impact on what is probably the greatest deterrent to a family who continues to provide long-term support for the head injured individual. This is out-and-out family abuse. Many of us were raised to believe that we should stand by our family members through thick and thin. Putting up with head injury behaviors can definitely qualify as a challenge to this type of commitment.

One of the most aggravating things that a family can experience is that the head injured loved one can be the picture of politeness when the rehabilitation nurse or someone similar comes to visit. Once you see that he can act appropriately, it is more difficult to accept the abusive behavior that is dished out on a regular basis. There are different explanations for this, none of which make it any easier to tolerate, but they do provide a framework for understanding.

First, we all tend to let our hair down with family, as opposed to strangers or acquaintances. Of course, a head injured person's interpretation of letting hair down usually goes beyond what you or I would consider acceptable. He is in the habit of saying whatever he thinks to his family, knowing that this is not a problem. However, family members may not be accustomed to the openness and abrasiveness that occurs after a head injury.

Second, the head injured individual often loses some of his social judgment capabilities and is not effectively able to reason out the appropriateness of either his own behavior or the behavior he expects from others.

Overall, a family's patience can be quite worn after months and months of care of this individual. What makes matters worse is that the head injured person has little insight into the impact that he is having on the family.

Examples

1. The adolescent spits in his mother's face when she says he is not yet allowed to drive the car.

2. The grandfather screams constantly at the young grandchildren he adored and spoiled prior to his accident.
3. The husband constantly accuses his wife of having an affair.
4. The head injured woman slaps her 60-year-old mother when the mother tries to help her into the shower.
5. The head injured man does not allow his daughter's boyfriend to come in the house, saying he is not good enough for his daughter. Therefore, she has to sneak around and go out without her father knowing. Even though he did not particularly like the boy prior to his accident, at least he kept most of his thoughts to himself before the injury.

Management Techniques

1. Do not allow a pattern of family abuse to become established in your home. Yes, you will need to make some allowances, but continued abuse is not acceptable.
2. Never continually bring up reminders of his abusive behavior. This will only serve to upset him and will not be conducive to change.
3. There should be family rules that the person is aware of prior to coming home. It is much better to present them ahead of time rather than setting them up after a person has broken some unwritten rule.
4. Do not take the abuse personally—this will only interfere with your ability to implement effective behavior controls.
5. Treat each occurrence as an isolated incident. He probably does not remember that he acted this same way yesterday.
6. Keep in contact with your support systems—you need to have someone with whom you can discuss problems of family abuse.
7. Have family meetings whereby all members are trained to treat family abuse in a consistent manner—this is the only way that you will keep the patient from learning to use family abuse as a method of manipulating or triangulating.
8. Remember that almost all threats are made without thinking.
9. Do not allow yourself to live in a reign of terror. If problems persist, you may need to consider a residential program geared at behavioral control.
10. Join a support group in your area so that you can find out how others have handled this problem.

EGOCENTRISM

One of the reasons the head injured individual continues to add to family abuse is the completely self-centered approach he often takes to life. The world revolves around him and his problems. All family members must address his issues immediately, if not sooner. No one understands the difficulties he is having.

To some degree, it is true that no family member completely comprehends what the injured person is experiencing. Nevertheless, this is no excuse for his insisting that his needs be put above the needs of others. Your loved one will have to relearn the reality that the world is made up of many other people and their wishes and desires are also important. This job falls on you because you are going to be the one to help him reintegrate into the community. He may need to be told in many different ways that the world does not revolve around him.

Examples

1. The individual constantly complains, "You don't know what it's like to have a head injury."

2. The husband does not understand why his working wife does not have supper ready right at 6:00 P.M. when she gets off work at 5:00 P.M.
3. The head injured parent finds himself in competition with his children for the attention and time of his spouse.
4. The injured individual believes that his rehabilitation nurse wants him to get therapy so that he will not have time to go back to work.
5. The individual believes that there should be a family member ready at a moment's notice to take him where he needs to go.

Management Techniques

1. Do not let your whole family schedule center around the injured individual. Let him know that his needs are important, but so are the needs of other family members.
2. Do not allow the patient to put you on a guilt trip.
3. Help the person to try to understand the point of view of other people. Sometimes he has to be guided to put himself in another person's place.
4. Help him to realize that people outside of the family will look negatively on him if he acts selfcentered.
5. Participation in a head injury support group often helps the person to focus on other people's problems and not just his own.

OVERDEPENDENCY

The role of rehabilitation is to help the head injured individual become as independent as possible. Thus, it is important that on discharge you know exactly what he can do for himself. The minute you start to give in and do things for him you will begin to undermine weeks or months of rehabilitation efforts. We all enjoy being waited on at times, and you may feel that you want to show the person that you love him; but doing things for him that he can do is not the way to show this love.

Head injured individuals also become dependent on others in making important decisions. If it is not a critical issue in which your loved one really needs your help to arrive at the right conclusion, force him to make the decision himself and accept whatever he chooses. You might also set up decision opportunities in the family structure so that he will have a chance to practice his decision- making skills.

Examples

1. The head injured individual will discuss the same issue over and over with the social worker, then the psychologist, then the therapist, then the neighbor, and so forth. And even after all this time, he may not have made a decision about the issue.
2. The adolescent expects that her best friend will do everything with her. If her friend does not, she will not go out with anybody else.
3. The injured wife expects her husband to make all the calls to cancel her therapy when she is not planning to go that day.
4. The young head injured male has his mother make all the contacts with his rehabilitation nurse.

Management Techniques

1. Allow the individual to make as many of his own decisions as possible.
2. Refuse to tell him what to do unless it is absolutely necessary.
3. Encourage outings with people outside the family.
4. Do not allow yourself to be overprotective.
5. Encourage him to become active in a support group—maybe the individual will find someone he can help rather than concentrate on being helped.
6. Assisting and guiding the individual to assume an independent role can be a long, tedious process. Be patient and do not get discouraged. Give it time.
7. Do not allow yourself to get caught up in the "guilt trap." This is when the loved one manipulates you by saying, "If you really cared about me you wouldn't make me do this on my own."

LABILITY

Lability means a loss of control over emotional responses. Many people become concerned about this and believe that the injured person must be tremendously upset about an issue based on the fact that he is openly sobbing. Yes, indeed he is sad, but he may not be feeling as much emotion as he shows. Instead, due to injury to the brain, he is not able to maintain the emotional controls he had developed over the years. See Figure 11-3.

This lability is due to damage to parts of the brain that allow the person to exhibit control. He may not be any sadder than you or I are about the dog that was run over, but he will appear outwardly to be devastated. A joke that is only moderately funny can send the head injured patient into an uncontrollable laughing fit. These extremes lead to the presence of intense, quick mood swings that make life with your loved one somewhat unpredictable and can be very wearing.

Examples

1. The passing of gas makes the individual go into a laughing fit.
2. Tears come quickly when someone asks him about the trophies he got for baseball prior to the injury.
3. The individual becomes very emotional when he talks about his grandmother who died 10 years before his accident.
4. He may begin to cry when he tries to do some simple arithmetic problems and finds that they are hard for him.
5. Looking at pictures from the past is a very emotional experience.



Figure 11-3 Lability

Management Techniques

1. Never criticize the individual for his excessive emotions—this is something over which he has little control.
2. Do not bring the crying to his attention. You can hand him a tissue, but continue on with your conversation.
3. If you think a change in the topic of conversation would help, change it.
4. If possible, try to keep your own emotions under control. This will present a good model for your loved one.
5. Remember that the head injured have difficulty dealing with stress at any level. Try to modify the stress levels within the home environment so that his emotions can be kept on an even keel.
6. If he has had trouble with excessive crying, try to notice when things are fairly even and praise him for maintaining this control.

SUSPICIOUSNESS

Head injury individuals often have difficulty drawing appropriate conclusions regarding social situations. As a result, they may become paranoid (have delusions) so that their behavior and thinking bear little relation to reality. This can be disconcerting to family members who are putting everything they have into helping this individual and are being unjustifiably accused of wrongful deeds.

The best way to handle this is to try to separate yourself from these false accusations—do not allow them to get you down. You can say something such as, "It disappoints me when you talk this way," or "It makes me sad to hear you say such things." Then walk away. You will only succeed in upsetting yourself and him if you dwell on the issue.

Examples

1. The wife interprets every call in which a person hangs up as some other woman calling for her husband.

2. The son accuses his mother of not allowing him to regain his competency because she wants to steal all his money.
3. The adolescent is convinced that his best friend is turning his girlfriend against him.
4. The head injured individual believes that the only reason he is not back at work is because his therapist called his boss and told him he could not do the job anymore.
5. Your son insists that you are giving away some of his clothes that he cannot find (they are actually stuffed under his bed where he put them when he cleaned his room).

Management Techniques

1. Do not argue about his suspicious thoughts. You will never convince him through arguments.
2. The best stance to take is to ignore, ignore, ignore.
3. Never show your anger—he will interpret this as an admission of guilt.
4. If there is a therapist involved with the individual, ask him to help you work through the issue that is of particular concern to the head injured loved one. Sometimes if you all talk together, it will alleviate the concern.
5. It is possible that the injured one should talk to a therapist about his suspicious thoughts. If not alleviated, such thoughts can eat at him and lead to greater problems in other areas.
6. If you think your loved one can handle it, it might be good to have the object of his suspicions confront him. For example, if he is accusing the male attendant of having "eyes" for you, have this person sit down with him and discuss the issue. This stance can be very effective or it can backfire, so proceed with caution.
7. Try to guide your family member's thinking in a more positive direction.

DEPRESSION

It seems unusual to think of any emotional state, particularly depression, as a sign of progress. However, in the field of head injury rehabilitation the occurrence of a depressed state indicates that the individual is giving up some of that denial that is often counterproductive to progress. It is important for the person to realize that he does, in fact, have deficits that will have an impact on his future. See Figure 11-4.

In spite of the positive effect of letting go of some denial, safeguards apply regarding an individual experiencing a depressive state. Once you recognize that your loved one is depressed, you must be able to walk the fine line between keeping him motivated and helping him to realistically modify his goals.

A reduction in energy and excessive sleep are physical changes that often occur following head injury. It is important for family members to differentiate these normal reactions from depression. This can best be addressed by first determining what is the normal rate of sleep or fatigue that the patient typically experiences. This can be accomplished by observing these behaviors and recording the data as described in Chapter 4. When changes occur or if you believe you see changes but are not sure, you can go back to these original data and make a comparison. For example, time spent sleeping may have ranged from 7 to 11 hours per day, with an average of 8.4 hours. You may find



Figure 11-4 Depression

that the range changed to 7 to 14 hours, but the average has remained at 8.5. In most cases, this would represent a possible short-term physical problem or emotional reaction.

Examples

1. Your loved one is impossible to get up in the morning (a change from the behavior you have seen since his injury). He sleeps 10 or more hours at night and naps in the day.
2. You note a change in his eating habits—either a noticeable reduction or increase.
3. Remarks regarding the futility of going to therapy are signs of depression. For example, 'What's the sense in all of this?' or "It would be better if I had been killed in the accident."
4. Your loved one may begin to remember the past with greater frequency and duration and with more emotion.
5. A person who was not an avid TV fan now spends hour after hour glued to the tube.
6. The spark of life has disappeared.

Management Techniques

1. Consult your physician to rule out that the increase in sleep is due to some physical factor.
2. Take all expressions of suicidal thoughts and plans seriously—seek professional assistance and guidance.
3. Do not allow the individual to vegetate—get him out and about as best you can.
4. Do not allow the person to make you feel that you are the cause of the depression. He probably knows better. Even so, do not accept the guilt.
5. If the depression is extremely severe, consult a physician familiar with head injury regarding the possibility of medication.

6. Do not allow yourself to get down, too.
7. Do not become over-protective once you have obtained professional help.
8. Work on your own mental health. Be optimistic in your thinking as much as possible.
9. You may have to remind your loved one daily of the good things that are happening. Remember that memory problems may keep him from being able to process and store positive events.
10. Watch carefully for signs that he may be turning to drugs or alcohol as a method of handling the depression.

LACK OF MOTIVATION/INITIATIVE

Has someone accused your head injured loved one of being lazy? Do they say that he could work if he would only get off his duff and try? Immediate family members are usually aware of the reasons for the appearance of lack of effort, but others may interpret this "no get up and go" as the individual's fault.

There are two main issues that lead to the appearance of lack of motivation in the individual. First, one of the cognitive (thinking) deficits related to head injury is that the head injured person has difficulty with planning and goal setting. He does not know where or how to start a project, so he does not begin.

On top of this, he understands to some degree that he does not have the abilities he had before, but does not want to admit to this deficiency. He acts like he is not interested—unmotivated. The reality is that he is interested but incapable of doing what would have been simple for him before the injury.

Examples

1. The boss says that the individual does nothing more than get ready to do the job. Rarely is he able to efficiently begin and follow through.
2. You have asked your loved one to wash a few loads of laundry while you are gone. When you return nothing has been done. He tells you the washing powder was not on the shelf above the washer so he assumed you were out of it. He had not looked on the floor beside the dryer where there was a 5-pound box ready to be opened.
3. He sits and listens to music all day long.
4. The therapist is having a difficult time finding a reinforcer that is powerful enough to keep him motivated in therapy.
5. The head injured loved one uses flimsy excuses to get out of going to therapy.
6. He shows little interest in a baseball-card collection that used to be his avid hobby.
7. He makes adequate plans and big promises, but he has great difficulty following through.

Management Techniques

1. Give the head injured individual the needed supervision to start a task, because you now know that getting started can be the biggest problem.
2. Never assume that, because he did a task perfectly before the injury, he is being lazy or obstinate if he does not complete it now.
3. If he asks for help on an activity, never assume that he does not need it. In fact, assume he does need help until he completes it on his own.
4. If possible, break tasks down into smaller parts so that he can easily understand, remember, and master them.

5. You may need to get help from a professional to set up a management program to break an inactivity cycle.
6. If your loved one has been excessively agitated for an extended period of time, do not breathe a sigh of relief once he is not agitated. Although this is much more relaxing for you, it is not better for your loved one.
7. Never ask questions such as, "Do you want to . . . ?" There is too much opportunity to remain passive and say, "No." Give him a choice of two or three activities from which he must agree to choose one.
8. Get your loved one involved in a support group. This will be at least one activity a month and might be twice a month depending on the group.
9. If you have the energy and time, offer your house as a place for head injury patients and their families to meet and engage in social activities.

INAPPROPRIATE SOCIAL BEHAVIOR

Although your loved one may not be recognized as head injured from outward appearances, it is sometimes the inappropriate social interactions that give him away. There are various reasons for the presence of this deficit. The first, of course, is cognitive issues whereby the individual does not completely understand what is going on, but still joins in the conversation. The fact that his topic is unrelated is a sure sign that he falls into a handicapped category.

Another factor that relates to inappropriate social behavior is the previously described area of egocentrism (being self-centered). Because the head injured person may interpret everything said from his own viewpoint, there is very little thought about others in his responses. The head injured individual may be able to turn this around to some degree, but the turn can be too sharp. He may go from talking only about himself to asking somebody how much money he makes.

The subtleties of social situations are lost. The person must be retrained to think before he acts or talks. He will need to learn to change his interactions, depending on the audience. This skill is an advanced one and may need the help of a therapist if you have the means and availability in your area.

Examples

1. Your family member asks the cashier at the grocery store if she is married.
2. He tells the teller at the bank that he talks this way because he had a head injury and then proceeds to tell her about the accident.
3. The head injured individual, in a support group of family and peers, starts to tell about some inappropriate actions a man took toward her the night before.
4. He becomes very upset when the family decides to go to McDonald's instead of a more expensive restaurant because of financial considerations.
5. He does not understand why his aunt cannot take him to the mall as she promised. The explanation that she has come down with the flu is not adequate.

Management Techniques

1. You will need to retrain your loved one in the social amenities.
2. Do not get discouraged—social skills are not acquired overnight.
3. When you get ready to go out, remind your loved one that he is not to talk to strangers about personal matters.

4. Devise a signal whereby you call his name and proceed with some kind of cue such as scratching your nose, licking your lips, or clearing your throat. He should be taught that the signal means that it is not the time or the place to bring up the subject matter he has started to discuss.
5. Do not reinforce inappropriate behavior by acting angry—he may continue to bring a subject up because he sees it upsets you.
6. Remember that bringing the head injured person back home is like starting all over again in helping him to become socialized in our complex world.

INCREASED SEXUAL FOCUS

An individual's sexual orientation and activity can be modified after a blow to the head. In some cases, the area of the brain that regulates various hormones can be thrown off. In others, the injured person's ability to restrict expressions can be altered. A small percentage of the head injured turn away or reject sexual activity. However, a larger percentage place their major focus on remarks, actions, innuendoes, or anything remotely related to the subject of sex.

For those of you who have had a fairly conservative family upbringing in relation to sex, this change can be very difficult. You are not used to the comments, jokes, or overtures concerning sex that are a daily occurrence in this person's life. You are not equipped to hear or see these things, much less to modify your responses.

Social contacts of both your family and the patient will turn away because they are uncomfortable in his company. They will be hard pressed to understand why he is making passes at their girlfriends or wives. The result, of course, will be social isolation. Once this occurs, the injured person begins to blame others for the isolation. He will have a difficult time understanding how he was offensive. We realize that this remains a major difficulty with many head injured individuals. We have seen cases in which there was an increase in sexual obsession after 4 or more years. The avid interest is predictable, but the manner of expression, intensity, and duration differs from individual to individual.

Examples

1. The patient has scared off all of his attendants because of his sexual advances.
2. He has been arrested or threatened with arrest because he showed his private parts in public.
3. He takes every opportunity to grab or touch other people.
4. He takes a very assertive approach that tends to scare people off.
5. He talks constantly about wanting to find a wife.
6. He refuses to allow anyone over 40 or of the opposite sex to be his therapist or attendant.
7. The husband becomes angry and threatening when the wife does not desire sexual intimacy at some specific time.

Management Techniques

1. Each time the individual behaves inappropriately, a designated family member should tell him in an unthreatening and noncombative manner that the behavior is unacceptable.
2. Therapists and attendants should, as much as possible, position themselves so that they are not within arm's reach.
3. One should never bother with excess verbiage such as, "I am a married woman," "Joe and I are happily married," or "I will tell your mother."

4. Never lecture about the morality of his behavior. It may make you feel better, but it will have little impact on any change in his behavior.
5. Consult a sex therapist in your area who has experience working with head injured individuals. If there is not one in the vicinity, you might consult with the Masters and Johnson Institute in St. Louis, Missouri.
6. Keep cool and do not overreact.

EXCESSIVE TALKING

Because of a combination of physical insult to the brain and the secondary effect of overwhelming anxiety, the patient may engage in excessive, seemingly nonstop verbalizations. During the course of initial hospital rehabilitation, family members and friends are elated when the patient begins to talk. There are times, however, when the patient's excessive talking can be annoying and inappropriate.

Patients engage in excessive talking for several reasons, including poor memory for what was previously said, inability to filter thoughts without verbalizing them, and poor problem solving ability. Initially, patients have little or no ability to control their excessive verbalizations. If your family member talks excessively, you will need to assist him in establishing new skills to control verbalizations. What we mean by control is teaching the patient to know when it is appropriate to say something, what to say, and how long to talk. Helping the patient establish control over his verbalizations can be a long, drawn-out process. One of the most effective procedures is to use nonverbal cues, such as snapping your fingers, pointing to your lips, or a gentle tap on the shoulder indicate that the patient has said enough. Do not use verbal cues or confrontation, as the patient might respond in an argumentative fashion. Use nonthreatening, nonverbal cues, as these will be most effective and will not increase the patient's level of anger. It is likely that you will notice that the patient verbalizes more than he did prior to the accident; but, you can successfully reduce the frequency and intensity of the patient's excessive talking by applying the suggested techniques. Remember, if you are consistent and firm with the patient, you will be successful in reducing his excessive talking.

Examples

1. The head injured individual talks incessantly about an incident that occurred 3 weeks ago.
2. He talks for an hour about something that could be communicated in only a few sentences.
3. He loses track of something he was talking about and begins rambling on from topic to topic.
4. You find that sometimes when your head injured loved one answers the phone, the caller hangs up.
5. Some of your friends, as well as his, have quit stopping by to visit.

Management Techniques

1. Use a nonverbal cue to alert the individual that he is talking excessively.
2. Remember that people sometimes talk as a means of reducing tension and anxiety.
3. Redirect him to a nonverbal task, such as completing a household chore or writing a letter to a friend.
4. Do not feel that you must respond to your family member. Do not feel guilty for not responding.

5. If your loved one is talking on and on about an issue, have him put his concerns on paper. If it is appropriate, he could put it in the form of a letter that you may or may not send, depending on the particular situation.
6. If your family member denies that he talks too much or that this bothers other people, ask one of your friends or his to discuss the negative aspects of his excessive talking. This will be a very delicate situation. Be careful that you do not put someone else on the spot. Make sure that the person is truly willing to assist.
7. Schedule times when he can vent about a particular issue. For example, "John, we will only talk about you living on your own for 15 minutes each day. Any other time you bring it up, I will walk away."

LOSS OF CONTROL

This is not so much a behavior, but rather a consequence of head injury that serves to escalate many of the problems described in this chapter. Because the injured individual feels that his life is out of his control, he shows anger, frustration, impatience, excess emotions, suspiciousness, and on and on. The hard fact is that much of his life is out of his control. Unfortunately, the family often takes the brunt of the blame. It is you who will not let him live on his own. It is you who are keeping him from working by making him go to therapies. It is your fault that he cannot drive a car because you won't buy him a new one. Do these accusations sound familiar?

The job of making your loved one feel like he has some control falls into your hands. As you can imagine or have already found out, this is one of the most difficult issues facing a head injured individual who feels that he is ready to get on with his life, and no one can give him what he needs to do this—job, money, and so forth.

Examples

1. There is not enough money to buy a replacement for the car that was wrecked in the accident.
2. His former employer says that the company does not have any light-duty jobs. If he cannot come back to his old job, there is nothing there for him to do.
3. The doctor says that your loved one has reached a plateau and he is not recommending any more therapy.
4. His wife is not allowing his children to visit because, she insists, it is bad for them to see him this way.
5. No matter which way you turn, funding sources are not available.
6. The restrictions of Social Security make it difficult for him to try to make enough income on which to live.

Management Techniques

1. Try to offer the individual some choices whenever possible so that he can feel in control in at least some ways.
2. If safety is not a factor, let him try to do something that he wants to do even if you are sure he will fail. At times it can be better for him to try, even if he fails, than to feel as if no one will give him a chance to try.
3. Do not take his accusations personally. It is only his way of expressing frustration.
4. Remember you are not responsible for your loved one's situation, so do not accept the responsibility.

Chapter 12

Emotional Problems Experienced by Families

To the health care professional:

This chapter is closely associated with the previous chapter. Because of their reaction to behavioral changes, family members can experience severe emotional problems. Counseling is often essential to guide them through these difficult emotions—for the sake of the client and to preserve the family unit.

