

# TRAUMATIC BRAIN INJURY SURVIVAL GUIDE

by

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## INTRODUCTION: Making It Simple

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Nearly all of the survivors of a traumatic head injury and their families with whom I have worked have had one complaint: There is nothing written that explains head injury in clear, easy to understand language. Most say the available material is too medical or too difficult to read. The goal of this book is to better prepare the head-injured person and family for the long road ahead. I will try to explain things in clear, non-medical terms whenever possible. When medical terminology is unavoidable, I will try to give clear explanations.

This book cannot explain all types of head injury. The largest number of patients that I see are described by professionals as having a "mild" head injury. ***Just to be very clear--having a "mild" head injury does not mean the person has "mild" problems. A "mild" head injury can prevent someone from returning to work and can make family relationships a nightmare.*** Those who appear "normal" are sometimes those who suffer the most. They may look the same and talk the same--but they are very different.

There is a lot of information in this book. Despite my efforts to simplify, there are overwhelming issues that a head-injured person and family members need to deal with. Each section of the book is designed to be read on its own. If you want to skip parts of the book, go to the index and read chapters on problems that apply to you.

This book will be an ongoing process. When I can find time, I will try to add new information and improve material in this book. If you have access to the Internet, an "on-line" version of the book will be found at:

[www.tbiguide.com](http://www.tbiguide.com)

My e-mail address is [debglen@yahoo.com](mailto:debglen@yahoo.com) . Again, depending upon my available time, I will try to answer e-mail messages.

## COMMON INDICATORS OF A HEAD INJURY

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This questionnaire is not meant to be a formal “test” to see if you have a head injury. If you have multiple “YES” answers, bring this questionnaire to your doctor. Additional tests (medical and neuropsychological) may be ordered.

### HEADACHES

- Yes No Do you have more headaches since the injury or accident?
- Yes No Do you have pain in the temples or forehead?
- Yes No Do you have pain in the back of the head (sometimes the pain will start at the back of the head and extend to the front of the head)?
- Yes No Do you have episodes of very sharp pain (like being stabbed) in the head which lasts from several seconds to several minutes?

### MEMORY

- Yes No Does your memory seem worse following the accident or injury?
- Yes No Do you seem to forget what people have told you 15 to 30 minutes ago?
- Yes No Do family members or friends say that you have asked the same question over and over?
- Yes No Do you have difficulty remembering what you have just read?

### WORD-FINDING

- Yes No Do you have difficulty coming up with the right word (you know the word that you want to say but can't seem to “spit it out”)?

## **FATIGUE**

- Yes No Do you get tired more easily (mentally and/or physically)?
- Yes No Does the fatigue get worse the more you think or in very emotional situations?

## **CHANGES IN EMOTION**

- Yes No Are you more easily irritated or angered (seems to come on quickly)?
- Yes No Since the injury, do you cry or become depressed more easily?

## **CHANGES IN SLEEP**

- Yes No Do you keep waking up throughout the night and early morning?
- Yes No Do you wake up early in the morning (4 or 5 a.m.) and can't get back to sleep?

## **ENVIRONMENTAL OVERLOAD**

- Yes No Do you find yourself easily overwhelmed in noisy or crowded places (feeling overwhelmed in a busy store or around noisy children)?

## **IMPULSIVENESS**

- Yes No Do you find yourself making poor or impulsive decisions (saying things "without thinking" that may hurt others feelings; increase in impulse buying?)

## **CONCENTRATION**

- Yes No Do you have difficulty concentrating (can't seem to stay focused on what you are doing)?

## **DISTRACTION**

Yes    No    Are you easily distracted (someone interrupts you while you are doing a task and you lose your place)?

## **ORGANIZATION**

Yes    No    Do you have difficulty getting organized or completing a task (leave out a step in a recipe or started multiple projects but don't complete them)?

\_\_\_\_\_ **Total Number of Yes Answers**

If you have 5 or more Yes answers, discuss the results of this questionnaire with your doctor.

## HOW THE BRAIN IS HURT

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Each year in America, one million people are seen by medical doctors due to a blow to the head. Of that number, 50,000 to 100,000 have prolonged problems that will affect their ability to work and/or affect their daily lives. The majority of people that I see are injured in car accidents. It is important to note that you do not have to be traveling at a high rate of speed to get a head injury. Nor do you have to hit your head on an object (steering wheel, windshield) to injure the brain. Even at moderate rates of speed, traumatic brain injuries can and do occur. Three separate processes work to injure the brain: *bruising (bleeding), tearing, and swelling*.