Chapter 12

Emotional Problems Experienced by Families

You do a lot of thinking, talking, and worrying about your head injured loved one, but do you put as much importance on your own physical and mental condition? If you do not, you need to take a closer look at yourself and how you are holding up under the stress and strain of being part of family with a head injured member.

Many families seem to go into their own traumas by putting the welfare of the patient above everything. At first, this stance is necessary. However, as time goes on, you need to recognize that you are also changing and probably experiencing emotions and behaviors that are not consistent with your former personality. You are wearing down. You find yourself saying things that you would rarely have blurted out before. You cannot seem to shake the upper respiratory infection that has lingered for months on end.

Before you suffer a physical or mental breakdown, stop now and take some time for yourself. Is your response to this "How could I possibly take time for myself?" If so, please start to look at your own well being. The only way that you can continue to provide quality assistance to your loved one is to also pay attention to your own needs. To maintain your emotional well being, it may be helpful for you to seek support, through either a psychiatrist, psychologist, or counselor.

Do not consider yourself weak if you need this outside help—many families who are in these circumstances require treatment intervention. If you think that you require medication for excessive anxiety, sleeping difficulty, loss of emotional control, or feelings of despair, you should contact your family physician. Your doctor may want to refer you to a psychiatrist who specializes in medications for these symptoms. Do not feel upset because you are being referred to "a shrink." Your physician may feel more comfortable with a specialist monitoring a particular type of medication. You may also need to speak with a psychologist or counselor regarding all the stresses that are currently interfering with your ability to function at your best level. In addition, assistance through a head injury support group is extremely effective. Contact the social worker, psychologist, or case manager involved in your loved one's care and ask about the time and location of any local head injury group meetings. There is no substitute for talking with others who, from personal experience, truly know your feelings.

As with the behaviors described in Chapter 11, the original ideas for these family reactions were presented in *A 'How To Handle' Manual for Families of the Brain Injured and Coming Home: A Discharge Manual for Families of the Head Injured* (see Bibliography).

SHOCK

In the first hours, days, and sometimes weeks after the head injury, family members are in a state of shock. This period is characterized by disorientation, memory loss, and an overall feeling of numbness. As you look back on these days, they seem to run together, and you have little or no idea how you functioned on a day-to-day basis. This state is normal for most family members, but the duration and intensity vary from individual to individual.

Some people stay in this protective state much longer than others, and still others are forced out because they are the only ones who are there to take control. Others stay withdrawn and out of touch because they are not ready to face the reality of the event. Within reason, it is best to allow each family member to work through this period at his own rate.

Examples

1. You go to bed at night and have no clear recollection of how today differed from yesterday.
2. You find you are obsessed by a comment the doctor made that suggested your loved one may never be the same.
3. You are sure that the patient hears all that is being said, even though he is considered to be in a coma.
4. You wake up at 3:00 A.M. every morning and worry, yet you lie in bed until the sun rises.

Management Techniques

1. Allow this stage to run its course.
2. If you get through this period before others in your family, do not force them to look at reality before they are ready.
3. Do not try to take control—this will only lead you into experiencing disappointment and frustration.
4. If you believe that someone in your family has remained in this stage for too long, consult a professional to determine if counseling is warranted.

ANXIETY

Anytime a trauma is experienced by a family, one expects that anxiety levels will rise. This will occur not only in relation to matters regarding the injured party, but also regarding people within the family. Consequently, tension rises to the point that the family members are forced to band together to avoid being consumed by their individual anxieties and fears.

If there are members of your family that tend to be excessively anxious, even under normal circumstances, this will be a particularly hard time for all of you. There is the danger that these individuals will completely fall apart when an anxiety-provoking event occurs. This can be especially hard for others who, year after year, have had to put up with this overly anxious individual.

Even more disconcerting is the situation in which the strongest and calmest individual completely breaks down. In this case, family members who have relied on this particular person are thrown off—kilter as they lose their "rock." Usually, necessity dictates that another person step in to take the controls.

In many families, however, there is probably one individual who takes the lead, putting his initial anxiety aside, and takes control. If you have been that person, you know that you had to squelch your fears and insecurities to assist others in their adjustment. If you were not that person, you probably recognize the one who played this role.

In any event, the entire family needs to take a careful look at the one who most assisted others through the trauma. After weeks, months, and sometimes years of giving support, that person can use a break from this role. If you are the leader, ask for this break. If not, help to convince that person to take some time for himself.

Examples

1. You are concerned about whether the loved one's wife will be able to accept his deficiencies.
2. You worry that there will not be enough money or adequate insurance to handle his lifelong care.
3. You wonder if the doctor was correct when he told you that your loved one would never go back to work.
4. You are not sure what is meant by "adequate supervision."
5. You think that his depression is interfering with his reintegration back into the community.

Management Techniques

1. Schedule your times to worry, such as between 8:00 and 9:00 A.M. Then forbid yourself to think about your many concerns for the rest of the day.
2. If your head injured family member is engaged in constant verbalization about a concern of his, do not allow yourself to get trapped into constantly worrying with him. One worrier at a time is enough.
3. Remember that excessive worrying is bad for your health, and the entire family needs to stay healthy.
4. If you find yourself going "over the edge," contact a mental health professional.
5. Remember that your worries should not control your life—you should control your worries.
6. Participate in a support group for head injury. Many of the members will have already resolved some of the worries that are new to you. There is nothing like the voice of experience.

DENIAL/OVEROPTIMISM

Denial is a double-edged sword for the family experiencing head injury. On the one hand, it provides you with a needed hope that helps you get through many difficult days. All families want to have the loved one back the way he was. If changes occur, you want to believe that they will be only minimal. This position gives many of you the stamina to find the best programs and best therapists and to follow through with whatever is recommended. From this vantage point, some denial allows you to maintain your efforts. See Figure 12-1.

At some point, however, if you hold on to the undaunted position that there is a perfect rehabilitation program somewhere (if you could only find it) that will allow your loved one to reach his potential (absolute cure), you could eventually interfere with realistic efforts at community reintegration. If you believe that your son needs only a few more years of rehabilitation before he can go back to law school, you may be doing him a disservice by not allowing him to look at other possible careers. This does not mean that some head injured individuals cannot return to school or their previous jobs; rather, it suggests that you not automatically expect this outcome.

By setting goals for the patient, you may think that you are providing him with the proper motivation and that this is the best way to support his recovery. However, you must be careful that your encouragement does not inadvertently lead to him seeing himself as a failure.

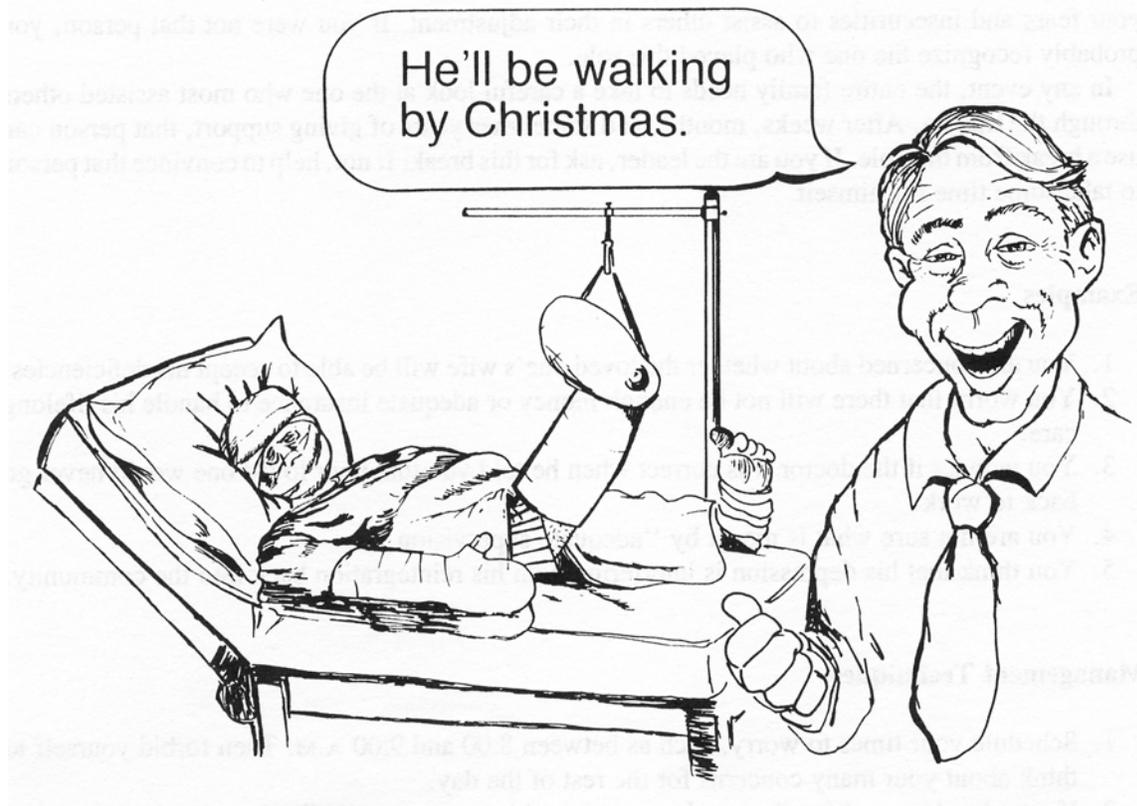


Figure 12-1 Denial

To get a handle on where to draw the line, find a therapist with whom you feel comfortable. Make sure he has worked with your loved one long enough to know him, and then ask him to tell you honestly (to the best of his ability) what goals are realistic. Remember, if you have not convinced him that you are ready to at least consider his opinion, he may waffle and feel uncomfortable at being up-front with you. In the main, it is best to take things one at a time and set very small, yet definitive, goals to work on each month.

Another important point to bring up here is that denial can bring about 'rehab shopping,' similar to the familiar concept 'doctor shopping.' We all know that there are differences in rehabilitation facilities. It would be naive to suggest otherwise. However, families can expend much energy and sacrifice looking for the perfect facility that they feel will accomplish the goals they have determined are obtainable. We are not suggesting that you accept every program at face value, but we do encourage you to consult a professional you trust when you are thinking that another program is the answer to accomplish the goals for your loved one.

Examples

1. You have told his old boss that he will be ready to come back to work after he is discharged from the center
2. His wife is expecting that his personality changes will be gone, or at least considerably diminished.
3. You feel that all has been a failure if he is not walking independently at discharge.
4. You have told the head injured loved one that he can do anything if he just tries hard enough.

Management Techniques

1. One day at a time—make that your motto.
2. Do not make the loved one feel that he has failed if he has not met your expectations.
3. Remember, people in wheelchairs can live productive lives.
4. Try to make him feel he is worthwhile, even within the current limitations.
5. Emphasize all of the positive recovery that has occurred.

ANGER

After you have allowed yourself to let go of some of the denial described in the previous section, you may open the floodgates for feelings of anger. Facing the reality that your loved one may not become exactly as he was before the injury often gives rise to feelings of unfairness. This anger may be directed toward everything and everybody in general or you may have particular people or circumstances that you abhor.

Remember, it is natural that you should have these feelings. However, it is important to get a hold on the anger and channel it into positive actions rather than letting it eat away at you. Many constructive actions can come from the energy initiated by anger—use it constructively.

Examples

1. The mother is irate because the nurse only spent 30 minutes attempting to get her daughter to eat her lunch.
2. The father refuses to cooperate with the police investigation, saying they are not making accurate reports.
3. The husband says that the county is responsible for allowing such a dangerous intersection to exist.

Management Techniques

1. Recognize that you are angry about what happened.
2. Identify what is causing your anger, such as a specific nurse or particular friend of the patient, and avoid the cause if possible.
3. Substitute a vigorous or productive activity for anger (for example, exercise, house cleaning, or yard work).
4. Do not allow the anger to eat away at you and affect your own health.
5. Seek counseling to deal effectively with anger.

FATIGUE

Having a head injured family member can be exhausting, especially if you work yourself to the bone without allowing for some rest and relaxation. You may be saying, "How can I rest in a situation like this?" or "If I let down, we may miss doing something for him that may be crucial." If these statements sound familiar to you, then we want you to take a close look at your own physical condition.

Do you feel as if you can hardly go another step at 8:00 P.M.? Do you wake up feeling fatigued? Do you become disoriented? Do the days run together with little recollection of what happened and when? If so, you need to take some time for yourself. If you have difficulty doing this or you are not sure how to go about it, consult a counselor. You must take time for yourself if you are to maintain the energy needed to assist your head injured loved one for a lifetime.

Examples

1. The parents stay up until 2:00 A.M. night after night providing each other with needed emotional support.
2. Attempts to nap are fruitless due to racing thoughts regarding unresolved problems.
3. A back problem reoccurs and increases the problem of insomnia.

Management Techniques

1. Use relaxation techniques for insomnia. If you are unfamiliar with these, consult a psychologist.
2. Put off until tomorrow anything that is not absolutely necessary.
3. Delegate responsibilities. Others will usually be glad to help.
4. Do not feel that you have to constantly be by the patient's side. Ignore accusations that you do not visit often enough.

IRRITABILITY/IMPATIENCE

All of the previously mentioned behaviors result in you becoming an irritable and impatient person. This change may have been so gradual that you do not see yourself as any different from before. If you do not believe that this section applies to you, ask someone else in your family to verify this—and do not get irritated with him if his response is not in agreement with your opinion of yourself.

Being on edge is understandable, but remaining on edge for the remainder of your life is not. Do not excuse yourself by saying, "I'll change as soon as John is well." That can be a long, drawn-out process, so it is best not to let yourself get caught up in becoming something less than you were before.

Examples

1. You think that if you have to go through another conversation about driving, you will scream.
2. You find that you are much less tolerant toward the children and their shenanigans.
3. You feel as if your life is not your own.
4. You blow up at the rehabilitation nurse who is really trying to help, but somehow you cannot see that at the time.

Management Techniques

1. Again, "one day at a time" is a great motto.
2. Do not expect all agencies to perform in a proficient manner.
3. Do not expect all people to respond to your problems as you do.
4. If you lose your cool with someone you love, take time to apologize.
5. Tell the children that you are under a great deal of pressure and you could use their help rather than their resistance.
6. Assign priorities to your projects and tackle them one at a time.

FRUSTRATION

It appears that the word that best describes the lifelong battle with head injury is frustration. After families have worked through the shock, denial, anxiety, and anger, they still continue to

face frustrating experiences. You hear of newly developed services, but your loved one does not meet the criteria. Your funding resources keep you from taking advantage of therapies you feel would be helpful. Your son will not adjust his vocational goals and thus fails at job opportunities. His suspiciousness keeps him from accepting help from those who might be able to provide alternatives.

Some people would say that you are setting yourself up for frustration because you are expecting things that are not feasible or appropriate. At times, families will do this. The reason for these somewhat unrealistic expectations often goes back to the time when the physician said, 'He will not live past the morning'; but he did live. Then it was said, "He will be nothing more than a vegetable"; but now he's talking. When families see that those in the know have previously been wrong, they have a tendency to doubt the things that are said to them now. There is an additional frustration when you are not sure what to believe.

Examples

1. Your physician says that he will not authorize any further treatment because your loved one is at maximum medical improvement (MMI).
2. Vocational rehabilitation does not see your family member as an appropriate candidate.
3. The rehabilitation nurse says that the insurance company will not pay for a day-treatment program.
4. You are told that his psychiatric problems are unrelated to the head injury.
5. His friends are turning away from him, and he is becoming more depressed.
6. His employer now says his job is no longer waiting for him.

Management Techniques

1. Frustrations are a reality—it is how you handle them that makes a difference.
2. Never allow yourself to be worked into a frenzy—you will never solve the problems in that state of mind.
3. Take a rational-emotional therapy seminar on how not to become unproductively upset.
4. Remember that the head injured individual will pick up on your frustration and may use this in a negative manner.
5. Speak with others in a support group and find out how they managed their disappointments.
6. Develop alternative methods of reaching your goals for the patient if you find that certain avenues are blocked.

FEELINGS OF HOPELESSNESS/HELPLESSNESS

Feelings of hopelessness and helplessness may come and go at many stages in the recovery process. You obtain renewed hope as your loved one masters critical goals. When a plateau occurs over an extended period of time, the doubts set in.

The best support at these times is often the families of other head injured individuals. Professionals mean well and they have a wealth of knowledge from which to draw; however, there is nothing like personal experience. A word of caution is warranted here. You may find yourself hooked up with a family who is having their own problems. For whatever reasons, they are not the most objective in their outlook. In this case, try to use the advice of other families and professionals and continue to maintain your own thoughts and feelings above and beyond what others are saying you should feel.

At times you may sense that you cannot shake these "blue" thoughts. If they last for days or weeks on end, consult a therapist for assistance. It is not unusual to feel depressed, but it certainly is counterproductive to allow these thoughts to consume you.

Examples

1. You feel sleepy all the time and find that you have a hard time getting out of bed.
2. You find that you are drinking more than before.
3. You have a difficult time getting motivated.
4. You are no longer overoptimistic—you have gone in the opposite direction.
5. Hopeless thoughts occupy your mind.

Management Techniques

1. Take your feelings seriously—seek professional counseling before you find yourself going under.
2. Do not set yourself up for disappointment and depression by assuming or expecting too much.
3. Do not let yourself obsess on negative thoughts.
4. Join a support group where you can voice your concerns to people who really understand.

GUILT/AMBIVALENCE

Guilt and ambivalence (conflicting thoughts about a person) can feed on each other. Conflicting emotions or thoughts can bring guilt, and guilty feelings can lead to ambivalence. There is hardly a family around who has not looked at their head injured loved one at some point in time and thought, "I wonder if it would have been better if he had died." This statement taken out of context seems cruel and startling, but those of you who have lived through the ups and downs of head injury recovery will understand.

However, some of you were raised to believe that thoughts like this are inappropriate, so that in entertaining them, you open yourself up to the guilt that goes along with this thought. At times, you will think that all is going well and you are moving in a positive direction. At other times, you will be less encouraged and feel that all is for nought. Do not allow yourself to be self-critical if your feelings change from day to day—you are human like the rest of us.

One or more family members may feel guilty about either contributing to or not preventing the cause of the accident. On top of your own guilt, others may subtly, or not so subtly, reinforce the idea that you are to blame. These types of thoughts and words can seriously affect your family interactions. It is very important to seek help when working through feelings of self-blame as well as accusations from others. Marriages can be particularly influenced if these issues remain unresolved.

Examples

1. You may feel guilty every time you go out of the house without your loved one.
2. You may feel guilty that you have not done more to help the head injured individual improve in cognitive skills.
3. You may feel guilty that you have ignored or avoided your friends.
4. You may feel guilty that at times you fantasize about a 3-week vacation alone.

5. You may feel guilty that you have not been able to help the loved one get the vocational training he needs.

Management Techniques

1. Accept guilt as a normal human feeling over which you have minimal control.
2. Substitute some engrossing activity to get your mind off the guilt—gardening, exercising, hiking, and so forth.
3. Schedule your guilt time—feel guilty only on Mondays.
4. Go to a rational-emotive therapist who can help you to quit focusing on what you should have done.

FAMILY DISUNITY

The care of a sick or injured person within a family structure can bring out either the best or the worst in the individual family members. Each person believes he knows what is right and wrong for the patient. The most difficult scenario is when the person is emphatic about what should be done, but is not at all interested in carrying out the care. Instead, that person would rather sit on the sidelines and give advice.

If you are not the primary caretaker, you should refrain from offering criticism unless you are willing to share in the caretaker role. If you are the primary caretaker and others are offering their unsolicited advice, you should invite them to relieve you for a week's vacation.

Other difficulties arise when jealousies occur regarding the amount of time that is spent with the injured individual. Brothers and sisters of head injured children may have a difficult time understanding why the focus is always on the patient. Problems can also arise with a stepparent who becomes jealous of the time the natural parent must now spend with the injured child. No matter what the situation, as the primary caretaker, you will not be able to please everybody. You will have to decide what you believe is right and not let others sway your thinking. You may need the support of a counselor to maintain your balance on these matters.

Examples

1. Aunt Marie thinks that you take your loved one out too much and get him too excited. That is why he is acting out.
2. Uncle George insists that a vegetarian diet is a must to help with memory problems.
3. You find that you are too tired to communicate with your spouse because you spend night and day planning for your head injured son's future.
4. Your head injured husband feels neglected when you spend time with your children.

Management Techniques

1. Before the head injured individual comes home, promise yourself that you will set aside some time each week to iron out family issues.
2. Never assume everybody loves him or that they will not resent all the time he needs.
3. Set up an open communication system whereby all family members feel free to constructively communicate their feelings.
4. If family unity seriously deteriorates, consider counseling to improve communication and regain a positive family unit.

5. If there were serious problems in the family prior to the injury, you can expect them to remain and possibly increase. Try to work on these issues prior to the loved one's return home.

DECREASED SOCIAL CONTACT/LEISURE TIME

From the very beginning you should never, never lose contact with your friends. Most of us are familiar with the usual procedure of bringing a sick individual home. For a while, the family devotes all their energy to taking care of this person until he is well. Friends stay clear until they hear from you that you are again ready to socialize. They should hear this immediately. Do not allow yourself to become consumed by the loved one's care to the point that you do not stay in contact with your support system—your friends. You may mistakenly feel that you are no good for anybody but the family and you will steer clear of friends until you feel human again. Do not do this. Make yourself take the time to keep in contact with those outside the family.

In some cases, even if you follow this advice, there will be a few friends who drift away, even though you make the effort to stay friends. There will be some people, no doubt, who are too uncomfortable with interacting with you or your head injured loved one to maintain the friendship. If this occurs with a large number in your social circle, make sure that you put the time into making new friends. Head injury support groups can provide contact with new people who will not be hesitant to relate to you or your injured family member.

Examples

1. A retired woman takes on the responsibility of her head injured daughter with three children, and does not make arrangements to see her friends on a social basis.
2. A wife quits her job and gives up outside contacts to attempt to meet all the needs of her husband.
3. The family refuses to go out until the loved one can go to social engagements with them.
4. The husband devotes his entire energy into trying to provide cognitive therapy to his wife. He refuses to go out with his friends from work or to play golf or tennis with his sports companions.
5. A mother gives up her bridge club and discontinues writing letters to her good friends.

Management Techniques

1. Do not set up an early pattern of decreased social contacts.
2. Do not quit your job unless absolutely necessary.
3. When friends call, talk about things other than the patient and how or what he is doing.
4. Schedule outings for social activities and then follow through.
5. Do not convince yourself that you are the only one who can care for the patient.

LOSS OF LOVE

For those of you who are fortunate, the head injury may be mild and the return of your loved one's original personality may just be a matter of time. Others, however, are faced with the realization that this is a very different person either physically, mentally, or both, than the one that existed prior to the injury.

The greatest difficulty seems to arise in the instance where either a married man or woman is injured. Some people are able to adjust to the changes and accept the person as he is now. Others

find this very difficult and say such things as, "I'm married to a stranger." When intimacy is expected, they have a very difficult time learning to love a "new" person. For this reason, marriages often falter. If you are in this position, it is best to give it time. However, at some point you may want to seek counseling to help clarify your thoughts about the relationship.

You may go through a grieving process, just as if you actually lost this person in the accident. This reaction may seem very strange to you because you did not physically lose him, but the end result may be that the person you knew is no longer with you. You will need to allow yourself time to adjust to this state of affairs.

Examples

1. The head injured individual, who has always been the stronger of the two in the marriage relationship, suddenly becomes dependent on the other.
2. The older couple just beginning to enjoy retirement find themselves with the equivalent of a child to care for, even though their son has been functioning independently for 20 years.
3. The woman who, prior to her husband's accident, played the dominant sexual role, finds that he is offended when she approaches him.
4. The mellow, mild-mannered husband has turned into a boisterous and offensive partner.
5. The previously active and exciting woman sits all day in front of a television and eats continuously.

Management Techniques

1. Talk to him the way you used to.
2. Let him make as many decisions as possible.
3. Ask his opinion (even if it is not necessarily needed).
4. Approach the situation as you would a new relationship.

ROLE CHANGES

The role played in the past by your head injured family member will undoubtedly change, at least for a period of time. For some people this change is not difficult, but for others it is extremely demeaning, embarrassing, or unacceptable for a variety of reasons. See Figure 12-2.

A wife may be trying very hard to manage a job, care for the children, and write out all the bills. Instead of appreciating her efforts, her head injured husband may be critical about the manner in which she is attempting to assume his former role. His anger and irritability is directed toward her, but in reality is meant for the circumstances that have brought them both to the necessity of a change in roles.

Children may find that they are now the parent or that they have to compete with their parent for the attention of the other parent. It is a confusing and frustrating situation for all concerned.

Examples

1. A woman who has never balanced a checkbook finds herself in charge of all the family finances.
2. A man who has rarely cooked a meal finds that if the children are to eat, he must learn to cook something other than TV dinners.
3. A daughter finds that her head injured mother does not like the idea that she is running all the errands for her father.

4. A stepfather finds that he resents the fact that a teenage daughter has to be babied again by her mother.
5. A woman finds that she has to try to get things in the house repaired before her head injured husband discovers something is wrong. He becomes irate when he tries to fix things because he has such a hard time doing things that used to come easily to him.

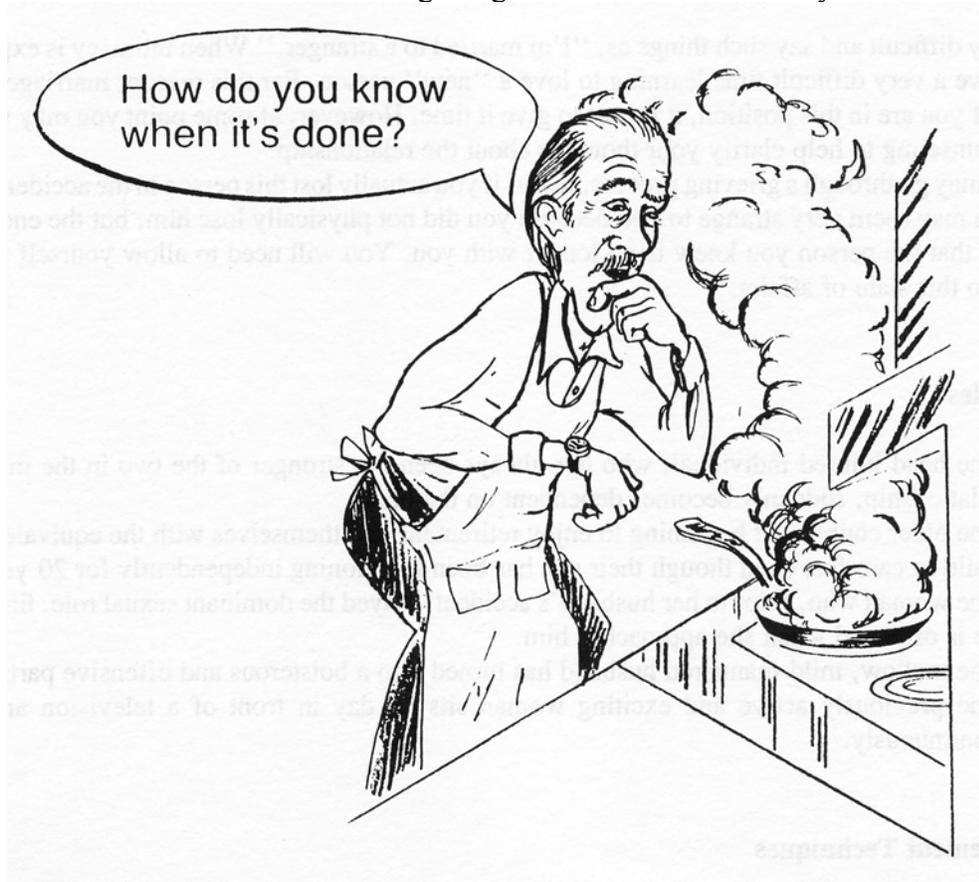


Figure 12-2 Role Changes

Management Techniques

1. Try not to complain about assuming a needed role in front of the patient—he feels bad enough about the situation.
2. Make sure that the children of head injured parents understand the reasons for the behavioral changes by exposing them to educational material.
3. Ask your outside support system to help you assume this role if it is not manageable for you.
4. See a therapist if home stressors are beyond your control.

Chapter 13

Long-Term Medical Problems

To the health care professional:

Only one or two of these problems may pertain to an individual case. If one occurs, it is essential that a specialist experienced in that issue fully discuss it with the family.

Chapter 13

Long-Term Medical Problems

POSTTRAUMATIC EPILEPSY

Posttraumatic epilepsy or seizures were discussed in Chapter 2. This occurs in 5 of patients with traumatic brain injury, but is most commonly associated with the situations listed in Table 13-1. Patients without these risk factors have less than 1 incidence. Whether seizures will occur in an individual cannot be predicted. Epilepsy is important to prevent as it can occur in unpredictable settings. Also, in many states, driving is prohibited within 1 to 2 years of a seizure. See Figure 13-1.

Various types of epilepsy occur, but seizures associated with traumatic brain injury are different from the more common epilepsy that has no identifiable cause. Head injury often produces focal motor seizures that result in jerking movements of arm, leg, or face. These are called partial seizures, as consciousness is not lost. More extensive seizures can originate from an activity near a site of brain damage that spreads across the brain to cause movements in all four extremities. This leads to a complex seizure in which consciousness is lost and frequently results in movements that are tonic (muscle contraction) or clonic (rhythmic contraction and relaxation of muscles leading to jerking movements). In old medical terminology, this was called a grand mal seizure. Temporal lobe seizures are somewhat unusual and they cause bizarre purposeful activities, behavioral changes, and unusual sounds or smells rather than jerking movements. They make up 20 of seizure activity.

Seizures are usually brief. If a focal motor seizure occurs, nothing special needs to be done. If a generalized seizure occurs, the patient should be removed from any dangerous situation in which he might hurt himself. Clothing around the collar must be loosened. Glasses should be removed. He should be helped to lie down on his side or stomach—not on his back (in case he should vomit). Let the arms and legs move freely. It is no longer felt necessary to put something in the patient's mouth. A physician should be called. If a seizure persists (status epilepticus), medical attention should be sought immediately.

During a generalized seizure, your loved one may cry out, lose consciousness, and fall. There are movements of the arms, legs, and face. Bowel and bladder control is often lost. Breathing may be irregular. Following the seizure, he will stop moving and will start breathing normally again. He usually awakens in a few minutes to complain about sore muscles or headache. Confusion or fatigue can persist for hours after a seizure episode.

The number of seizures can be increased by certain medications. These drugs irritate the brain tissue so much that the brain is more likely to have an epileptic seizure. This effect of alcohol and

certain drugs is called lowering the seizure threshold. Medications are used both to prevent and to treat seizures. A decision about prevention by the physician will consider risk factors, drug side effects, and the special needs of the individual patient. The usual medications are phenobarbital,

Table 13-1 Occurrence of Posttraumatic Epilepsy in Patients with Traumatic Brain Injury

Situations	Frequency
Intradural Hematoma	45
Extradural Hematoma	20
Early Seizures	25
Depressed Skull Fracture	15

phenytoin (Dilantin), carbamazepine (Tegretol), and valproic acid. Of these, phenobarbital is the most sedating. Tegretol is often considered the drug of choice for focal seizures. (See Chapter 16 on medications.)

ALCOHOL AND DRUG ABUSE AND THE RISK OF REPEAT HEAD INJURIES

Alcohol and other drugs commonly lower the seizure threshold and should be avoided after head injury. Alcohol or drug use is common in our society and can be one of the factors that lead to head injury. By definition, improper use of such substances turns "one for the road" into alcoholism and "just one joint" into drug abuse. Counseling and appropriate referral are recommended in such circumstances. It is especially important after head injury, as judgment and cognitive functions are damaged by the injury and cannot tolerate further insult from drugs and alcohol. Also, a head injured person has a fourfold chance of having another head injury! A second head injury is associated with a 16-fold chance of suffering a third. Therefore, all efforts must be made to prevent another, possibly even more devastating, head injury. See Chapter 15 for a more detailed explanation of alcohol and drug issues.

LATE HYDROCEPHALUS

Hydrocephalus (an abnormal increase of fluid within the skull) was also discussed in Chapter 2. It is sometimes seen late after head injury, particularly in those with intraventricular bleeding. It shows up as drowsiness, nausea, vomiting, and headaches. In children, enlargement of the head is seen. A deterioration or leveling in function is often noted. Hydrocephalus can be indicated by a CT or MRI scan that shows enlarged ventricles and compressed cortical sulci (the wrinkles and the spaces between them on the outside of the brain). These findings can be confirmed with an indium cisternogram that measures the flow of cerebrospinal fluid through the ventricles of the brain. Hydrocephalus is halted and sometimes improved by the placement of a ventricular-atrial (brain to

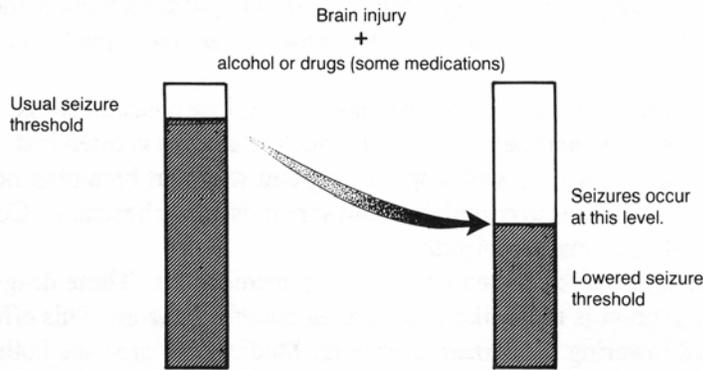


Figure 13-1 Alcohol and Drugs Increase the Likelihood of Seizures

heart) or ventricular-peritoneal (brain to belly) shunt. So called "normal pressure hydrocephalus" is a treatable cause of dementia in the elderly and is associated with an earlier history of head injury. Early senile dementia has also been associated with traumatic brain injury.

DEEP VEIN THROMBOSIS AND VENOUS INSUFFICIENCY

Acute deep vein thrombosis (DVT) is discussed in Chapter 2. DVT can also develop later in a paralyzed limb and can recur in a limb that previously had phlebitis (inflammation of the vein). It results in swelling of the leg and is sometimes associated with warmth and pain. Also, a limb that previously had DVT can, after years, develop a chronic problem with insufficient venous (vein) drainage. Chronic venous insufficiency causes massive leg swelling and pain and can lead to infection, cellulitis, and ulceration. It is treated with elevation of the limb, firm support garments, and early antibiotics in the event of infection.

UNPLANNED PREGNANCY/VENEREAL DISEASE

Problems with judgment, as well as a loosening of inhibitions, can lead to unplanned pregnancies in some women with head injury. In appropriate cases, passive birth control devices, such as the birth control pill or an intrauterine device (IUD), should be considered with the help of a gynecologist.

Inappropriate sexual decisions can lead to venereal diseases of various types. Although the best protection is avoiding infected partners, condoms offer some protection against AIDS, herpes, syphilis, and gonorrhea. Of course, impaired judgment limits the ability to use such devices.

ACNE VULGARIS

Acne often occurs for the first time or recurs following traumatic brain injury. Treatment with steroids for brain swelling (i.e., Decadron) leads to red papular acne of the face, chest, and back. Others with head injury seem to develop acne as a response to a change in hormone levels. Acne is treated by washing the face with soap and water regularly and by applying 5 or 10 benzoyl peroxide. A dermatologist can be consulted for more resistant cases that fail to respond properly to this simple treatment.

TEMPOROMANDIBULAR JOINT DYSFUNCTION

A problem with temporomandibular joint dysfunction (TMJ) is sometimes seen after head injury. The jaw moves in the TMJ, creating great pressure. TMJ problems produce chronic headaches, face pain, trouble with chewing, and jaw clicking. Some orthodontists, oral surgeons, and general dentists specialize in this cause of chronic pain.

DIPLOPIA (Double Vision)

Double vision can be noted immediately after head injury and is due to injured eye muscles, their cranial nerves, or some of the brainstem pathways between them. Early symptomatic treatment involves alternating eye patches from one eye to the other, but this eliminates depth perception at the same time it eliminates the diplopia. Eye surgeons (ophthalmologists) can perform eye muscle surgery to balance the eyes after about a year. Prism glasses are helpful for some patients.

OBESITY AND OVEREATING

Although insufficient nutrition is a significant problem early after serious head injury, hyperphagia (overeating) is a later problem. It is not yet fully understood why some head injured will eat almost continuously. There is speculation that it is due to an injury to the appetite center in the hypothalamus. Medications are of little value in this condition. Proper supervision, diet, low calorie snacks, and counseling are the current therapeutic tools.

PSYCHOSIS AND SEVERE LOSS OF CONTROL

Head injury can lead to severe injury to the frontal lobes, temporal lobes, and limbic system, as previously discussed. With the loss of the moderating influence of these control centers on the personality and emotions, some people reach extreme states of confusion and loss of control. Personality factors and emotional instability before the accident are also important factors. Some patients require treatment for psychosis (a severe loss of contact with reality) with antipsychotic medications. When the confusion and loss of contact with reality become more of a problem than the behavioral issues involved in emerging consciousness following head injury, psychiatric hospitalization is a possible treatment option.

Even though people with head injury are often found in psychiatric wards, they should not be categorized in the same way as patients with schizophrenia or manic-depressive illness (bipolar depression). Their condition has a totally different basis, but they are often treated with the same medications. Head injured patients respond to an appropriate behavioral environment and will usually improve with time in the proper rehabilitation program.

Chapter 14

Long-Term Psychosocial Problems

To the health care professional:

There are many psychosocial problems that can develop after discharge. Families should be alerted to this possibility and be advised as to what to watch for and where to seek specific help.

Chapter 14

Long-Term Psychosocial Problems

Head injured individuals have a multitude of problems to conquer, including cognitive deficits, behavioral difficulties, and physical rehabilitation. It is assumed that, if each of these problems is individually tackled and the problem areas are reduced to a minimum, the individual is then ready to effectively return to society. Why, then, do some of the most promising head injured patients go back into society and face what appear to be insurmountable roadblocks?

In most cases, these additional difficulties are related to a completely new set of problems. These are called psychosocial problems, or the issues involved in interacting effectively with the world in which we live. Let us offer an example to show you how these can make up a different set of issues, also requiring rehabilitation.

Larry is a 30-year-old accountant who was in a coma for 6 days. He participated in a comprehensive acute head injury program in which he received physical therapy, occupational therapy, speech therapy, cognitive rehabilitation therapy, and psychological counseling. His physical problems were primarily resolved before he left the inpatient program.

On discharge, Larry was referred for outpatient cognitive rehabilitation therapy and psychological counseling. The cognitive therapist worked on problems of visual organization and planning, verbal hypothesis testing, attention and concentration, reducing irrelevant responses, and handling auditory interference. The psychologist met with Larry and his wife. When he returned home, he would easily fly off the handle at his wife and children. When his wife would be away from the house longer than she originally said, he would question her accusingly about where she had been. Although Larry was very anxious to return to work, he agreed to continue the outpatient treatment for 2 months. He was released after this time, with follow-up sessions with the psychologist to continue on a weekly basis.

After 2 months back on the job, Larry was demoted from his supervisory position to a lesser job. Larry said that his boss did not like him and never had. He said his boss had never wanted him to have the supervisory position. He also accused his boss of using the accident to take him out of the job. When the psychologist called, the employer said Larry had consistently criticized upper management in front of his subordinates. After three reprimands, he was warned that another incident would result in a demotion. A closer look at the situation revealed that Larry had some legitimate gripes, but the manner in which he handled them was not appropriate for a man in his position in the accounting firm.

Did the cognitive therapist fall down on the job by not providing appropriate problem-solving techniques? Did the psychologist fail to teach Larry to filter his response or control his behavior? Was he discharged too soon from outpatient therapies? None of these is the sole problem. What

would have been appropriate for Larry is a type of therapy called affective rehabilitation. Affective rehabilitation addresses the problems of psychosocial skills. Using Larry again as an example, one of his cognitive problems was in his difficulty in understanding how to spatially plan a visual motor task. Emotionally, he was anxious about doing well when he returned to work. Behaviorally, he had difficulty inhibiting the verbalization of his thoughts. When his boss insisted that he have a particular project done by a set date, Larry became confused about how to tell his subordinates what to do. He had difficulty planning their tasks and became anxious that he would fail. Instead of admitting his confusion, he criticized his boss in front of all of the employees and blamed him for assigning a job that had too many problems to complete by the deadline. Here, Larry is exhibiting the psychosocial problems related to "sense of being different" and "difficulty returning to work." Somehow he sensed that this task should not be hard for him, so he was embarrassed to ask for help. In not doing so, he was having difficulty reintegrating himself back into his job.

Although there are numerous psychosocial issues that could be delineated here, we have chosen to describe six of the more general problem areas. Many of the examples come from those originally presented in the manual *Life After Head Injury: Who Am I?* (see Bibliography).

SENSE OF BEING DIFFERENT

In almost all instances of head injury, from mild to very severe, the individual is different in some respect. The magnitude of these differences depends on the severity of injury, the degree of physical changes, and the level at which they were functioning before the accident. The awareness of these differences depends on the degree to which denial is present.

When the injury is severe and accompanied by very noticeable physical changes, such as being wheelchair bound, having contracted limbs, or displaying speech patterns that are difficult to understand, the patient does not typically deny such differences. He knows he is different—he can see it as well as perceive it. In this case, he has to develop all over again and the end result is often a very different individual. This does not mean that he is completely someone else, but it does mean that goals and dreams must obviously be altered. Although this group may accept obvious physical changes, there is a tendency for them to minimize their cognitive (thinking) difficulties. Their focus is primarily on the realization that they are very different physically, and for that reason their lives are not the same.

Those who are moderately injured are in a second group. They have both physical and cognitive problems, but they are fairly sure that they will be the same as before when their physical deficits are remedied. Until these individuals are faced with going back into the world, they often continue to feel that very few lasting changes will remain.

Those who have had only mild injuries with few physical problems are in a third group. Although one would think that this group would have the greatest chance of adjusting, this is not always the case. In fact, it is often this group that holds onto heavy denial. They are convinced that they are ready to go back and do their previous jobs just as efficiently as before with minimal cognitive rehabilitation, and they know exactly why they are ready.

In any event, all individuals in these three groups discover at some point that they are different. Not only are they different from who they were before, but they are different from other individuals.

This discovery is a sign of progress because it indicates that they are letting go of some denial. However, with the shedding of denial can come an increase in anger, depression, and confusion.

To help your loved one, you will need to help him work through these feelings that come from recognizing his "difficulties."

Examples

1. The patient knows that he was a star forward on the soccer team before the accident. He can no longer play any position in a competitive situation.
2. He says, "Employees act like I'm retarded and I know I'm not."
3. "When you're in a wheelchair, people act like you don't exist or have no brain at all."
4. he patient realizes that he flies off the handle so much easier than before.
5. Going to meet somebody at an unknown location is a major project that brings thoughts of tearfulness of getting lost.

Management Techniques

1. Help him to realize that he can be a productive individual even with these changes.
2. Never tell him he can do what he did before if he would just try hard enough. You may think you are doing him a favor by kicking him in the behind, but his deficits may be such that doing what he did before is impossible.
3. Encourage him to participate in a support group where he can share his feelings about "differentness."
4. Encourage him to explore who he is now and feel comfortable with his current self.
5. Try to present all your suggestions for behavioral changes in a positive and constructive manner.
6. Do not allow the individual to wallow in self-downing sessions because he is not his former self.
7. If possible, point out changes that are positive. In some cases, previous drug users become drug free. Sometimes individuals who have not cared about family now find themselves closer to them or they have a greater understanding for those that stick by them through all aspects of the injury and rehabilitation.
8. If you see the injured person is having great difficulty with depression or anger, arrange for counseling to help him change the self-doubting thoughts that are leading to these negative feelings.

STRAINED FAMILY RELATIONSHIPS

At first, following a major trauma, the whole family typically becomes a very cohesive unit. All efforts are centered on the recovery of the loved one. Most members are willing to pitch in and do all they can to make him better. When it is time for him to come home, everyone is excited and hopeful.

Homecoming is something all parties are looking forward to as a return to normalcy. However, things do not get back to their original state. The family member finds that his injured spouse cannot handle the stresses of living with three teenage children. The mother finds herself being overprotective about who her injured son is going with and where he ventures. The daughter finds that having her injured mother at home is like having another child. Is it any surprise that the family relationships become strained?

On the other side, the injured party begins to see that he is not being treated as he was before the accident. At first, he may have enjoyed all the attention, but now he feels put out by the

different treatment. All he wants to do is go back to being the same person with the same family relationships, and he is sure that family members are keeping him from being his old self.

Examples

1. The injured son feels he is being treated like a child again.
2. The injured father says that his adolescent children do not listen to him or respect his opinion.
3. The injured wife believes that her husband works later at night because he does not want to be with her at home.
4. The parent is confused about what he should allow his son to do or not do.
5. The spouse is afraid to allow her injured husband to continue to keep the checkbook and take care of the family budget.
6. The son is afraid to let his injured father live alone again.

Management Techniques

1. Accept the fact that there are differences, and you cannot expect your loved one to be the same as before.
2. Remember that cognitive problems often lead to behavioral changes, so that the injured party is not completely in control of his actions and interactions. (Read Chapter 10 of this book.)
3. Remember that many of the behavioral changes are brain related and that it will require patience and understanding to accomplish an even keel within the family structure. (Read Chapter 11 of this book.)
4. Do not forget that you are entitled to your own emotional reactions. (Read Chapter 12 of this book.)
5. Consider family counseling with a professional who is familiar with head injury.
6. Join a support group that allows families and head injured individuals to meet together and discuss problem areas. Contact your local rehabilitation center for information about the nearest support group. If there is not a rehabilitation center nearby, contact the National Head Injury Foundation or your state organization for this information.

LOSS OF FRIENDS

Friendships are extremely important when one has been through the trauma of a head injury or any other major medical event. There always seem to be some people that you expect will visit at the hospital who never come. In most cases, they are afraid or fearful about seeing your loved one, and it is easier to stay away. Then there are those who visit the hospital frequently for a while, but gradually find excuses for staying away. Last, there are those who stick by the patient through the hospital stay and months after returning home, but they begin to form other friendships over time that take them away from contact with your loved one. This does not always happen, but it happens enough to be considered fairly typical. See Figure 14-1.

Is it your loved one's fault? Are you being too critical? Is it the friend's fault? No one is entirely to blame. You have family bonds and ties with your loved one, so you overlook many of the obvious problems that exist that might interfere with maintenance of a friendship. You love the person, so it does not matter if he is different. Friends expect him to be "good ole Fred" again. When he's not, they are confused.

The loss of these old friendships could be softened by finding new friends; however, that presents another problem your loved one will encounter. First, there are reduced opportunities to make new friends. Second, the reduction in social skills may affect the manner in which he interacts with new acquaintances. Third, lack of initiative or motivation may prevent him from approaching individuals. And last, his feelings of inadequacy may lead him to avoid new social contacts.

Examples

1. Your husband believes that his friends no longer call because they do not want to be associated with someone who is down and out.
2. Your teenage daughter's friends have confided in you, saying that she is unpredictable in what she says. Only her closest friends have been willing to deal with this on a regular basis.
3. Your loved one says that his friends are pleasant enough, but they do not relate to him in the same way as before.



Figure 14-1 Loss of Friends

4. Old friends call less frequently with each passing month. They promise to call, but never seem to follow through. The statement, "We'll have to get together sometime" remaining unfulfilled.

Management Techniques

1. Encourage your loved one to call friends who have not kept in touch. Maybe they need to hear from him first so that they feel comfortable renewing the friendship.
2. Allow him mobility so that he can have the opportunity to meet new people.
3. Remind him that some people have difficulty relating to those with disabilities—this is not his fault.

4. Help him to make new friends by becoming involved in a local chapter of the National Head Injury Foundation or a local support group for persons with head injuries.
5. If there is a local rehabilitation center in your community, contact them to see if they have any psychosocial skills training groups.
6. Ask one of his old friends to tell you the changes he sees, and then discuss these with the loved one at a time when you think he will be receptive.
7. Help him to cultivate a new friendship. If he has at least one new close friend he will begin to perceive himself more positively.
8. Discourage any lengthy criticism of old friends who have not remained in contact. Focusing on the negative will be counterproductive.

DIFFICULTY RETURNING TO WORK OR SCHOOL

When your loved one was in the hospital, all he talked about may have been getting back to his former job, school, or whatever he enjoyed doing prior to the head injury. One reason for this usual obsession is that returning to work or school means being well again. So, naturally, he thinks that the sooner he is back doing what he did before, the sooner that he will be cured. However, returning to any previous activity will be filled with obstacles.

For the more severe injuries with noticeable physical problems, your loved one will have to overcome or manage whatever limitations exist. The school or work environment may need to be wheelchair accessible, and modifications in both job tasks and environmental setting may be necessary. In addition, because of the extreme fatigue that follows head injury, your family member may have trouble maintaining an adequate amount of stamina to complete what is required or what he expects to be able to do. In general, the person with head injury must learn to accept these physical modifications.

In contrast, your loved one may exhibit but not accept the multitude of cognitive and behavioral deficits described in Chapters 10 and 11. He may be willing to admit to some minor memory deficits, lapses in concentration, and possibly a tendency to have trouble getting organized. However, he will very likely have difficulty understanding the impact that these admitted problems, not to mention the nonadmitted problems, will have on his performance. It is not until your loved one is obviously failing that he may be willing to change his school schedule, reduce his workload, or make other modifications that will allow for success.

The key here is that your family member can be successful. This success, however, depends on his ability to recognize the deficits and work within the existing limits of his capabilities and skills. These issues are described further in the Back to Work section of Chapter 20.

Examples

1. After 18 months in a residential treatment facility, a 15-year-old adolescent returned to a regular classroom setting. Within 6 months, she had been suspended three times and was failing the majority of her classes. A special program was necessary to get her back on track.
2. A college student returned to the junior college and found that he had to study much harder just to obtain passing grades.
3. A manager found that he had trouble keeping track of more than one major project at a time. Before his accident, he was able to keep three or four projects organized in his head at the same time.
4. A mechanic discovered that it took him twice as long to do a job, in comparison with his efficiency before the injury.

5. A factory worker found that extreme fatigue after lunch made it very difficult for him to return to work full time.

Management Techniques

1. Strongly encourage your loved one to listen to therapists who know him well enough to make an appropriate determination about his readiness to return to work or school.
2. Do not allow your own biases to interfere.
3. Remember that head injured individuals can look very good on the outside (physical appearance, general conversing, and so forth), yet not be ready to compete in the open market.
4. Be sure to prepare the classroom teachers for any special allowances that should be made for the student. If you are not sure what these are, ask a therapist to help provide this information.
5. Assist the patient in taking advantage of any available community vocational services, such as work evaluation, work hardening, adjustment training, or vocational counseling.
6. If your loved one lost his job and requires further training for which you do not have the funding, contact your local state vocational rehabilitation office for possible assistance.
7. Consider the possibility of his returning to work or school on a part-time basis. You will really be glad he did not jump in head first after you see how fatiguing part-time work has become.
8. Do not allow your loved one to stop or reduce sessions of psychosocial remediation too early. Remember, it is these skills that are the primary reasons for an unsuccessful return to work or school.
9. Have him attend courses on stress management, time management, or good study skills to assist him in acquiring all the skills he will need to reenter successfully.
10. If he is going to go to college for the first time, or even if he is going back, consider having him take only one or, at the most, two courses the first semester. Also, it is best for these classes to be during the day when he is fresh rather than at night.

LOSS OF JOB OR CAREER

The first thoughts that all family members, as well as injured patients, have is that of returning to exactly what they were doing before. If it can work out, that's great. However, other options will have to be considered in many cases. It is fairly easy to say, "Well, you can't be a mechanic anymore, but there are lots of other jobs to consider." However, it is very difficult for the person to change his whole future. Why? Many of us identify who we are with what we do, and what we do is the job we hold. Thus, it is traumatic for many people when a change is required. See Figure 14-

If your loved one is facing loss of job or career, he will experience a wide gamut of emotional responses, including depression, anger, sadness, bitterness, despair, and grief. At times, you will be able to tell the source of these reactions. At other times, he will be very difficult, but you will not know the basis of the reaction. Many people grieve for years over the loss of a specific career. When they meet new people they start by saying, "I used to be an accountant before my accident, but now I . . ." It can be a very long road to the acceptance of a new job, and the reality is that some

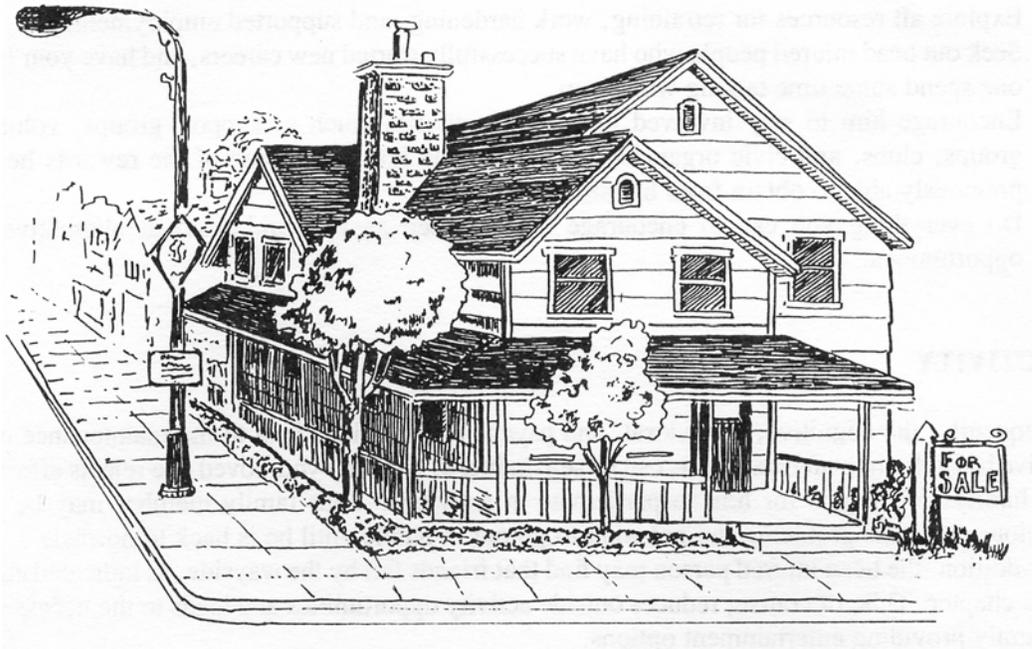


Figure 14-2 Loss of Job

individuals never get to the point at which they accept the fact that they are something or somebody different from before.

It is important that family members accept this difference so that they can help the injured person accept it. If you keep insisting that he can go back to a computer analyst job, he will never be happy in a data entry-level position.

Examples

1. A manager in a furniture company is told that he must go back on the floor as a salesman because he has been too slow in arranging the deliveries.
2. A bachelor's level graduate in psychology finds that graduate school in psychology is no longer an option.
3. A master mechanic finds that his lack of visual-spatial skills keeps him from continuing in the line of work he has been in for 15 years.
4. The man who has always loved outdoor construction jobs discovers that his physical limitations prevent him from doing any type of construction work again. He is only being offered some type of desk job inside the office.
5. The insurance company wants your loved one to go through a retraining program that works with individuals who are retarded. He completely refuses this type of help.
6. The factory worker no longer has the speed to be on a production line. The employer is considering her for the maintenance crew.

Management Techniques

1. Never push your loved one to try a job that therapists have said would be difficult for him to handle.
2. Be supportive of his feelings without allowing him to wallow in despair.
3. Encourage him to try a job that is offered, even if he is convinced it is not for him.

4. If he loses his job after trying to return, be sure he gets the psychosocial support or counseling that is needed to deal with this event.
5. Explore all resources for retraining, work hardening, and supported employment.
6. Seek out head injured people who have successfully started new careers, and have your loved one spend some time talking with them.
7. Encourage him to stay involved in outside activities, such as support groups, volunteer groups, clubs, and civic organizations, to provide him with some of the rewards he was previously able to obtain from his job.
8. Do everything you can to encourage him to keep an open mind about alternative job opportunities.

INACTIVITY

Frequently, the cognitive, behavioral, and psychosocial deficits lead to the maintenance of an inactive lifestyle. In many ways, this can be self-induced, whereby your loved one rejects efforts by both family and friends for him to participate in activities. Your family member may be self-conscious about his problems and not want to go out in public until he is back to normal.

In addition, the head injured person may find that friends fall by the wayside, as indicated earlier in this chapter. This, of course, reduces outside activity opportunities and leads to the necessity of the family providing entertainment options.

The greatest danger is that a sedentary or inactive lifestyle will become a habit that will be hard to break. It is important that you as a family attempt to increase your loved one's activity level as soon as possible and that you continually encourage him to engage in outside gatherings and contacts.

Examples

1. He wakes up at noon each day and spends the rest of the day (and into the night) watching television.
2. He refuses to go to family reunions.
3. He continually criticizes other people, using their inadequacies as an excuse to not associate with them.
4. He uses the medications as an excuse for not getting out. He says he is tired.
5. He has lost all interest in the hobbies that were important to him before the accident.

Management Techniques

1. Never take *no* for an answer—make him get up and do things with you.
2. If the TV needs repair, do not get it fixed (unless you are also a couch potato).
3. If possible, invite others over who would be good visitors to relate to your loved one.
4. Encourage him to become involved in group activities—support groups, volunteer groups, clubs, and so forth.
5. Do *not* push him into too much too soon.
6. If depression is a major factor in his inactivity, seek professional help.

Chapter 15

Substance Use I Abuse and the TBI Survivor

What's Wrong with an Occasional Drink, Toke, Snort?

Holli Bodner and Deborah Kurtz

To the health care professional:

In some cases, the life style of the head injured person or the family may predispose them to substance abuse after discharge. This is doubly dangerous; it can complicate recovery and may precipitate another injury. Careful assessment of family life style must be made to determine possible postdischarge problems of the client.

Chapter 15

Substance Use/Abuse and the TBI Survivor

What's Wrong with an Occasional Drink, Toke, Snort?

Holli Bodner and Deborah Kurtz

INCIDENCE

The circumstances are familiar to everyone, yet the details are different in each case. A high school cheerleader driving to a football game is hit by a drunk driver as she turns into the school parking lot. A 35-year-old alcoholic and substance abuser with a family history of alcoholism leaves work one Friday afternoon, has a few drinks with his buddies, hops on his motorcycle, and ends up in a ditch. A neurosurgeon toasts with one too many glasses of champagne at a wedding and falls down a flight of stairs. A twice-divorced mother of three, with a history of family alcoholism and psychiatric problems, has been barhopping and arguing with her husband, who is known for his extensive gun collection. She goes into the bedroom and impulsively shoots herself in the head.

Although all of these cases are different, each of these individuals sustained brain injury as a result of their own or another person's substance use. Although the prevalence of alcohol use is widespread in our society today, it is important to note the rise in usage of other recreational drugs as well. This chapter primarily addresses the detrimental effects of alcohol use following a traumatic brain injury because it is the drug that has most frequently been associated with head traumas.

Surveys of alcohol consumption in the general population indicate that approximately two thirds of all Americans drink at least occasionally. Interestingly, about two thirds of all people with traumatic brain injury had significant blood alcohol levels at the time of their accidents. It is also important to take into account the studies demonstrating the likelihood of a family predisposition to developing problems related to alcohol and other substances. These statistics, and the fact that alcohol has been found to complicate both the injury and the subsequent recovery, highlight the importance of accurate assessment and honest family reporting of the nature and extent of problems from the outset. This will enable the treatment team, which includes you, the family, to plan the best course of treatment for your family member. Be honest with them from the beginning.

TREATMENT CONSIDERATIONS

The problems that substance use may cause need to be considered during every stage of recovery. Although a patient who is in a coma does not require direct intervention, the family may begin to collect information regarding the effects of traumatic brain injury (TBI) and drug or alcohol use. Communication with friends and co-workers can also provide valuable information about the patient's recreational or problematic drug or alcohol use.

There are many similarities between the symptoms of intoxication and TBI. For instance, a person who has too much to drink will often exhibit slurred speech, incoordination, impaired balance, decreased reaction time, and visual-perceptual problems. In addition to these physiological changes, impaired insight and judgment and unpredictable behavior (abrupt mood swings, aggression) are frequently seen. Ironically, these physiological, cognitive, emotional, and behavioral changes are the most predominant deficits caused by a head injury. Adding alcohol to a brain that is already impaired magnifies these problems tremendously.

Complications

Nutritional, metabolic, and medical aspects are other areas essential to consider. Following a brain trauma, the body may not be able to absorb, use, and store nutrients, medications, and toxins as it once did. Alcohol or substance use further complicates the body's ability to metabolize necessary medications and nutrients. For instance, a person on medications to prevent seizures will decrease the effectiveness of the medicine if he drinks. In fact, he may increase the chance of further seizures. Medical research has shown that head injured patients who drink alcohol have more problems with epileptic seizures. As a central nervous system depressant, alcohol may combine with other medications to increase the depressant effects. As an example, we are all too familiar with reports of well-known public figures who combined alcohol and prescription drugs and accidentally overdosed.

Therapeutic Options

First, you must emphasize to the head injury survivor that he should not drink any alcohol during the first year or two following his injury. There are two main reasons for this precaution.

1. Alcohol poisons the brain. The use of alcohol may interfere with the recovery process.
2. By lowering the seizure threshold (see Chapter 13), alcohol and some drugs may cause the head injured person to have epileptic seizures.
- 3.

As a family member, you might be wondering how treatment of this very difficult problem can be incorporated into a comprehensive rehabilitation program. There are several schools of thought on how best to address the issue of substance use following a traumatic brain injury. Nevertheless, the treatment team must know when there is a history of personal or family use, when a person may have been described as a social drinker (having a few drinks on the weekend) and even when the teenager who had not yet begun to drink may return to an environment (whether at home or with peers) that encourages it. Treatment must take into consideration the individual circumstances, history, and level of functioning. There are some approaches, such as the traditional support group models (Alcoholics Anonymous) that advocate participation in their own structured program. In some cases, this may be the best treatment option. However, because individuals with a head injury often demonstrate unique cognitive problems (memory, attention and concentration, concrete thought processes), traditional approaches may not be effective unless modified to take into account the special needs of this population. It has been our experience in a

rehabilitation setting that treatment must be incorporated into the patient's daily schedule. Individual, small group, and family therapy are all important parts of the treatment program. An educational approach that recommends abstinence, random drug screenings, and the use of healthier and more effective coping strategies is also important.

Family Recommendations

If your family member is presently living at home or is soon to be discharged, the following recommendations are made:

1. Encourage him to socialize with positive role model friends who are not active users or who will not use the substance in the presence of your family member. Following a head injury, it is easy to be persuaded to go along with the crowd for better or for worse.
2. Educate family members and friends about what has happened, either by talking to them or by giving them reading material.
3. Help your family member strengthen the positive alternatives to drinking or drug use.
4. Do not have alcohol in the home, or perhaps store it in a less accessible place.
5. Be aware of your own drinking habits to help your family member maintain abstinence. It will be easier for the head injury survivor to abstain if people do not drink in his presence (at home or in restaurants).
6. When family gatherings, holidays, and other events in which alcohol will be present are coming up, discuss the situation with other family members, and perhaps have a nondrinking buddy at functions.
7. Help your family member broaden his leisure skills by investigating local head injury support groups or encouraging his participation in swimming programs, horse riding lessons, art classes, and so forth, to replace time he previously spent in drinking or drinking-related activities.
8. Keep a variety of hobbies, other interests, and activities available to help him improve his self-esteem and explore possible new areas of interest. Avoid letting your family member have too much unstructured time.
9. Allow the survivor of head injury to help with household chores to the extent that he is able. This will further enhance his self-esteem and help him feel productive, needed, and part of the family.

The question posed in the title of the chapter is "What's wrong with an occasional drink, toke, snort?" Like that of Alcoholics Anonymous, it is our belief that for a patient with a history of significant addictive behavior or a family history of addiction, one drink is all that it would potentially take to return the head injury survivor to a self-destructive cycle of addiction. Therefore, if family members or friends feel sorry for the injured person, the best way they can help is by fostering abstinence rather than encouraging a relapse or a return to problematic drinking by allowing them to drink occasionally. It has been our experience that, even after years of abstinence, non-head injured people who try to drink occasionally fall right back into problematic drinking patterns. It follows that, given their deficits as discussed in Chapters 10 and 11 of this book, the head injury survivor is at even greater risk.

In the best of all possible worlds, head injured individuals would abstain from alcohol or drug abuse, period. However, given the wide spectrum of severity of injury, combined with preinjury personality and history of other problems (psychiatric, substance abuse), some TBI individuals

will resist change in their life styles. This is particularly true if they were only so-called "social drinkers" and have no other complicating factors (seizures). For people who will not accept abstinence, we still strongly suggest a thorough education about TBI and substance use to guide the decision-making process.

There are no easy answers to either substance abuse or TBI. Both problems may go on for a lifetime, resulting in great emotional and financial costs to everyone concerned. We encourage family members and survivors to never stop trying, and to remember that a journey of a thousand miles begins with a single step.

Chapter 16

Medications and Side Effects

To the health care professional:

Everyone involved, particularly the family, must be alert to possible side effects from medications. Although this chapter presents only some of the possible medications, families should be encouraged to review it so they will be aware of what to watch for in their family member.

Chapter 16

Medications and Side Effects

During or after hospitalization, it is likely that your loved one will be treated with drugs. Although this is an important part of medical treatment, not all drugs are good for everyone. Different people may respond to the same medication in different ways. And although some are more dangerous than others, all have the potential for undesirable—sometimes serious—side effects.

Your doctor will decide whether the benefit is worth the risk. It is up to you to keep your doctor informed of all past and present drug allergies, any adverse reactions with the new medication, and all other drugs being taken—including vitamins, alcohol, and over-the-counter medications. The medications should be taken in the dosage and frequency prescribed; ask your doctor what to do if a dose is missed. The doctor should be advised immediately if someone taking drugs becomes pregnant; many drugs will affect the unborn child.

Although there are hundreds of drugs available, many share common properties and side effects with other drugs in the same class. Common drug classes are listed below in upper-case letters. Within a class, there are generic names for specific medications. Generic names are listed below in upper-case letters following the drug class. A manufacturer will have its own brand name for the same generic medication. For example, Tylenol, Datril, Anacin-3, and Excedrin all contain acetaminophen as their active ingredient. Because they have catchy names and are so widely advertised, brand names are easier to remember. Some common brand names are listed in lower-case letters and their side effects are listed under the generic and/or class headings.

The numbers following some of the listings give additional information about how the drug should be taken.

- (1) Take with food or drink.
- (2) Take on an empty stomach.
- (3) How it is taken does not matter.
- (4) Avoid or restrict alcohol.

Accutane (ISOTRETINOIN)—Used to treat severe acne. Side effects: birth defects when used in pregnant women—avoid if pregnant or if breast feeding! Eye or lip irritation (burning, itching, peeling, or redness), headache, pains in joints or muscles, sensitivity to sunburn, and skin rash. Inform your physician if you may be pregnant, are taking vitamin A, or if you have diabetes. (2,4)

ACE (ANGIOTENSIN-CONVERTING ENZYME) INHIBITORS (Capoten, CAPTOPRIL, ENALAPRIL, LISINOPRIL, Prinivil, Vasotec, Zestril)—Used to treat high blood pressure and heart failure. Side effects: appetite loss, change in taste sensation, constipation, bronchial spasm, cough, swelling, itching, rash, dizziness, low blood pressure, rapid or slow pulse, chest pain. (2)

ACETAMINOPHEN (Anacin-3, Darvocet-N, Datril, Excedrin, Tylenol)—Side effects: rare, causes liver damage in overdose. (3)

ACETAZOLAMIDE (Diamox)—Used to reduce cerebral edema, treat epilepsy, treat glaucoma, and promote fluid loss. Side effects: tingling of lips and fingers, hearing changes, stomach upset. See DIURETICS.

Adapin (DOXEPIN, see ANTIDEPRESSANTS, TRICYCLICS)

ADRENOCORTICOIDS (Decadron, DEXAMETHASONE, METHYLPREDNISOLONE, PREDNISONE, Solu-Cortef, Solu-Medrol, etc.)—Used to reduce swelling in the brain or spinal cord. Used topically for rashes. Side effects: acne, fluid retention, poor wound healing, stomach upset, and ulcers. Inform your physician if there is a history of blood clots, diabetes, glaucoma, heart disease, peptic ulcer, or tuberculosis.

ALPHA-ADRENERGIC BLOCKERS (Hytrin, Minipress, PRAZOSIN, TETRAZOSIN)—Used to treat hypertension and avoid heart failure by relaxing and expanding walls of the blood vessels. Also used to relax muscles in the bladder neck to improve voiding. Common side effects: ANTICHOLINERGIC, dizziness, drowsiness, weakness, vivid dreaming, rapid heartbeat, low blood pressure—sometimes even causing blackout spells with the first dose, bladder accidents, inability of the erect penis to relax.

AMANTADINE (Symmetrel)—Used to treat Parkinsonism and influenza type A. Side effects: rash, swelling, insomnia, dizziness, lethargy, confusion.

AMITRIPTYLINE (See ANTIDEPRESSANTS, TRICYCLICS)—Side effects: see ANTI-CHOLINERGICS, overeating.

ANALGESICS—Medications used to treat pain—from mild to severe.

ANTACIDS (Amphogel, Maalox, Mylanta, Turns)—Medications used to treat "heartburn" and stomach upset by neutralizing acid in the stomach and esophagus.

ANTIARRHYTHMICS (DIGITALIS, Lanoxin, QUINIDINE, Norpace, PRO-PRANOLOL)—A large and varied group of medications used to treat irregular beating of the heart.

ANTIARTHRITICS—Medications used to treat arthritis, including aspirin, gold, non-steroidal anti-inflammatory drugs, and others. (1)

ANTIASTHMATICS (Alupent, AMINOPHYLLINE, Brethine, Bronkosol, Theo-Dur, THEOPHYLLINE, Ventolin)—Used to prevent and relieve bronchial spasm, wheezing, or asthma.

ANTIBIOTICS (Also ANTIBACTERIALS)—A varied group of medications used to treat or prevent infections. It includes several classes. Most share common side effects: nausea, vomiting, stomach upset, diarrhea, allergic reactions, and rash.

ANTICHOLINERGICS—Side effects: dry mouth, dry eyes, blurred vision, constipation, nausea, vomiting, difficulty urinating, fatigue, headaches, insomnia, confusion, hallucinations,

rapid pulse. Problems with asthma, bronchitis, glaucoma, heart disease, liver disease, myasthenia gravis, peptic ulcers, or prostate may be worsened.

ANTICOAGULANTS—Used to reduce blood clots. (Oral types: **Coumadin, DICUMAROL, WARFARIN SODIUM**) Side effects: bleeding! Bleeding may be obvious or hidden, such as showing up in the stomach with dark stools. This class interacts with many other classes to affect the ease of bleeding as well as the other drug's effect. **HEPARIN** is an anticoagulant given intravenously or by injection. Its primary side effect also is bleeding. Other side effects: dark stools or urine, easy bruising, fatigue, fever, hair loss, nausea, sore throat, rash, yellow jaundice. (2,4)

ANTICONVULSANTS (CARBAMAZEPINE, Depakene, Depakote, Dilantin, Paradione, PHENOBARBITAL, PHENYTOIN, Tegretol, VALPROIC ACID)—Used to treat and prevent epileptic seizures. Side effects: dizziness, drowsiness, interactions with other medications, rash. See specific drug for other side effects.

ANTIDEPRESSANTS, MONAMINE OXIDASE INHIBITORS (ISOCARBOXAZID, PAR. GYLIN, PHENELZINE, TRANLYCYPROMINE, Eutonyl, Marplan, Nardil, Parnate)—Used to treat depression. Side effects: see ANTICHOLINERGICS, dangerously high blood pressure if interacting with other drugs, dizziness, swelling. Consult your physician about the many foods with which the medications can react.

ANTIDEPRESSANTS, TRICYCLICS (AMITRIPTYLINE, Desyrel, DOXEPIN, Elavil, Endep, FLUOXETINE, NORTRIPTYLINE, Pamelor, Prozac, TRAZODONE)—Used to treat depression, pain due to nerve damage, and sometimes bedwetting or insomnia. Side effects: see ANTICHOLINERGICS, fatigue, change in appetite or weight, constipation, dizziness, drowsiness, confusion, dry mouth, headache, tremors, hallucinations, insomnia, irregular heartbeats, itching, rash, seizures, sore throat, yellow jaundice due to effect on the liver. See specific drug for additional effects. It may take 3 weeks to obtain a significant effect from the medication. There may be interactions with several other types of medications. (3,4)

ANTIEMETICS (Compazine, Dramamine, Phenergan, Reglan, Vistaril)—Used to treat motion sickness, nausea, and vomiting. Side effects: see ANTICHOLINERGICS, drowsiness, abnormal eye or facial movements.

ANTIFUNGALS—A varied group used to treat fungal infections of the skin or within the body. They have few side effects when used topically (on the skin), but many side effects when used for severe internal infections.

ANTIHISTAMINES (Atarax, Benedryl, CHLORPHENIRAMINE, DIPHENHY-DRAMINE, Seldane, and many others)—Primarily used to treat allergies, itching, rashes, and insomnia.

ANTIHYPERTENSIVES—A wide variety of drugs used to treat high blood pressure. Primary groups include **ACE INHIBITORS, ALPHA BLOCKERS, BETA BLOCKERS, CALCIUM CHANNEL BLOCKERS, DIURETICS, VASODILATORS.**

ANTIINFLAMMATORY MEDICATIONS (See ASPIRIN, NSAIDs, ADRENOCORTICOIDs) (1)

ANTIPARKINSONIANS (AMANTADINE, BENZTROPINE, Cogentin, Eldepryl, L-DOPA or LEVODOPA, Sinemet)—Used to treat abnormal movements, rigidity, slowness, or tremor seen in Parkinson's disease and sometimes in brain injury.

ANTI PRURITICS (See ANTIHISTAMINES)—Used to treat itching.

ANTIPSYCHOTICS (CHLORPROMAZINE, Haldol, HALOPERIDOL, Mellaril, Navane, THIORIDAZINE, THIOTHIXINE, Thorazine)—Used to reduce severe anxiety, agitation, and psychotic behavior. Side effects: see ANTICHOLINERGICS, abnormal movements of face,

limbs, or tongue, constipation, dizziness, drowsiness, interactions with many drugs, jaundice, restlessness. (4)

ANTIPYRETICS (ACETAMINOPHEN, ASPIRIN, Tylenol)—Used to treat fever.

ANTISPASMODICS (Bentyl, Dicyclomine)—Used to treat bladder spasms, intestinal cramp, and irritable bowel. Side effects: see ANTICHOLINERGICS.

ANTISPASTICITY MEDICATIONS (See BACLOFEN, BENZODIAZEPINES, Dantrium)—A group of medications used to reduce muscle cramps and spasms.

ANXIOLYTICS (See ANTIPSYCHOTICS, BENZODIAZEPINES)—Used to reduce anxiety and nervousness.

ASPIRIN (Anacin, Bayer, Bufferin, Ecotrin, Empirin, and many others)—also a component in various combination medications—Used to reduce fever, inflammation, joint stiffness, swelling, and pain of various types. Side effects: black stools, heartburn, indigestion, nausea, stomach pain, ulcers, vomiting, ringing in the ears. Rare, but dangerous, are severe allergic reactions and, in children, Reye's syndrome—confusion, coma, kidney and liver damage. (1)

Ativan (LORAZEPAM, see BENZODIAZEPINES) (3,4)

Axid (NIZATIDINE)—Uses and side effects: see H2 BLOCKERS.

BACLOFEN (Lioresal)—Used to relieve muscle cramps and spasms; sometimes used to reduce hiccoughs or pain. Side effects: confusion, dizziness, drowsiness, lightheadedness, nausea, numbness and tingling, rash, weakness of muscles. (3)

BETA BLOCKERS (Corgard, Inderal, PROPRANOLOL, NADOLOL, Tenormin and others)—Used to lower blood pressure, stabilize an irregular heartbeat, reduce angina, reduce the frequency of migraine headaches, and reduce agitation after head injury. Side effects: cold hands and feet, constipation, depression, diarrhea, dizziness, drowsiness, dry eyes or mouth, fatigue, nausea, low blood pressure, slow pulse, tingling of hands and feet, weakness. Do not stop this medication suddenly.

BARBITURATES (PHENOBARBITAL, SECOBARBITAL, and others)—A group of strong sedatives used also for treatment of epilepsy. (4)

BENZODIAZEPINES (ALPRAZOLAM, Ativan, Dalmane, DIAZEPAM, Doral, FLURAZEPAM, Halcion, Librium, LORAZEPAM, OXAZEPAM, QUAZEPAM, Restoril, Serax, TEMAZEPAM, TRIAZOLAM, Valium, Xanax)—Uses: mild tranquilizers for anxiety, nervousness, and tension; muscle spasm; and acute treatment of epileptic seizures. (3,4)

BUMETANIDE (Bumex)—Uses: see DIURETICS, a strong "fluid" pill used to reduce fluid retention (edema). Side effects: cramps, dehydration, fatigue, irregular heartbeats, unsteadiness, weakness.

BUPROPIN (See Wellbutrin)

Butazolidin (PHENYLBUTAZONE, see NSAIDs)

Calan (VERAPAMIL, see CALCIUM CHANNEL BLOCKERS)

CALCIUM CHANNEL BLOCKERS (Calan, Cardizem, DILTIAZEM, Isoptin, NIFEDIPINE, Procardia, VERAPAMIL)—Used to prevent angina attacks and hypertension by reducing spasm of blood vessels. Also used to stabilize irregular heartbeats. Side effects: constipation, dizziness, nausea, headache, swelling, slow heart rate, low blood pressure, shortness of breath, fatigue, rash, soreness and swelling of the breasts.

CARBAMAZEPINE (Apo-Carbamazepine, Mazepine, Tegretol)—Used to treat and prevent epileptic seizures. Side effects: blurred vision, nausea, vomiting, diarrhea, confusion, slurred speech, headache, rash, sensitivity to sunlight. A rare side effect is a lowering of blood counts

causing easy bleeding or bruising, excessive fatigue, sore throat, fever. Alcohol increases the sedation. (1,4)

Cardizem (DILTIAZEM), see CALCIUM CHANNEL BLOCKERS)

Capoten (CAPTOPRIL), see ACE INHIBITORS, ANTIHYPERTENSIVES)

CIMETIDINE (Tagamet)-Uses and side effects: see H2 BLOCKERS.

CIPROFLOXACIN (Cipro), see ANTIBIOTICS)—Side effects: abdominal pain, diarrhea, headache, nausea, rash, vomiting.

Clinoril (SULINDAC), see NSAIDs) (1)

Corgard (NADOLOL)—Uses and side effects: see BETA BLOCKERS.

Coumadin (WARFARIN SODIUM)—Used to prevent and treat blood clots. See ANTI-COAGULANTS. Notify your physician of any medication changes and take the medication 1 hour before or 2 hours after eating. (2,4)

Dalmane (FLURAZEPAM)—Uses and side effects: see BENZODIAZEPINES. With prolonged use, can accumulate causing overdose. (3,4)

DANTROLENE SODIUM (Dantrium)—Used to relieve muscle spasticity caused by conditions such as head injury, multiple sclerosis, spinal cord injury, and stroke. Side effects: abdominal pain, appetite loss, blurred vision, confusion, constipation, depression, diarrhea, difficulty with erection or emptying the bladder, headache, hepatitis, insomnia, rapid pulse, rash, sore muscles and back. It should not be used by people with liver disease such as cirrhosis or hepatitis. (1,4)

Decadron (DEXAMETHASONE PHOSPHATE)—Uses and side effects: see ADRENOCORTICOIDS. Commonly used after head injury to reduce brain swelling.

Depakene (See VALPROIC ACID)

Depakote (See VALPROIC ACID)

Desyrel (TRAZODONE)—Uses and side effects: see ANTIDEPRESSANTS, TRICYCLICS.

DIAZEPAM (Valium), see BENZODIAZEPINES)

DICUMAROL (See ANTICOAGULANTS)

Didronel (ETIDRONATE DISODIUM), see DIPHOSPHONATES)

Dilantin (PHENYTOIN)—Used to prevent and treat epileptic seizures. It is also used to stabilize irregular heartbeats. Side effects: blurred vision, bruising, confusion, constipation, diarrhea, dizziness, drowsiness, hallucinations, headaches, increased body or facial hair, jumping movements of the eyes (nystagmus), nausea, rash, slurred speech, staggering, swollen gums, vomiting. Many of these side effects are signs of overdose. The medication interacts with many other drugs and vitamins to cause other side effects.

DIPHOSPHONATES (Didronel)—Used to prevent or treat heterotopic ossification (HO). HO is the abnormal formation of bone in areas that usually have only muscle. It usually occurs around joints and can restrict motion and cause pain. Also known as myositis ossificans, it can be seen following head injury, spinal cord injury, hip replacement, and some other medical conditions. This medication is also used to treat osteoporosis (thinning of the bones). Side effects: constipation, diarrhea, stomach upset, and, rarely, rash and swelling. No food should be eaten within 2 hours of dosing. (2)

DIURETICS (Bumex, Dyazide, FUROSEMIDE, HYDROCHLOROTHIAZIDE, Lasix, Maxzide, TRIAMTERENE)—Water pill used to reduce fluid retention (edema) and treat high blood pressure (hypertension). Side effects: blurred vision, bleeding or bruising, dizziness, fatigue, low blood pressure, rash, lightheadedness, nausea, vomiting, weakness, stomach pain, thirst, yellow jaundice. There may be interactions with other drugs.

Doral (QUAZEPAM), see BENZODIAZEPINES)

DOXEPIN (**Adapin, Sinequan**, see ANTIDEPRESSANTS, TRICYCLICS)

Elavil (**AMITRIPTYLINE**, see ANTIDEPRESSANTS, TRICYCLICS)

FAMOTIDINE (**Pepcid**, see H2 BLOCKERS)

Flexeril (**CYCLOBENZAPRINE**)-Used as muscle relaxant. Side effects: ANTI-CHOLINERGIC, depression, unsteadiness, drowsiness.

FLUOXETINE (**Prozac**, see ANTIDEPRESSANTS, TRICYCLICS)

FLURAZEPAM (**Dalmane**, see BENZODIAZEPINES)—Promoted for sleep. May accumulate and cause sedation if used regularly.

FUROSAMIDE (**Lasix**, see DIURETICS)

H2 BLOCKERS (**CIMETIDINE, FAMOTIDINE, Pepcid, RANITIDINE, Tagamet, Zantac**)—Used to treat and prevent peptic ulcers by reducing acid production by the stomach. Side effects: breast swelling or soreness in men, confusion, decreased sex drive or impotence, diarrhea, dizziness, hair loss, muscular pains. Rare side effects that necessitate calling the doctor right away: unusual bleeding or bruising, unusual fatigue, fever, sore throat. H2 blockers can interact with many other medications, and usually increase their effects. (3)

HALOPERIDOL (**Haldol**, see ANTIPSYCHOTICS)

HYDROCHLOROTHIAZIDE (**Dyazide, Maxzide**, see ANTIHYPERTENSIVES, DIURETICS)

HYDROXYZINE (**Vistaril**, see ANTIHISTAMINES)—Used to relieve anxiety as well as itching.

Hytrin (**TETRAZOSIN**, see ALPHA BLOCKERS, ANTIHYPERTENSIVES)

IBUPROFEN (**Advil, Motrin, Rufen**, etc., see NSAIDs)

INDOMETHACIN (**Indocin**, see NSAIDs)

INSULIN (**Regular, Lente, Ultralente, NPH, Humulin**, etc.)—Injectable medication used to control diabetes.

Isoptin (**VERAPAMIL**, see CALCIUM CHANNEL BLOCKERS, ANTIHYPERTENSIVES)

ISOTRETINOIN (**Accutane**)—Used to decrease cystic acne formation in severe cases by reducing size and activity of sebaceous glands. Side effects: dry mouth, eye burning/redness or itching, joint or bone pain, hair thinning, fatigue, lip scaling, abdominal pain. Avoid vitamin A while on the medication. Because it causes birth defects, it must not be used during pregnancy. (1,4)

Lasix (**FUROSAMIDE**, see DIURETICS)—If you are allergic to sulfa drugs, you may also be allergic to this strong fluid pill.

LEVODOPA (**Larodopa, Sinemet**)—Used to treat Parkinsonism. Side effects: depression, fainting, mood changes, upset stomach, ANTI-CHOLINERGIC effects, involuntary movements.

Lioresal (See BACLOFEN)

LITHIUM (**Carbolith, Eskalith, Lithane, Lithobid, Lithotabs**)—Used to treat manic-depressive psychiatric illness and manic behaviors following head injury such as hyperactivity, aggressiveness, and a reduced need for sleep. It works by normalizing mood and behavior. Side

effects: confusion, dizziness, drowsiness, dry mouth and increased thirst, decreased sexual function, increased urination, hand tremors, diarrhea, nausea, vomiting, weakness. Notify the physician right away if you note balance problems, blurred vision or loss of vision, rash, stomach pain, or a very large urine output. There are many drug reactions. Salt should not be restricted. (1,4)

LORAZEPAM (Ativan, see BENZODIAZEPINES)

MANNITOL—An injectable medication used to reduce brain swelling (cerebral edema) in the early stages after head injury.

Meclomen (MECLOFENAMATE, see NSAIDs) (1)

MEPERIDINE (Demerol, see NARCOTIC ANALGESICS)

METHICILLIN (See ANTIBIOTICS)

METHYLPREDNISOLONE (Depo-Medrol, Depo-Predate, Medrol Acetate, see ADRENOCORTICOID)

METOCLOPRAMIDE (Reglan)—Used to speed passage of food through the stomach and reduce nausea. Side effects: confusion, drowsiness, jerking movements of face, head muscle spasms, tremors.

Minipress (PRAZOSIN, see ALPHA BLOCKERS, ANTIHYPERTENSIVES)

MORPHINE SULFATE (See NARCOTIC ANALGESICS)

Mysoline (PRIMIDONE, see ANTICONVULSANTS)

NAPROXEN (Naprosyn, see NSAIDs) (1)

NARCOTIC ANALGESICS—Used to relieve moderate to severe pain. Side effects: see ANTI-CHOLINERGICS, confusion, dizziness, drowsiness, constipation, nausea, vomiting, sweating, headache, weakness, and addiction with long-term use—more than 2 weeks.

NITROFURANTOIN (Macrofantin, see ANTIBIOTICS)—Commonly used for bladder/urinary tract infections. May commonly color urine a brown or rusty color. Contact your physician for these symptoms: diarrhea, nausea, vomiting, chest pain or breathing difficulty, numbness or tingling of skin or limbs, unusual weakness or fever. (3,4)

NITROGLYCERIN (GLYCERYL TRINITRATE, Nitro-Bid, Nitro-Dur, etc.)—Used to prevent or treat angina attacks of heart pain. Side effects: dizziness, flushing, bad headaches, nausea, vomiting, rash, low blood pressure. (3)

NORFLOXACIN (Noroxin, see ANTIBIOTICS)

NSAIDs, Nonsteroidal anti-inflammatory drugs (Advil, Butazolidin, Clinoril, DICLOFENAC, DIFLUNISAL, Dolobid, Feldene, IBUPROFEN, Indocin, INDOMETHACIN, MECLOFENAMATE, Meclomen, MEFENAMIC ACID, Motrin, Naprosyn, NAPROXEN, PHENYLBUTAZONE, PIROXICAM, Rufen, SULINDAC, Tolectin, Tolmetin, Voltaren)—Used as a general pain reliever as well as to treat the stiffness, swelling, and joint pain of arthritic conditions. Some must be taken several times daily, some once daily. Side effects: abdominal pain, constipation, heartburn, nausea, stomach upset, ulcers, dizziness, headache, fluid retention. Prolonged use is more likely to cause stomach problems and may lead to kidney problems. PHENYLBUTAZONE causes more blood problems, including fatal aplastic

anemia (failure of the bone marrow to produce blood cells) than the other drugs. DICLOFENAC causes more liver problems than the other drugs. (1,4)

NYSTATIN (Candex, Mycostatin, Milstat, etc.)—Used to treat fungus infections such as thrush involving the mouth or throat. Side effects: diarrhea, nausea, vomiting, stomach pain.

OXAZEPAM (Ox-Pam, Serax, see BENZODIAZEPINES)

OXYCODONE (Lorcet, Percocet, see NARCOTIC ANALGESICS)

Pavulon (PANCURONIUM BROMIDE)—Used to temporarily paralyze muscles so that emergency life support measures can proceed more smoothly.

Pepcid (FAMOTIDINE, see H2 BLOCKERS)

PHENOBARBITAL (See ANTICONVULSANTS)—Used to prevent or treat epileptic seizures. Side effects: confusion, dizziness, drowsiness, depression, slurred speech, diarrhea, nausea, vomiting, rash, swelling of the eyelids, muscle or joint pain. There are many interactions with other medications—many producing dangerous oversedation. Avoid alcohol. (1,4)

PHENYTOIN (See ANTICONVULSANTS, Dilantin)—Used to prevent or treat epileptic seizures.

PRAZEPAM (Centrax, see BENZODIAZEPINES)

PREDNISONE (See STEROIDS)

PREDNISOLONE (See STEROIDS)

PRIMIDONE (Mysoline, Sertan, see ANTICONVULSANTS)

Prinivil (LISINAPRIL, see ACE INHIBITORS)

Procardia (NIFEDIPINE, see CALCIUM CHANNEL BLOCKERS)

QUAZEPAM (Doral, see BENZODIAZEPINES)

Reglan (See METOCLOPRAMIDE)

Restoril (TEMAZEPAM, see BENZODIAZEPINES)

Sinemet (CARBIDOPA and LEVODOPA, see LEVODOPA)—LEVODOPA is combined with another medication to reduce its side effects.

Sinequan (Doxepin, see ANTIDEPRESSANTS, TRICYCLICS)

STEROIDS (See ADRENOCORTICOIDS)

SULCRAFATE (Carafate)—Used to treat peptic ulcers by coating the ulcer site and protecting it from stomach acid. Side effects: abdominal pain, constipation, indigestion, nausea, vomiting, dizziness, sleepiness, rash. It will absorb other medications so it should be taken 1 hour before meals and at bedtime—at least 2 hours apart from other medications. (2)

SULFA DRUGS (SULFAMETHOXAZOLE, Bactrim, Gantrisin, Septra, SULFISOX-AZOLE, see ANTIBIOTICS)—For those who are very allergic, some sulfa drugs that are not antibiotics include DISULFURAM (Antabuse), FUROSAMIDE (Lasix), and SULFONUREA drugs used for treatment of diabetes. Side effects of the antibiotics include: appetite loss, diarrhea, nausea, vomiting, dizziness, headache. Contact your physician right away for rash, peeling,

blistering, painful urination, unusual bruising, fatigue, sore throat, or fever—which could reflect an effect on the blood count. It can increase the effects of alcohol. (2)

SULINDAC (Clinoril, see NSAIDs)

Symmetrel (See AMANTADINE)

Tagamet (CIMETIDINE, see H2 BLOCKERS)

Tegretol (CARBAMAZEPINE, see ANTICONVULSANTS, CARBAMAZEPINE)

TETRACYCLINE (See ANTIBIOTICS)—Side effects: abdominal pain, diarrhea, nausea, vomiting, headaches, sore mouth and tongue, itching around rectum and genitals due to development of a fungal (yeast) infection. It may make the skin extra sensitive to sun. It can interact with other drugs and foods. (2,4)

THEOPHYLLINE (Slophyllin, Theo-Dur, Theolair)—Used for bronchial asthma. Side effects: seizures, anxiety, confusion, irregular heartbeat, stomach upset. It is better absorbed if taken on an empty stomach, but can be taken with food to lessen stomach upset.

TRAZODONE (Desyrel, see ANTIDEPRESSANTS, TRICYCLICS)

TRIMETHOPRIM (Trimplex, Bactrim, Septra, see ANTIBIOTICS)—Side effects: headache. See physician if rash, breathing trouble, blue lips, or blue skin develop. (3)

Valium (DIAZEPAM, see BENZODIAZEPINES)

VALPROIC ACID (Depakene, Depakote, see ANTICONVULSANTS)—Used to treat and prevent epileptic seizures. Side effects: irregular menstruation, depression, emotional changes, headache, incoordination, rash, hair loss, nausea, vomiting, abdominal pain, easy bruising or bleeding, liver damage, lethargy, weakness. It can interact with other anticonvulsants to change their effect and with several other medications. (1,4)

Vasotec (ENALAPRIL, see ACE INHIBITORS)

VERAPAMIL (Calan, Isoptin, see ANTIHYPERTENSIVES, CALCIUM CHANNEL BLOCKERS)

Voltaren (DICLOFENAC, see NSAIDs)

WARFARIN SODIUM (Coumadin, see ANTICOAGULANTS)

Wellbutrin (BUPROPIN)—Used to treat depression. Its side effects are similar to the TRI-CYCLICS, but there are fewer ANTICHOLINERGIC and sedative effects as well as less sexual dysfunction. It does not affect heart rate or cause weight gain. Other side effects include appetite loss, constipation, dizziness, headache, insomnia, psychotic reactions, seizures, and weight loss. The incidence of seizures is higher than with the tricyclic antidepressants.

Xanax (ALPRAZOLAM, see BENZODIAZEPINES)

Zantac (RANITIDINE, see H2 BLOCKERS)

Zestril (LISINOPRIL, see ACE INHIBITORS)

Chapter 17

The Family as Educator

To the health care professional:

Primarily addressing relationships with others after discharge, it is well to introduce the concept of the family as an educator early in the recovery process, at least by the time of discharge planning.

Chapter 17

The Family as Educator

You may be a little confused by this title, because the main focus of the other chapters of this guide is to educate you, the family. However, now that you are learning about this special disability, you have gained both academic and personal knowledge that you may need to offer to other significant people in your loved one's life. These others include attorneys, teachers, employers, physicians, and insurance companies. Some of these significant individuals may have extensive experience with the head injury field, but others may be new to this type of information. Even if they are experienced with head injury, never assume they know everything there is to know. One thing that can be helpful is to provide them with selected chapters from this guide as you determine the information they need to know. Also, the selections listed in the Bibliography can help provide additional resources for them.

ATTORNEYS

If and when you find the need for legal services regarding your family member, it is most important that you choose an attorney who is intimately aware of head injury. You may already have a family or business attorney. Determine if they have the appropriate experience and, if not, ask them to refer you to someone who is known for expertise in this area. If you find yourself dissatisfied with the legal advice, you can obtain additional referrals from the national or local head injury chapters.

TEACHERS

Classroom teachers have excellent training in regard to normal child development and normal type of instruction. Special education teachers should possess this knowledge plus specialty skills for adequately educating a variety of exceptional students. Refer to the Back to School section in Chapter 20 for a detailed discussion of these various special education areas. Unfortunately, because the federal and state departments of education do not yet recognize a separate category for head injured students, many teachers trained in special education do not undertake any formalized courses in this body of knowledge.

After the school system has determined how they can best serve your head injured child, it may be important for you to provide specialized information to the specific teacher. Do not assume this educator will have the needed facts, and do not be afraid that they will be offended if you bring them information. A good teacher is able to admit to the need for assistance in this field. The National Head Injury Foundation has written a manual for educators that can be ordered from

them. Other manuals, such as *Teaching the Head Injured: What To Expect*, are listed in the Bibliography. Read this information yourself, and then share it with school personnel who are involved in planning your child's education.

EMPLOYERS

Employers, and many others, are often fooled by the deceptively good presentation made by the head injured individual. On the one hand, this is a positive attribute because each of us wants to look our best and make a good impression with a prospective employer. Getting a job is not generally going to be your loved one's main problem; keeping his job may be something of constant concern.

If your loved one is returning to his former company, it is important that they be informed of the differences that may exist so that they will not expect the head injured victim to be completely back to normal. This is further complicated by the fact that the patient himself may not believe there are differences, and he will be greatly offended if you or anyone else conveys this "inaccurate" information to his employer. There is no cut and dried answer to this dilemma, yet it is important that the job supervisor have at least some awareness of the possibility of potential problems. This can best be communicated by a therapist who has worked with your family member. However, if you know this employer or feel comfortable talking to him, it would be helpful to provide your input. Also, if the employer does rehire your loved one, it is very important for the boss to agree to contact either family or professionals before considering termination.

The situation is even more difficult when the job is new and the employer is not familiar with your loved one. Many questions arise regarding the best approach. Should the employer be approached with twenty things that might go wrong on the job? Should the issue of deficits be addressed only after he has secured and already started the job? Should you wait until something goes wrong? Obviously, there is no single answer to these questions. Those of us who work in the treatment of head injury have generally discovered that it is better to provide at least a minimum amount of information up front about potential cognitive effects, such as possible problems that may be caused by interference, decreased concentration, and memory deficits.

You, as family members, can encourage your loved one to recognize and share his problems with the employer. A cognitive therapist, behavior specialist, or vocational counselor can assist him in how to best present this information to minimize negative effects.

PHYSICIANS

Most doctors, regardless of their specialty, will have adequate knowledge regarding the physical effects of head injury, including problems demonstrated on CT scans, headaches, seizures, orthopedic issues, dizziness, and vision difficulties. Their intimate awareness of the more subtle cognitive issues, however, is more the exception than the rule. With the help of your physiatrist (doctor with specialty in rehabilitation) as well as rehabilitation therapists, the family may need to inform other doctors of these thinking or behavior problems. Remember, a doctor cannot know everything about every field—you can help him understand by being explicit about what is going on. Never assume that he knows "head injury behavior."

INSURANCE COMPANIES

Insurance companies operate in different ways in their management of head trauma cases. If the injury has been severe or the company is large, they will probably have a registered nurse

(RN) on the case, and the RN will most likely have a specialty in rehabilitation. As long as your loved one needs medical management, this nurse will maintain contact. In most cases, this person will be knowledgeable in head injury deficits and will not need additional education.

If, however, there is not a nurse on the case, your loved one's services may be administered by a claims representative for the insurance company. The level of expertise for this individual can vary widely—from having already handled twenty-plus head injury cases to your case being his first. In the latter instance, it is important that this individual understand the cognitive and behavioral issues as they relate to returning to work, school, or life in general. Do not be afraid to share with this individual your knowledge or the materials that you have found helpful.

Although it was never your plan, you have become an expert in the field by virtue of having a head injured family member. Do not feel afraid or hesitant to share this information with those who are significant to your loved one's rehabilitation progress.

Chapter 18

Special Considerations for Children

To the health care professional:

No two head injuries are alike for children. More importantly, young children cannot be grouped with adolescents, because brain injury at different ages will have different manifestations and implications for treatment.

Chapter 18

Special Considerations for Children

NEUROANATOMY

Children are not just young adults. Their brains are very different, and this has implications in their recovery from brain injury.

The child's brain is a developing brain. The brain began forming in the womb as a mass of cells (astrocytes). As the brain matures, some cells drop out, but connections develop between the nerve cells (neurons) that remain. Dendrites (branches) form to take in information, and a single axon (core of a nerve fiber) exits the cell body to transmit information to other neurons. With maturity, glial cells grow around the axons of the mass of cells and "coat" them with myelin (a material that forms a protective sheath). The neuron transmits electrical messages along its dendrites, cell body, and axon just as a wire carries an electrical message. The myelin keeps the electrical impulse from exiting the nerve and allows the message to be carried along faster. Becoming more mature is then a process of developing more and more interconnections between fewer and fewer neurons. It is also a process of insulating certain neurons so their message will be transported more quickly.

This process occurring among the brain cells is reflected in the maturing of the child. At birth, the child is helpless, barely able to hold up its head, and capable of only such basic acts as sucking and crying. Reflexes make up most of the child's behaviors. As the child grows, he becomes capable of doing more and more. These "milestones" occur at fairly typical ages. See Table 18-1.

The skull surrounding the brain is also maturing. All bones start out as soft cartilage. They gradually harden as calcium is deposited within this structure. Many bones start out in several parts that ultimately grow together and fuse. The long bones of the arms and legs, for example, are in three parts that fuse together in adulthood.

Likewise, the skull is made up of several plates. There are sutures separating the bony plates—both longitudinally (front to back) and transversely (side to side). Blockage of the circulation of cerebrospinal fluid (CSF) in a baby shows up with enlarging head size, bulging of the soft spot or fontanelle, separation of the cranial bones, as well as other adult manifestations that include nausea, vomiting, and drowsiness. Normally, the plates fuse at approximately age 2 years, but untreated hydrocephalus (fluid on the brain) will interfere with this fusing. See Figure 18-1.

REHABILITATION ISSUES

Because the brain and the child's responses are different at different ages, the same brain injury will have different manifestations and different implications for treatment. This must be

considered by the rehabilitation team. Goals must be based on, and progress measured against, expected

Table 18-1 Motor and Cognitive Milestones

<i>Age</i>	<i>Act</i>
1 month	Head holding, prone
3 months	Head holding, supine
5 to 9 months	Sitting up
6 to 12 months	Crawling
9 to 16 months	Walking
12 to 18 months	First words

developmental sequences for a child of that age. For example, because the young child is not capable of sophisticated communication, it is often difficult to tell when posttraumatic amnesia (PTA) ends. Also, the child is capable of performing less sophisticated behaviors than an adult. The young child cannot be expected to participate in formal therapy, but must be approached through structured play and manipulative activities, with gradually increasing demands as cognition improves.

Adolescents present a special challenge. Although young children take direction from adults relatively easily, adolescents often wish to be self-directing. They will frequently resist an adult's suggestions, just because the ideas are not their own. They will resist activities that do not relate to their own immediate goals. This normal adolescent resistance increases due to the cognitive deficits of head injury. Particularly problematic is anosognosia (the inability to recognize the presence and significance of one's own deficits), largely caused by a right parietal lobe, or sometimes bifrontal, injury. Anosognosia may show up in the form of poor judgment. For example, adolescents may wish to drive when they cannot do so safely. They may drink or use drugs even though they know these substances increase the risk of seizures and can dull judgment that is already impaired. They may act out sexually in unsafe ways even though they know about AIDS and other venereal

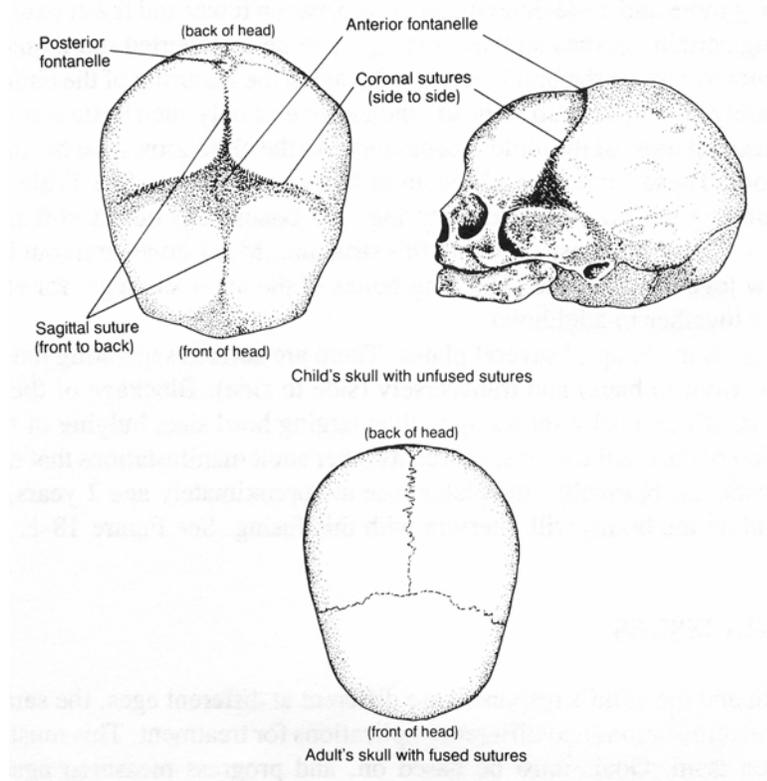


Figure 18-1 Views of a Normal Skull of a Child (Top) and a Normal Skull of an Adult (Bottom)

diseases. One must make special efforts to carefully define and link short-term rehabilitation goals to the patient's long-term goals, and then urge them to accept responsibility for the success of their own rehabilitation program. It is important that the adolescent find motivation other than "reminders" from parents and other adults, which the teenager will resent and resist.

PROGNOSIS

Whether it is because the brain is developing and has more potential for change (plasticity) or it is for other reasons, physicians have long felt that a child's brain could absorb a more severe injury than an adult's brain. Classically, this is seen in reports of cold water drowning in children. Despite 30 or more minutes of oxygen deprivation, some children can still emerge from coma and, eventually, walk out of the hospital.

Yet, although better motor recovery is frequently observed in children, there may be devastating cognitive effects. Disruption in the ability to learn new information at a young age because of head injury may ultimately lead the individual, as an adult, to possess a more limited fund of knowledge than he would if he had suffered the head injury after age 18.

Certainly, the majority of children surviving severe brain injury and prolonged coma are capable of good functional recovery—ambulation and self care—with proper rehabilitation. Nevertheless, there is a consensus that long-term impairment after serious brain injury is not rare—just unrecognized. Classically, the child emerging from severe brain injury has more impairment of performance and motor skills than language. Later, the child may be found to have subtle cognitive deficits, learning disabilities, or behavioral problems, all of which show up in school. Dealing with these requires a concerted effort between an alert parent, a dedicated teacher, and a perceptive psychologist. The team must be aware that children often have *preinjury* deficits

in attention, learning, and behavior that limit the ultimate rehabilitation potential. Also, teachers and parents must be attentive to emotional and social interactions between the child and his peer group at home and at school.

SEIZURES

There are significant differences between adults and children when the effect of seizures is considered. Seizures are frequent in the early period of brain trauma in the child. Yet, late recurrent seizures (posttraumatic epilepsy) are only half as common in children as adults. The social problems with late seizures are also not as significant in children. For example, there is less concern about social embarrassment and accidental injury. Children are not concerned with the loss of driving privileges or the loss of a job. For these reasons, one must think carefully before committing a child to long-term use of anticonvulsants. Whichever drug is chosen, none will cure the underlying condition and, if anything, will only suppress the incidence of late epileptic seizures. Of even more concern are the side effects of the anticonvulsants (see Chapter 16). For example, Phenobarbital causes sedation and slows thought processes. Dilantin slows thought processes less, but is associated with frequent rashes, gum hypertrophy, and abnormal bone growth. Tegretol causes the least sedation, but can produce blurred vision, and low blood-cell counts, the latter requiring regular blood tests to monitor for side effects. Depakene is also less sedating, but requires blood tests to follow its effects on the liver. Whichever drug is used, the parents should not suddenly stop anticonvulsant medications without consulting the physician, as this can precipitate seizures.

OTHER MEDICAL ISSUES

One infrequent event that can cause seizures and other problems is hydrocephalus—fluid on the brain (discussed in Chapter 13). Although uncommon—less than 1 of children develop hydrocephalus—parents must be aware of its symptoms and the signs that usually show up in the first year. Parents need to be aware of the symptoms discussed above, and in Chapter 13 and also in Chapters 2 and 4. These include drowsiness, loss of vision, crossed eyes, headaches, nausea, vomiting, bulging of the opening in the skull, enlarged head, and separation of the cranial sutures.

Trauma to the pituitary gland can result in different problems for children than for adults. Deficiency of growth hormones can lead to delayed growth, and other hormonal abnormalities lead to precocious (early) puberty. Excessive urination and extreme thirst (diabetes insipidus) occur in approximately 3 of severely brain injured children. It is also caused by injury to the pituitary gland or the hypothalamus, and is treated with medications. Later development of overeating can also be due to injury to the hypothalamic appetite center.

Problems with double vision (diplopia) are caused by injury to cranial nerves (especially the third and sixth). See Figure 18-2. Injury to the third nerve causes the pupil to enlarge (mydriasis), the lid to droop (ptosis), and the eye to turn outward (lateral deviation). Injury to the sixth cranial nerve causes the eye to turn inward. Injury to the fourth cranial nerve can cause double vision without obvious eye deviations. A specialist is often required to detect this type of nerve injury. Eye muscle weakness caused by nerve injury from brain trauma often resolves within the first year. Surgery should be considered to correct the double vision if it persists beyond a year.

EPIDEMIOLOGY

Traumatic brain injury in children also differs from that in adults in terms of its causes and epidemiology (the study of the frequency and relationship of events). Accidents are the most

common cause of death in children, and head injuries are an important cause of death. Falls are responsible for most pediatric head injuries (60), and auto/pedestrian accidents are the second most frequent cause (20). Because many of these accidents are related to bicycle riding (according to a recent Swedish study), the need for routine use of bicycle helmets is obvious. Australia recently passed legislation requiring the use of appropriate safety helmets while bicycling. Many have suggested mandating the use of helmets for bicyclists, as is done for motorcyclists. Shocked by this high incidence of bicycle-related injuries, some pediatric trauma surgeons have suggested requiring the sale of a helmet with purchase of a bicycle. Falls from a height also cause many deaths. Fall-related deaths in New York City were reduced by nearly 50 by a program requiring bars on windows in public housing for families with children under 10 years old.

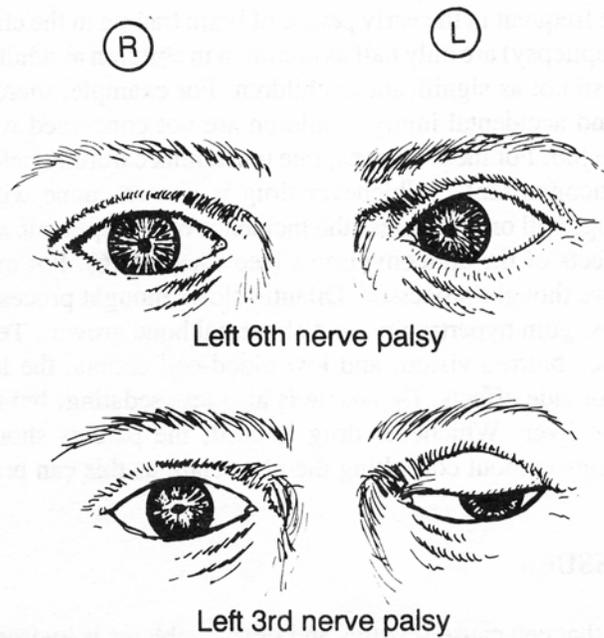


Figure 18-2 Cranial Nerve Injury as a Cause of Double Vision

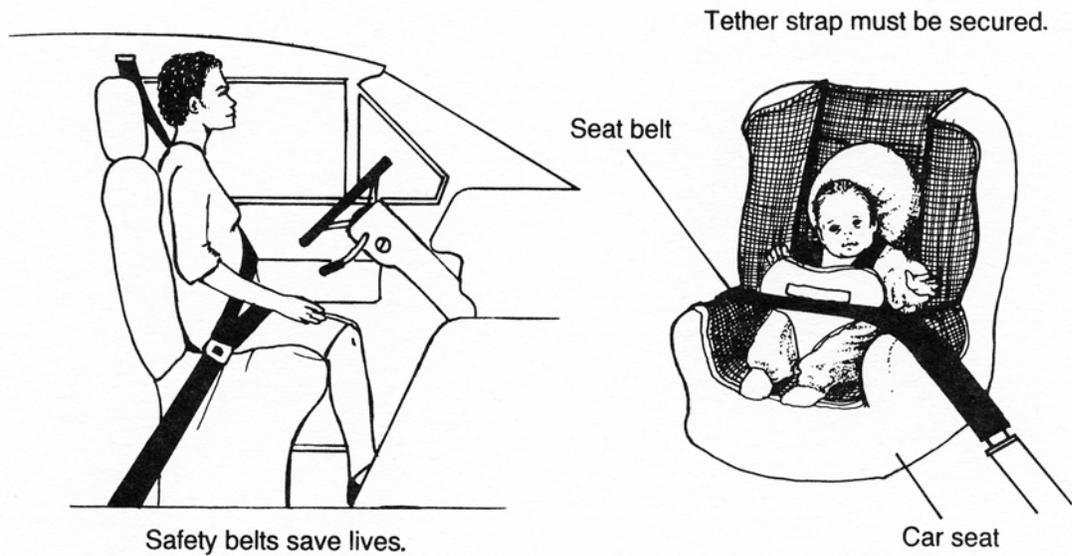


Figure 18-3 Automobile Restraint Devices

Automobile accidents are responsible for many head injuries. Legislation requiring car seats for infants has been shown to markedly reduce pediatric deaths and head injuries. The first state to require car seats for infants under 5 years, Tennessee, noted a two-thirds reduction in deaths of children from automobile accidents. It is estimated that 90 of fatalities could be prevented with the consistent use of automobile restraint devices; yet, tragically, restraints are often not used. Use of restraints is even more important after recovery from traumatic brain injury, as a second injury is unusually devastating. See Figure 18-3.

Head injury is most common in children 16 and over (driving age) and in children under age 1. Child abuse may be involved in many of the cases in younger children. Prevention of child abuse is currently under intense study.

Chapter 19

Special Considerations for the Elderly

To the health care professional:

As with children, the head injured elderly require special consideration. The implications of head injury on the aging process can have a profound effect on all phases of treatment and recovery.

Chapter 19

Special Considerations for the Elderly

EFFECTS OF AGE

Head injury is not uncommon in the aged. Although head injury has highest frequency in the 15-to 24-year-old group, there is another peak in the later years, making it more common in the elderly than in the middle aged. This peak affects the fastest-growing segment of the American population: a tenfold increase in the number of people over 65 is expected in the next century. The results of head injury are superimposed on the normal aging process. This has a profound effect on treatment and recovery. In our society, where the number of elderly is increasing, there will be more elderly with head injuries. See Table 19-1.

The brain begins infancy with the most nerve cells it will ever have and with few interconnections between the cells. With aging, nerve cells are gradually lost, and more and more connections are established between the remaining cells. This continues until age 70 (and higher), when interconnections between cells begin to decrease and levels of certain chemicals within the brain (neurotransmitters) begin to decline.

The aging process is part of the natural evolution of the human system—part of living and adjusting. Normal aging produces slow changes in certain functions such as physical capacities for exercise, but some other functions show few changes. There are many misconceptions about the normal aging process. For example, studies have shown that a substantial proportion of people do not show an intellectual decline with aging through age 70. There is little decline over time of the store of information. Verbal test scores show little change in normal people through their 70s. People in their upper years are normally oriented to time and place. Although memory loss is a common complaint with aging, some aspects of memory are well preserved with normal aging. Some examples are: immediate memory of a list of names or numbers, semantic memory of the content of a meaningful paragraph, and remote memory to retrieve information from the brain's long-term storage.

On the other hand, many changes occur normally with aging. The learning of new complex information, learning of nonsense information, and short-term learning of information presented briefly can become impaired with age. Mental changes with aging are most remarkable for a slowing of the thought processes rather than an impairment of them. Although one is aware of a variety of age-related changes, it is important not to overlook treatable causes of impairment.

Presbycusis (hearing loss) is a major affliction, affecting over a fourth of those over 65. People with hearing loss may seem confused, but they are just not hearing properly. Hearing aids can significantly help hearing-impaired elderly people get more in touch with the environment.

Visual loss is also common in the older population. Treatable causes range from focusing problems, correctable with glasses, to cataracts, correctable with surgery. A cataract is the development of an opaque area in the lens of the eye that blocks light. Glaucoma, another cause of visual loss, is due to excessive pressure within the eye that leads to retinal damage. Glaucoma can be controlled with medication. Significant visual loss affects nearly half of those over 85—the majority due to senile degeneration.

Table 19-1 Increasing Number of Elderly in the United States

Age	1900	1980	2000 (estimate)
Over 65 yrs	3 million	25 million	35 million
Over 75 yrs	900,000	10 million	13 million

Although the basic touch sensation in the fingers and toes is relatively preserved with aging, there is a substantial loss in the ability to feel vibration and small changes of position in the joints. This leads to progressive difficulty with balance in many, often seen as difficulty rising from a chair, standing on one leg, and walking on uneven surfaces. By age 75, many have slowed in the ability to perform motor skills such as tapping feet or fingers, handling safety pins or buttons, and putting on a shirt or zipping a jacket.

Other systems are also affected. Insomnia is common. There may be impairments in taste or smell. Although sexual desire is frequently preserved, sexual responses are frequently slowed, with more time and stimulation necessary for arousal.

Problems with other body systems are common in the elderly. Frequent medical problems include arthritis, diabetes, hypertension, heart disease, atherosclerosis and associated difficulties with the circulation, lung diseases such as emphysema or chronic obstructive pulmonary disease (COPD), osteoporosis (softening of the bones), malnutrition, alcoholism, tobacco abuse, and cancer. Some may experience decreased intellectual faculties, such as Alzheimer's disease or multi-infarct dementia. Geriatric patients may be on numerous medications. Problems with liver or kidneys can impair the body's ability to handle medications—sometimes leading to more than normal side effects from what would usually be a normal dose.

MEDICATIONS

Medications are a special concern in the elderly. They are on more medications at higher cost than the young. See Table 19-2.

Many elderly patients take many medications. These medications may interact in harmful ways. For example, a person taking codeine for mild pain might have the side effect of constipation and need a stool softener and a laxative. A person on digoxin (also Lanoxin—a heart medication) might take kaolin-pectin (Kaopectate) for diarrhea and cause the level of digoxin in the body to decrease. People should always show all their current medications to the physician before starting something new—including nonprescription drugs. Substitution of generic drugs may sometimes save money,

Table 19-2 Average Cost of Medications According to Age Group

Age	Prescriptions/Person (Number/Year)	Cost of Prescriptions (Over \$50/year)
19-24	2.6	4%
25-54	4.2	9%
55-64	8.2	22%
65-over	10.7	34%

Footnote (from Prescribed Medicines: Use, expenditures, and source of payment. Data Preview 9. National Health Care Expenditure Study, U.S. Department of Health and Human Services, Publication No. [PHS] 82-3220, J.A. Kasper, 1982.)

but it may lead to problems if improperly substituted. High costs of medications may lead to a drug being discontinued prematurely—sometimes with dangerous side effects, such as hypertension or epileptic seizures. Too many medications may make keeping track of doses very complicated. Also, the appearances of the pills may be confusing to the elderly.

The elderly are more susceptible to the side effects of drugs. Besides the kidney or liver problems mentioned earlier, there is a normal reduction in the body's ability to handle medications. In addition, there is an increased time to pass through the stomach and intestines. Some medications well tolerated over 1 or 2 days may build up in the system over a longer period. A classic example is the sleeping pill, flurazepam (Dalmane). Flurazepam may take 4 or more days to be eliminated from the body. It will build up in the system with repeated use as well as cause sleepiness during the day. This may lead one to continue to need a sleeping pill at night.

PROGNOSIS

Of course, all of these considerations make management of brain injury more complicated in the elderly. A good history of the underlying mental condition is vital. In addition, it is important to look for associated medical conditions that can be improved or treated. Sometimes, it is difficult to tell if a patient is confused from the head injury, is overmedicated, or has a hearing loss. Sometimes, it is difficult to tell if a patient is confabulating (making up stories) or drawing from a wealth of past experiences. People with brain injury sometimes slip back into past experiences and may even start speaking their native language as if those around them could understand. Physicians and therapists need to know if your loved one was totally lucid before the head injury or if he had problems with memory loss and confusion.

Head injury is also more difficult in the elderly because the brain has less plasticity (capacity to change and repair itself). Recall the concept of sprouting between nerve cells from the chapters on normal brain function and prognosis. Many think that sprouting is important for recovery after head injury as it gives the remaining nerve cells a means of communicating with each other. Unfortunately, sprouting decreases with age. (One study found a 13 decrease, when comparing normal 74- to 90-year-old patients with those under 70). An early loss of the ability to sprout is noted in Alzheimer's disease. Patients who have suffered a head injury earlier in life may be at

greater risk later for the development of normal pressure hydrocephalus (NPH). NPH often brings about the gradual onset of gait disturbance (difficulty walking), incontinence (loss of bladder control), and dementia (intellectual decline). Some research suggests they are also at risk for the development of senile dementia of Alzheimer's and Pick's diseases.

Head injury in the aging also presents some complicated social issues. A person may feel great disappointment or resentment when head injury disrupts the retirement plans of a lifetime. On the other hand, the elderly sometimes too readily accept that they may need to decrease their involvement with life and become dependent on others. This must be resisted; there is no need to accept what can be overcome or treated.

Discharge plans can be complicated in the elderly. Parents are usually no longer alive. If living, spouses may have their own medical problems and disabilities. Yet, discharge to a nursing home may be more disorienting and increase confusion. Home health care support and attendance should also be considered.

PREVIOUS HEAD INJURY

As they grow older, people who have suffered head injuries in earlier years face some of the same issues with a different perspective. Although they were able to cope with the problems when they were younger, age may cut into the reserve capacities on which they depend to overcome their disability. After years of fighting for independence, they are often more reluctant to accept a nursing home. Yet, it may be impossible to function in a single-family home. Independent-living centers with shared caretakers should be considered in these cases to maintain independence as long as possible.

Because most elderly are at or near the end of their vocational careers, education and retraining issues are less important than in the young. Yet, rehabilitation must help the elderly victim of head injury develop other meaningful interests. Counseling and recreational therapy are therefore of prime importance in helping geriatric head injured persons achieve their highest quality of life.

Chapter 20

Community Reintegration

To the health care professional:

Although return to school or return to work is the primary objective in most cases, it can be quite frustrating to the family. The discharge planning can be most helpful in counseling the family through the maze of academic and business bureaucracies.

Chapter 20

Community Reintegration

BACK TO SCHOOL

The reintegration of a student into an educational system is possibly the most important aspect of his rehabilitation process. Success in the educational setting is as important to the child, if not more important, as returning to work is to the head injured adult. The rehabilitation setting should assist in providing for a systematic return to school. A number of issues need to be considered in effecting this return to school. One such issue is whether your child should return to school on a part-time or full-time basis. This decision should be made in connection with the treatment team and a representative from the school system.

It is often best to return a child to school on a part-time basis, while using supportive services from the rehabilitation center. Other times, it is best for him to be gently eased into a full-time schedule without supportive rehabilitative services. Seldom is he ready to begin with full days of school and a full academic schedule.

As a parent, it is wise to be familiar with the return-to-school process. Contact the program coordinator or social worker at the rehabilitation center to determine if they have a working agreement with a local school system. You will want to familiarize yourself with these programs. Names may vary from state to state, but the emphasis of the program will be the same.

If you are not familiar with the working of the school system, it is helpful to be acquainted with the services offered. Early in the rehabilitation process, you may request a hospital/homebound teacher to visit your child in the hospital and assess readiness for that program. This particular program provides services to all children who are not able to attend school because they must either remain home or are confined to the hospital. Its goal is to keep students involved in education at their proper level during hospitalization or confinement at home. Often, with a head injury, this is not a realistic goal and numerous modifications must be made.

The mechanism used for the return to school is usually a staffing, or meeting, at the school level. This will usually include representatives from each special education area, curriculum specialists, student services personnel (psychologists and social workers), family members, and the treatment team from the rehabilitation center. During this staffing, decisions can be made regarding needs for special education programs, special counseling, schedule revisions, or particular course needs. Expert planning can be made for the student before he even sets foot in the school.

A special education program may be recommended for your child. He must meet the criteria for this program, and you will want to familiarize yourself with these requirements. Names may vary from state to state, but the emphasis of the program will be the same.

After your child is involved in the school system, his progress should be monitored on an on-going basis through an individual educational plan or through the guidance department of his school. It is important to stay in close contact with the people involved with your child so that you will be able to help in planning and monitoring his progress.

Specific Learning Disabilities

A program for specific learning disabilities (SLD) may be recommended for your child. Children who have specific processing problems in relation to their intellectual level qualify for SLD programs. Children who qualify for SLD services also demonstrate academic abilities at least 1 to 2 years below their expectancy level. It may appear that working on the processing difficulties your child may have in the SLD program would enhance his possibility of succeeding in the school setting. However, because the processing problems are often measured as being consistent with both the cognitive level and the academic level, many head injured students do not qualify for this program. A complete neuropsychological evaluation addressing the specifics of this population is needed to provide the school system with the information necessary for placement in the SLD program.

Emotionally/Behaviorally Handicapped

A program for the emotionally/behaviorally handicapped may be recommended for your child. This placement is usually determined by the classroom teacher or others in your child's environment who can make objective observations regarding the frequency of acting out and noncompliant behavior. Typically, the classrooms for the behaviorally handicapped have a student to teacher ratio of 6 or 8 to 1. The curriculum is handled through an individual educational plan (IEP). The major focus of the classroom is to deal with the behavioral problems of the student. It is important that you and the teacher are aware of the fact that the basis for the behavioral problems is neurologic in nature. Consequently, the behavior-management techniques will need to be generalized to settings other than the small classroom setting. This should be accomplished through the IEP. Your child should get into the mainstream of some regular education classes as soon as his behaviors are manageable.

Educably Mentally Handicapped

A program for the educably mentally handicapped (EMH) student may be recommended for your child. Placement in this setting is based on your child's overall intellectual functioning level. For a child to meet criteria for being educably mentally handicapped, his IQ score must fall 3 standard deviations below the norm, or a score below 70, on an intellectual assessment.

Information regarding adaptive behavior needs to be consistent with the intellectual level. The head injured student usually does not present a clear EMH picture, but his IQ may fall within this range, especially early in the recovery process. If your child is placed in this type of setting prior to 6 months past injury, he should be reevaluated within the next 6 months to determine the effect of neurologic recovery on the overall cognitive intellectual level (IQ).

Typical EMH programs address those children who suffer from brain damage that occurred at birth or whose intellectual capacity has been diminished. Your child's case is very different from either of the above cases. The major focus of the individual educational plan should be on those

issues that relate to head injury, such as attention, concentration, memory, sequencing, problem solving, abstract reasoning, and behavioral problems. Because there are major differences between your child and other children within the EMH class, it is important to be sure that your child gets into the mainstream of regular classes as much as possible.

Physically Handicapped

A program for the physically handicapped may be recommended for your child. Part of the purpose of this setting is to provide a safe environment for those students who have physical difficulties that limit their mobility, balance, vision, or stamina. They may exhibit a combination of physical difficulties that may limit their ability to function within a regular classroom setting. A usual requirement for the physically handicapped program is that the limitations must be physically based and documented by a physician. Therapies are administered under a physician's prescription. Placement in a classroom for the physically handicapped most likely involves the inclusion of physical, occupational, and/or speech/language therapy.

The curriculum in the program for the physically handicapped is usually provided through an individual educational plan. Academics may well be presented at your child's grade level, with modifications in curriculum made only in areas of difficulty. Again, the areas that should be addressed in the IEP are attention, concentration, memory, problem solving, abstract reasoning, and behavior. Many centers for the physically handicapped are attached to a regular education elementary, junior, or high school. This allows your child to readily get into regular classes. Because his physical limitations may not be as evident as some of the other students in his physically handicapped classes, it is an excellent idea to encourage the program to get him into regular classes whenever possible. A physically handicapped placement, although the most appropriate in some cases, could potentially lead to some difficulties for your child. Of some concern to you as a parent may be the fact that your child just spent months in rehabilitation to be out of a wheelchair and walking and he is now in a classroom in which the majority of the students are confined to wheelchairs.

Neurologically Impaired/Varying Exceptionalities

In some states there are specific classrooms for children who have certain documented impairments or who qualify for a number of programs and need a particular setting. In most cases, these are the classes for those students who are neurologically impaired or have varying exceptionalities. This may be an appropriate placement for your child. Again, the curriculum is based on an individual educational plan, which may well address the issues of attention, concentration, memory, problem solving, abstract reasoning, and behavior. Children in this setting demonstrate what educators call splinter skills. This simply means that in some areas, they are above average in what they can do academically and cognitively, but they have significant difficulties in other areas. In some cases, this definition best describes the head injured child. The student-to-teacher ratio in these classrooms may be 10 students to 1 teacher. Getting the students into regular classroom settings is an integral part of the program for the neurologically impaired.

Resource Classrooms

Earlier in this chapter, we described various classroom placements that have a particular curriculum focus. In educational settings, these programs are offered on resource room basis, which means that your child goes to the regular classroom for part of the day and to a special class within the school for the rest of the day. The purpose of this class may be to provide assistance in

the academic area or to provide process training and teach compensatory techniques. Again, this will be determined by an individual educational plan.

Because many of the head injured students who return to school are adolescents of high-school age, it is important for them to return to an academic setting that will allow them to complete the credits necessary for graduation. In this way, a resource room provides the necessary remediation, yet allows the student to remain in regular classes.

The educational system at this time is doing all it can to meet the needs of these students. They are a new population for the education system, just as they are for the rehabilitation settings. There are many advocates within the school system who are willing and able to assist you in securing the best services for your child. It is important that you consider yourself just as much a part of the educational team as you were a part of the rehabilitation team.

BACK TO WORK

To many family members, a head injured loved one is not considered well until he can return to gainful employment. The head injured patient has a similar opinion. From the time a patient leaves the hospital, there is the constant concern and focus on getting back to work.

Some families make the mistake of pushing return to work (even against therapist advice) because they truly believe that the best therapy for him is getting back to his former routine. In only a few cases is immediate return to work appropriate and successful. The length of time needed for rehabilitation is directly related to a large number of factors that are often interrelated. These factors include severity of head injury, type of job previously held, premorbid intellectual level, degree of physical disability, degree of employer support, amount of denial, and level of emotional and behavioral stability.

Severity of Injury

If one looks solely at the severity of the injury, there appears to be an inverse relationship between employability and severity. Severity is measured in a number of ways, such as length of coma and/or duration of posttraumatic amnesia (PTA) (the length of time after the injury in which the patient has little or no recollection of daily events). If your loved one has experienced what the therapists and physician describe as a severe injury, then you must realize that there may be serious limitations as to the type of work that he can ultimately accomplish. See Figure 20-1.

However, there are exceptions to the very simplistic representation as seen in Figure 20-1.

Case 1

Randy, who was injured at age 28, was in a coma for 6 months. During his recovery period, he lost his wife and three children to divorce. Through the assistance of the state vocational rehabilitation office, he progressed from a sheltered workshop setting to junior college to a 4-year state school and, ultimately, obtained his master's degree in social work. This process took a total of 11 years. He is employed in a social service position with an employer who is willing to make allowances for his deficit areas. Randy has remarried and has two small children.

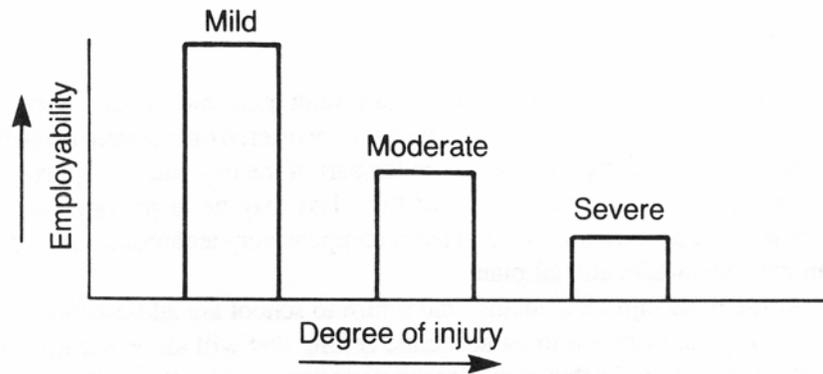


Figure 20-1 Relationship Between Employability and Severity of Injury

Previous Employment

Although there are a few exceptions, most head injury patients want to go back to doing exactly what they did before the injury. Many times this is their strongest motivation to participate in rehabilitation. Because of the impact that this motivating factor can have on the individual, it is best for families to take a hopeful, but noncommittal, stance. Because no one knows the rate and degree of recovery in the beginning, you can indicate that he should put everything into the therapies so that returning to his old job will possibly be an option. On the other hand, you should never promise him that he will be able to return 'just as long as you keep trying.' This belief can later lead to feelings of self-directed failure as well as anger toward family members who assured him of a complete recovery.

Once you add the element of severity with the type of job previously held, the relationship of these issues to employability becomes more complex.

It is interesting to note that a moderate head injury can actually do better than a mild head injury for different levels of employment.

Case 2

Susan, a 33-year-old attorney, had worked as a prosecutor prior to slipping on ice in a parking lot and hitting her head on the bumper of a car. She was unconscious for 30 minutes, but was awake when the paramedics arrived. She was checked at the hospital and released shortly thereafter. She stayed home for 3 days and returned to work on the fourth day. She found that she was confusing cases, forgetting court dates, and missing appointments with colleagues. Her past reputation for thinking on her feet diminished over a 6-month period. She was gradually given fewer and less complicated cases. After 18 months, she left the field of law.

Case 3

Robert is a 29-year-old man who received a moderate head injury in the summer right before he was getting ready to enter college. He had worked in his father's hardware store for 4 years while he attended high school. He made excellent progress in rehabilitation, but it was evident that he was not ready to go off to college 300 hundred miles from his home. Cognitive rehabilitation therapists worked with Robert after he was discharged, hoping to help him prepare for junior college courses. He took freshman English and failed it twice. He obtained a D in basic

mathematics. In the meantime, he returned to his father's hardware store and began working in stocking merchandise and as a cashier. He was able to continue with these duties with minimal assistance from his father or the store manager.

Although Susan experienced a much milder injury than Robert, her ability to return to her previous work and to function at her former level was significantly less than was Robert's. Susan had lost the cutting edge that had allowed her to work at her high-level job. This did not mean that she could not be gainfully employed in some other capacity, but it did mean that she could not perform at her former level. If Susan had accepted her deficits, she might have been able to stay in the field of law; however, after she found she could not function at her former level, she could not handle being faced with lesser duties.

Premorbid Intellectual/Academic Level

Previous level of intellectual functioning is also a variable that impacts upon employability.

Case 4

Mark (31 years old) had a moderate head injury with right hemiparesis (right-sided weakness of the arm and leg). He had previously been employed as a mechanic's helper when a tire blew up and hit him in the face. He was thrown 6 feet and landed on his head, rendering him unconscious for 3 days. Testing at 6 months postinjury revealed that he was in a borderline range of intelligence and functionally illiterate in academics. Mark had quit school in the eighth grade, in all probability because of learning problems. The vocational counselor, through job analysis, determined that his physical limitations would keep him from returning to his former job. Mark wants to receive training for small-engine repair, but his intellectual and academic capabilities keep him from learning a new skill. He is not satisfied with the menial jobs for which he is physically and intellectually qualified.

Intellectual scores measure old learning skills. Psychometric testing can show that your family member still has average or even above-average IQ. This is definitely a positive sign, but it should not be considered indicative that he can do his old job or a new job like a non-head injured colleague of the same intellectual levels. Further neuropsychological testing should be administered to determine his present learning ability.

Case5

George, a master welder, was injured in a motor vehicle accident on his way home from work. He was unconscious for 6 hours, and experienced severe behavioral problems in the acute care hospital. After receiving 8 weeks of cognitive rehabilitation, he insisted on returning to his job on a part-time basis. After he started going back for half days, he soon insisted that he work full time. Things went fine for 4 weeks, during which he finished an old project with which he was familiar. He was then asked to design a new project. In the past, he had been considered an extremely creative designer. Now, he had difficulty visually planning the job and initiating the plan. Within 4 months after returning to work, he was fired. His employer told the therapist that all George wanted to do was talk about what he was going to do.

In many head injured individuals, this difficulty with new learning is the greatest problem in handling a job that involves more than a group of repetitive tasks already mastered by the individual.

Degree of Physical Disability

Physical problems may keep your loved one from returning to his former job. These physical deficits can be due to injuries in the accident as well as from the brain injury. Problematic effects can occur with balance, coordination, strength, stamina, range of motion, motor speed, perception, and motor control.

Case 6

Sam was a 38-year-old painter who lost his balance and fell off a ladder. He was unconscious for 2 hours, and he remained hospitalized because of multiple injuries of the neck, shoulder, arm, and leg. Because of limitations in mobility of both his right shoulder and arm, as well as constant dizziness, Sam could not go back to his former line of work. In addition, because of his lack of formal education, it was difficult to find a job that he would accept and could handle mentally and physically.

Degree of Employer Support

The employer is a very important factor in return to work for the head injured. In fact, employers can have as much impact on the degree of successful return to work as the family has over a productive effort at rehabilitation. The ideal situation is when the former employer is supportive, is willing to learn about head injury, and promises to call for assistance if he experiences a problem.

Case 7

Mary was a regional sales manager for a well-known advertising firm. She had worked her way up through the ranks and had earned a great deal of respect from her superiors and fellow employees. While traveling in her job, she was involved in a motor vehicle accident. She was unconscious for 52 hours. Testing indicated that her IQ levels remained in the very superior range. Memory appeared adequate, with some slight difficulties in attention and concentration as well as self-monitoring. The greatest difficulties were seen in visual-spatial planning and organization. Mary's boss was ready for her to return to work on release from her neurologist. The neuropsychologist recommended some short-term cognitive rehabilitation, with an emphasis on skills that were needed in planning the activities of the 34 sales representatives that she supervised. Mary refused the cognitive rehabilitation. If her neurologist released her and she thought she could do the job, she was going to return to work immediately. Although she had difficulty with fatigue, things seemed to be going well until the neuropsychologist received a panic call from the rehabilitation nurse saying that Mary was going to have to return to a sales job. Apparently, her region had reduced its productivity by 50 from the last quarter because of her procrastination and lack of organization. Through an emergency meeting, we were able to talk the employer into giving her another chance. Without this employer support, Mary would have been demoted.

Amount of Denial

As indicated in other chapters, denial of deficits by your loved one can be a problem of great magnitude. If he cannot or will not admit to certain deficiencies, he cannot possibly make appropriate changes or tolerate constructive criticism. Whenever possible, the denial issue should be tackled and resolved before a return to work is initiated. If not, you are likely to find that your

head trauma survivor will have difficulty accepting any limitations that may be imposed on his vocational endeavors.

Case 8

When he was in high school, Fred had worked at a local grocery store stocking shelves and bagging groceries. On graduation, he enrolled in the local junior college to study business administration. After a few months of college, he was coming home from a party and stopped at a local all-night grocery. Four men ambushed him as he got out of the car, took him to an open field, severely beat him, stole his Datsun 300ZX, and left him for dead. After 10 hours of lying comatose in the field, a telephone repairman spotted him. He was taken to the nearest trauma center and remained in a coma for 5 months. After 2½ years of inpatient and outpatient rehabilitation, he began working as a bag boy again. There were notable cognitive and physical effects, but his former employer was willing to make concessions. Five years postinjury, Fred became convinced that he could handle a better job with more responsibility. He went to a state vocational rehabilitation counselor who referred him for a neuropsychological evaluation. This evaluation indicated moderate-to-severe problems. Fred, however, said that, "The only thing that is wrong with me is I sometimes have trouble remembering. Everything else is back to the way it was before the accident." Fred was not able to accept either the other cognitive problems or the type of job for which he was best suited.

Emotional and Behavioral Stability

Although cognitive (thinking) deficits will often keep a head injured individual from returning to the type of work he most desires, the emotional behavior is frequently the greatest problem in keeping a job. All the behaviors that are discussed in Chapter 11 can present potential difficulties in a job setting. For this reason, it is helpful for your loved one to be involved in psychosocial counseling to provide him with ways to control and reduce specific behaviors. Research strongly suggests that it is the behavioral issues that ultimately lead to employer and employee conflicts.

Case 9

Christine was severely injured in an industrial accident when she fell off a ladder and landed on a concrete floor. She was comatose for 10 weeks and went through extensive rehabilitative therapy for 18 months after the injury. Physically, her problems were minimal. Because she had worked in the stock room of a large department-store warehouse for 15 years, the company wanted to try to find something she could do to remain employed. The cognitive therapist indicated that she could perform repetitive-type tasks under moderate supervision. Christine returned to work and was cognitively able to handle the responsibilities. Things seemed to be going well until she thought she overheard a fellow employee complaining about her. She became suspicious of almost everyone, and her work performance dropped. After 4 months, her supervisor recommended a transfer to another department, as she had alienated all her fellow workers. Similar problems developed in the new department. It was not until she returned for counseling and participated in a psychosocial group focusing on vocational issues that she was able to begin to understand how she was setting up negative interactions on the job.

COMMUNITY RESOURCES

As you evaluate community resource systems, you need to assess as many avenues as possible. It is best to learn about these resources long before your family member is discharged. The community resources available to you will depend somewhat on your geographical location. Larger metropolitan areas may be able to provide you with more resources than smaller communities through their mental health system. In cases in which your funding is limited, you may need to look to the community for assistance.

This exploration of community resources should be coordinated with your case manager, social worker, or discharge planner, before and during the discharge-planning process. This person must be made particularly aware of how the available community resources will correspond with your funding options.

National Head Injury Foundation

The National Head Injury Foundation (NHIF) provides a variety of services for family members of the head injured. Their extensive library contains numerous resource materials, including books, video tapes, and articles relative to head injury. They will also provide you with information regarding facilities that provide services for the head injured.

The NHIF sponsors numerous educational programs for professionals, family members, and survivors of head injury. They also maintain information about the state associations of the NHIF. State associations provide many of the same services as the national agency. Many state programs also provide educational programs for the professionals, family members, and survivors. They maintain information regarding local chapters that provide education and support to their members. NHIF is comprised of family members just like you who are able to provide support and education to each other. NHIF operates a toll-free number to best meet the needs of the family.

Community Mental Health System

The community mental health system can provide services for you and your family member on both an inpatient and an outpatient basis. The range and complexity of services offered by this system is often related to the area in which you reside. Psychological, social work, and other therapies may be offered on an outpatient basis. Service charges are often calculated on a sliding scale, so you pay in accordance with your ability.

Many groups work within the community mental health system, both for therapeutic and adjustment purposes. These groups, which may address depression, change, substance abuse, coping skills, and various other issues, may be quite helpful in assisting you and your family member through a crisis situation, and in providing on-going support.

Inpatient services can also be offered through the community mental health system. It may provide a direct referral source within its own system or to another system that can provide for a temporary inpatient placement for your family member, who may be undergoing, for instance, severe depression or severe acting-out behavior.

Although community mental health systems do not specialize in the care of the head injured and usually address the needs of a much more varied population, they may be a valuable resource to you and the only one available to assist you and your head injured family member. The person responsible for the discharge from the hospital or head injury rehabilitation center should be able to provide you with information about the community mental health system in your area.

Adult Day Care

In our country, a growing emphasis is being placed on providing for the needs of our younger adults and our elderly without placing them in a long-term care facility. In some communities, the answer to that need has been the adult day care system. This allows the head injured person to live with his family, but be supervised during the day in a day care setting. Adult day care settings are activity focused and do not provide traditional therapies. However, they do provide excellent opportunities for socialization, community reintegration, and leisure development.

Adult day care facilities allow you to return to your daily activities (usually employment) with the assurance that your family member is well-cared for. You may be able to take some sorely needed and well-deserved time to yourself.

Unfortunately, adult day care facilities are not available in every community. You may need to explore this possibility on your own. Adult day care facilities are traditionally run by community service agencies, religious service organizations, or private agencies.

Recreational Services

Recreational and leisure activity services are available through county and city recreational departments. There are strong therapy components in the parks and recreational departments in some areas of the country. A variety of activities is offered at a nominal fee. Courses vary from aerobics to basic computer programming. This provides an excellent opportunity for your family member to actively pursue an interest or learn a new skill. Schedules for such activities are usually published periodically in newspapers or you can obtain information by telephoning your county or city recreation department.

Transportation Services

In many instances, the biggest obstacle to obtaining community services may be transportation. Few options may be available, and you may have to do some creative thinking.

Public transportation (bus, train system) is an option in some cases. If your family member is to become proficient in this area, it will take much work on the part of the rehabilitation professionals in addressing community reentry or on your part in teaching him to use the transportation system. You will want to feel comfortable that he is able to get back and forth safely. Unfortunately, public transportation is an option for only a few.

Another alternative to explore is specially equipped buses that provide door-to-door transportation for the handicapped. The guidelines for use of these transportation systems may vary relative to frequency of use, purpose of transportation, income status, and rehabilitation status.

Transportation systems of this nature are usually provided by the city or county transportation service or a civic organization that provides the transportation as a civic project. Again, the person responsible for discharge planning for your family member should be able to provide you with information and telephone numbers.

Medical and Therapeutic Follow-Up

Your family member may need intensive medical and therapeutic follow-up. Funding sources may be limited at some time, and you may need to rely on resource agencies for some of that care. The county health department may be able to provide you with some of the follow-up medical care at a reduced rate. Some of the services they offer are free. You may wish to contact your county health department for a listing of the services they provide.

Few community agencies are able or willing to provide therapies at a reduced rate; however, options that you may explore include programs managed by services clubs (such as Elks, Shriners, Lions Club) or United Way-funded programs (such as Easter Seals). Either may be able to provide therapeutic services to your family member.

Another option you may explore is the university system in your community. Many universities have a department concerned with communication disorders. This department may be able to provide speech/language therapy for your family member. Closely supervised, Master's level students could be a possible way of providing this therapy. A telephone call to your university will give you the necessary information regarding how to contact this department for assistance.

Obtaining community resources for your family member becomes similar to a treasure hunt. Much depends on what is available in your geographic area. Hopefully, the discharge planner will assist you in identifying what is available. In conjunction with him, you should be able to develop a creative system for providing your family member with the adequate medical, therapeutic, leisure, recreational, and psychosocial support he needs to live a full life. Your role as a family member is ever present and ever changing in meeting that need.

Glossary of Terms

Abstract reasoning—Ability to think or conceptualize beyond the concrete level. Abstract reasoning also refers to the ability to cognitively manipulate information for problem-solving purposes.

Acalculia—Inability to manipulate numbers in mathematical computations.

Activities of daily living (ADL)—Refers to everyday self-care activities of feeding, grooming, dressing, and homemaking. Also refers to home management and community reentry skills of budgeting, communication, transportation, and time management.

Acute care facility—Hospital responsible for acute medical care of patients.

Acute rehab unit—Unit that provides rehabilitation during acute rehabilitation recovery period. Rehabilitation begins when the patient becomes medically stable and continues throughout period of time of continued neurologic improvement.

Agnosia—Inability to recognize meaning of sensory stimulation.

Agraphia—Inability to express self through writing.

Alexia—Inability to read.

Anomia—Difficulty with word finding and object naming.

Anosognosia—Altered state of self-awareness.

Anoxia—Lack of oxygen to tissue, particularly to the brain, which may result from trauma or toxic substances. Results in brain damage or damage to central nervous system.

Anterograde amnesia—Inability to remember events that occurred after the TBI.

Anticoagulants—Medications used as "blood thinners" to treat or prevent blood clots.

Anticonvulsants—Medications used to treat and prevent epileptic seizures.

Aphasia—Impairment in receptive and/or expressive language abilities as the result of cerebral damage.

Apraxia—Inability to sequence movements to perform purposeful acts or manipulate objects.

Aspiration—Abnormal swallowing that causes food to pass into the airway.

Astereognosia—Inability to identify objects through sense of touch and object manipulation.

Ataxia—Disordered movements resulting from difficulty with muscle action and coordination.

Attention—Ability to focus correctly on pertinent auditory and/or visual information.

Basilar skull fracture—Breakage of the bones at the base of the skull. It sometimes does not show on standard X rays, but can lead to leakage of fluid from the brain and become a source of infection—meningitis. Basilar skull fracture is often associated with damage to cranial nerves.

Brain electrical activity mapping (BEAM)—A test of electrical activity within the brain in which several EEGs are averaged to produce a picture.

Brain stem—An area at the base of the brain before the spinal cord begins that contains several centers vital to consciousness and life, as well as being the origin of all nerves to the face—controlling sight, smell, hearing, taste, swallowing, and movements of the eye and face.

Brain stem auditory evoked responses (BAER)—A test of hearing and its pathways to measure function of the base of the brain. The test is not in any way dangerous.

Bulbar functions—Brain functions primarily involved with face, mouth, and tongue movements.

Catheter—Tube used to enter a body cavity such as the bladder (through the urethra) or bowels.

Central nervous system (CNS)—Part of nervous system made up of brain and spinal cord.

Central venous pressure (CVP) line—A special intravenous line used to measure pressures within the right side of the heart for the purpose of maintaining proper fluid balance.

Cerebrospinal fluid (CSF)—A clear, continuously produced and resorbed fluid that fills the ventricles within the brain and circulates down the spinal cord. Blockage of its circulation or resorption leads to hydrocephalus. A CSF leak can lead to brain infection—meningitis.

Cognition—Ability to perceive, understand, organize, recall, problem solve, reason, and make judgments in response to daily activities.

Coma—State of profound unconsciousness.

Comprehension—Ability to "understand" auditory, visual, and tactile kinesthetic information as it is presented.

Computerized axial tomography (CAT or CT) scan—A special X ray used to look at soft structures within the body that do not show up well on standard X rays.

Concentration—Ability to attend to a task for an extended period of time.

Contrecoup—Brain bounces against skull on impact in head injury. Injury results at the site of impact (coup) and the part of the brain opposite the impact (contrecoup).

Cortex—Most complex and organized center of the brain. Consists of frontal, temporal, parietal, and occipital lobes.

Cortical blindness—Blindness due to brain injury, even though the eyes are normal.

Cranial nerves—Nerves that exit the brain stem and pass through the skull and that control smell, eye movements, facial movements, hearing, and swallowing.

Craniectomy—Surgical removal of part of the skull.

Cranioplasty—Surgical repair of the skull.

Craniotomy—Surgical opening of the skull for the purpose of performing an operation on the brain.

Decubitus ulcers—Sores caused by pressure on the skin.

Diffuse—Refers to extensive damage to the brain as a result of trauma.

Diplegia—Paralysis of both arms and both legs due to brain injury—the arms are more affected.

Diplopia—Double vision.

Disinhibition—Inability to control emotions or impulses.

Disorientation—Inability to recognize who you are in relation to person, place, or thing.

Dysarthria—Neurologically based speech difficulty resulting from the inability to coordinate musculature for speech production.

Dysphagia—Disturbance in the ability to swallow either solid foods or liquids.

Edema—Swelling resulting from abnormal accumulation of fluid in intercellular tissue space of body (brain).

Electrocardiogram (EKG)—A test measuring the electrical activity of the heart. There are no significant side effects.

Electroencephalogram (EEG)—A test measuring the electrical activity of the brain. There are no significant side effects.

Electronystagmogram (ENG)—A test used to evaluate dizziness by measuring the effect on eye movements of spinning the body—used to test inner ear function.

Emotional lability—Lack of control of emotion, resulting in mood swings causing either excessive laughter or crying.

Endotracheal (ET) tube—A tube passed through the mouth into the airway to help breathing.

Epidural hematoma—Bleeding between the skull and the dura.

External catheter—A urinary catheter on the outside of the body—usually used on men as a condom over the penis. Some types have been tried on women.

Extremity—An arm is an upper extremity, a leg is a lower extremity.

Foley catheter—Brand name of a type of indwelling catheter—a balloon is inflated to keep the tube in the bladder.

Fractures—Broken bones are called open fractures when they penetrate the skin and closed when they do not.

Frontal lobe—Anterior portion of the brain responsible for controlling higher cognitive functions and impulsivity.

Frustration tolerance—Ability to maintain a sense of control of behavior in light of stressful environments.

Gastrostomy tube—A tube passed through the abdomen directly into the stomach. It is used for feeding.

GI bleeding—A general term for bleeding from somewhere in the gastrointestinal tract.

Glasgow coma scale (GCS)—System for assessing consciousness level immediately following injury. Scale rates communication, motoric, and eye opening responses.

Gray matter—Areas of brain and spinal cord that contain mostly nerve cells.

Hemianopsia—Blindness in the same side of both eyes. This occurs after some types of brain injury and shows up as an inability to see things on the left or right side. In some cases, the blindness is partial.

Hemiparesis—Muscular weakness on one side of the body.

Hemisensory deficit—Loss of feeling on one side of the body.

Hemorrhage—Bleeding that occurs following trauma as a result of damage to blood vessels in the brain.

Hemothorax—Blood within the chest—usually seen with lung injury.

Hydrocephalus—A build-up of pressure in the fluid filled cavities within the brain.

Ileus—Stoppage of bowel activity.

Inflexibility—Inability to adjust to changes in routine. Inflexibility is evident in TBI clients when structured routines are changed.

Intensive care unit—Hospital unit responsible for intensive level of medical care. Often a placement for TBI patient on admission to a hospital setting.

Intracerebral hematoma—Bleeding within the brain.

Intracranial hematoma—Bleeding within the skull. There are four types: intracerebral, sub-arachnoid, subdural, and epidural.

Intracranial pressure (ICP) monitor—A device used to measure pressure within the brain.

Intravenous (IV) line—Involves passing a needle into a vein to deliver fluid or medications directly to the bloodstream.

Judgment—Ability to make appropriate decisions based on information and possible consequences. Judgment is affected by a person's ability to use an appropriate problem-solving approach.

Limbic system—System within the brain that connects lobes and mediates moods, emotions, motivation, attention, and memory.

Magnetic resonance imaging (MRI) scan—Takes a detailed picture of the brain with the use of powerful magnets. No X rays are used.

Memory—Process of assimilating, storing, and retrieving information for later use. Later use may refer to immediate (recalling a telephone number), recent (recalling a therapy schedule), or long-term recall (for an extended period of time). Memory problems affect new-learning ability.

Motor point block—A technique to relax spastic muscles through the use of medications applied with a needle and injected where the nerve enters the muscle.

Nasogastric (NG) tube—A tube passed through the nose, down the esophagus, and into the stomach. It can be used for feeding or for suction—to remove contents from the stomach.

Neurogenic bladder—Abnormal bladder function due to nerve damage.

Neurological examination—Evaluation of the mind, brain, and nerves—usually performed by a physician.

Neuroophthalmology—The study of nerve pathways of the eyes.

Neuropsychology—Branch of psychology dealing with the assessment and rehabilitation of brain behavior relationships and cognitive functions.

Neuroradiology—The study of tests to visualize the nervous system.

Nondominant parietal lobe syndrome—A set of abnormal behaviors usually caused by an injury to the right side of the brain. Typical are problems with keeping track of time, remembering faces, paying attention to the left side of the body, recognizing one has any problems at all, short attention span, and a tendency to be more argumentative than usual.

NPO—Latin abbreviation for nothing by mouth.

Nystagmus—Abnormal side-to-side or up-and-down eye movements.

Occipital lobes—Most posterior portion of the brain, responsible for the sensation of vision.

Occupational therapy (OT)—A type of therapy emphasizing improvement of activities of daily living (ADLs) by maximizing arm use, thinking, and adaptive devices.

Orientation—Awareness of self in relation to person, place, and time in past and present environments.

Otorhinolaryngologist—An ENT—ear, nose, and throat doctor.

Paralysis—Neurologic muscular weakness to the extent of lack of movement. Paralysis causes muscles to contract and become smaller (atrophy).

Paresis—Muscular weakness caused by damage to the brain pathways that regulate movement.

Parietal lobe—One of four lobes of the cerebral hemisphere, posterior to the frontal lobes and anterior to the occipital lobes. The parietal lobes are responsible for integration of sensory information and muscular activity.

Partial thromboplastin time (PTT)—A blood test used to measure the effectiveness of a type of anticoagulant (blood thinner)—heparin.

Passive range of motion (PROM)—Exercises to keep the patient's joints loose in which the family, nurse, or therapist moves the arms or legs.

Perceptual deficits—Difficulty in correctly perceiving visual, spatial, auditory, or tactile kinesthetic information.

Perseveration—Becoming stuck on a thought or word and not being able to move on from that thought to the next.

Phenol block—A chemical, phenol, is applied with a needle to motor points or nerves for the purpose of relaxing spastic muscles.

Physiatrist—A physician specializing in physical medicine and rehabilitation—a medical field involving nonoperative treatment of bone, muscle, and nerve conditions and emphasizing care of people with disabilities.

Physical medicine and rehabilitation (PM & R)—The medical specialty that deals with rehabilitation. See Physiatrist.

Positron emission tomography (PET) scan—Takes pictures of the brain using radioactively labeled oxygen, sugar (glucose), or other substances to evaluate brain function.

Postacute rehab—Provides rehabilitation on a long-term or community reentry basis.

Posttraumatic amnesia (PTA)—The period of time that patients are unable to form new memories. This time may range from minutes to months.

Problem solving—Ability to evaluate all factors, generate possible hypotheses, and come to the appropriate solutions.

Progressive resistive exercises (PRE)—Exercises used to strengthen the limbs.

Prostheses—Artificial replacement for parts of the body lost in injury or accident, such as prosthetic eyes, hips, arms, or legs. Dentures are a prosthesis for the teeth.

Proximal instability—Difficulty controlling arms from the shoulder or legs from the hip_ frequently because of muscle weakness or incoordination.

PT—This abbreviation can mean either physical therapy or a blood test, prothrombin time. A protime is used to measure the effectiveness of some anticoagulants (blood thinners).

Pulmonary contusion—Traumatic bruise of the lung.

Pulmonary embolus—A blood clot in the venous system that passes to the lung. Usually the clot develops in an area of phlebitis in the legs or pelvis.

Pulmonary infarct—Damage to part of a lung that is sufficiently severe to cause it to die.

Quadripareisis—Weakness in all four extremities.

Quadriplegia—Paralysis of all four limbs.

Respirator—A ventilator or breathing machine.

Restraints—Devices used to keep someone with a brain injury from hurting himself or others.

Retrograde amnesia—Inability to remember events that occurred prior to the TBI.

Shearing—Type of brain lesion that results from TBI. Shearing refers to tears in nerve fibers, particularly the axons in the white matter.

Skilled nursing facility (SNF)—A possible placement for long-term rehab and medical management of the TBI patient.

Spinal tap—A procedure in which a needle is placed in the lower back to draw fluid from the area around the spinal cord for conducting tests.

Spontaneous recovery—Recovery that occurs after TBI. Usually refers to neurologic recovery.

Subarachnoid bolt or screw—A device placed by a neurosurgical operation through the skull and outside the surface of the brain. It is connected to an ICP monitor to measure pressure within the brain.

Subarachnoid hemorrhage—Bleeding between the brain and the thin arachnoid membrane lying over it. Subarachnoid hemorrhage is usually caused by the rupture of blood vessels that lie in this space.

Subdural hematoma—Bleeding above the arachnoid membrane but below the thick dura mater that is under the skull.

Swan-Ganz catheter—A special type of intravenous line similar to the CVP line, but passed even farther—all the way to the lung—and used to measure pressures within both sides of the heart in critical settings in which more detailed information is needed.

Tactile defensiveness—Adverse reaction to being touched or approached by anyone or any item in his environment.

Temporal lobe—One of the four lobes of the cerebral hemisphere, lying between the frontal and occipital lobes. Temporal lobes are responsible for the perception and understanding of auditory information.

Tetraplegia—Quadriplegia, paralysis of all four limbs.

Tracheal stenosis—Narrowing of the airway, sometimes seen days to weeks after removal of an endotracheal or nasotracheal tube. It presents as wheezing or difficulty in breathing, and can lead to severe breathing problems.

Tracheostomy—An operation in which a surgeon places a breathing tube through the neck, directly into the trachea.

Unilateral neglect—Lack of awareness of space on one side of the body. Neglect is on the side opposite the brain injury.

Ventricles—Fluid-filled cavities of the brain.

Ventriculoperitoneal (VP) shunt—A neurosurgical procedure performed to relieve a build-up of pressure within the brain—hydrocephalus. A tube is placed in one ventricle, tunneled through the neck and under the skin into the abdomen (peritoneum).

Ventriculostomy—A neurosurgical procedure in which a tube is passed through the skull and brain into the ventricles.

Vestibular stimulation—A type of therapy treatment that stimulates the inner ear system by movement.

Visual-field cuts—Loss of vision in one of four quadrants. This does not refer to blindness but rather loss of visual sensation to visual field.

White matter—Area of brain that contains nerve processes or pathways.

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