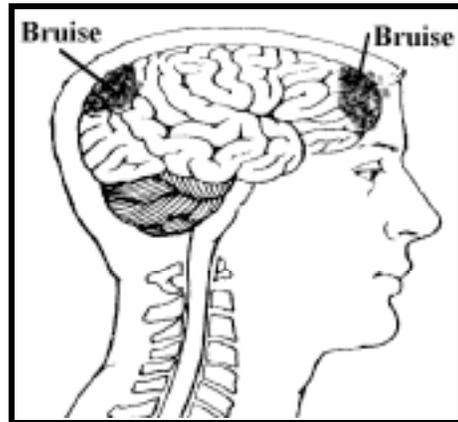
### **BRUISING (BLEEDING)**

If a person is driving a car at 45 miles per hour and is struck head-on by another car traveling at the same rate of speed, the person's brain goes from 45 miles per hour to zero in an instant. The soft tissue of the brain is propelled against the very hard bone of the skull. The brain tissue is "squished" against the skull and blood vessels may tear. When blood vessels tear, they release blood into areas of the brain in an uncontrolled way. For example, one might imagine a dam that breaks, causing water to flood the streets of a town.

Why do medical experts seem so concerned about bleeding in the brain? A major problem is that there is no room for this extra blood. The skull, being hard and brittle, does not expand. So the blood begins to press on softer things--like brain tissue. Brain tissue is very delicate and will stop working properly or may even die off. With large amounts of bleeding in the brain, the pressure will make critical areas of the brain stop working. Areas that control breathing or heart rate could be affected, and a life or death situation could develop within hours of the accident. Some people

have sustained a head injury from a car accident and seem "just fine" right after at the accident. Some have even gotten out of the car and directed traffic. Within a short period of time, they began to get more and more confused until they eventually lapse into a coma. So, you can see why Emergency Medical Technicians at the scene of the accident are so anxious to have people go to a hospital following a car accident.

There is also an "odd" thing that the brain goes through during a car accident. The brain, which is very soft, is thrown against the front part of the skull, which is very hard, and bruising can happen. But the injury process is not over. The brain, and rest of the body, fly backward. This bouncing of the brain first against the front of the skull and then against the back of the skull, can produce bruises in different parts of the brain. Thus people can have a bruise not only where their foreheads hit the steering wheel, but other areas of the brain as well. Doctors call this a "contra coup" injury.



## TEARING

At some point in time, we've all played with the food "Jell-O". If you put a thin cut in a square of Jell-O with a knife and let it go, the Jell-O will come back to shape if you jiggle it. The Jell-O will look perfectly good up until the time you go to lift it up, and there will be the slice. The brain has a consistency slightly firmer than Jell-O, but the same effect applies. In the case of the car accident, the brain is thrown forward, then bounced backward (remember those car commercials where the crash dummy flies forward, then comes flying backward). In this forward/backward motion, the brain can be torn. The brain can also be torn by the effects of "energy". If you take a block of ice and hit it with a hammer (assuming you don't completely shatter the ice), you will see little cracks in the ice. Energy from the hammer has been transferred to the ice,

producing the web-like cracks. Tearing in the brain is very serious. Tearing in the brain "cuts" the wires that make the brain work.

One of the problems with tearing is that it happens on a microscopic level (the brain has about 100 billion of these "wires"). This tearing may not show up on typical medical tests. Devices that take pictures of the brain will not see these small tears. Two common ways of viewing the brain are with a CT Scan (using X-rays) and an MRI (using magnetic fields) to create pictures of the brain. Both of these techniques are very good at seeing blood and tumors in the brain, but they are not good with tears (which are very small). In a number of medical studies with people who have head injuries, only 10 to 15 percent had "positive" CT Scans or MRI findings. By the way, a "positive" in the medical business is NOT a good thing. It means that they found something that is abnormal in the brain.

## **SWELLING**

If I drop a bowling ball on my foot, my foot will turn "black and blue" due to blood leaking under the skin. But my foot will also do something else--it will swell up. The body realizes that the foot has been injured and sends agents to heal the injured area. The problem with the brain is that there is no extra room and the pressure begins to build up. This pressure pushes down on the brain and damages structures in the brain. If there is too much pressure, this can stop important structures that control breathing or the heart rate. Sometimes, doctors will install a "relief valve" (intra-cranial pressure monitor or ICP) to let off the excess pressure.

## **OPEN VERSUS CLOSED HEAD INJURY**

Not too long ago, doctors made the distinction between open and closed head injury. In an open head injury, the skull is fractured and doctors assumed this would produce a severe head injury. In closed head injury, the skull is not broken and doctors assumed these produce less severe injuries. Wrong! In closed head injury, pressure builds up and damages brain tissue. If you fracture the skull, you may let off excess pressure thus

saving the brain from further damage. Because of the wide variation in patients, these terms are no longer used.

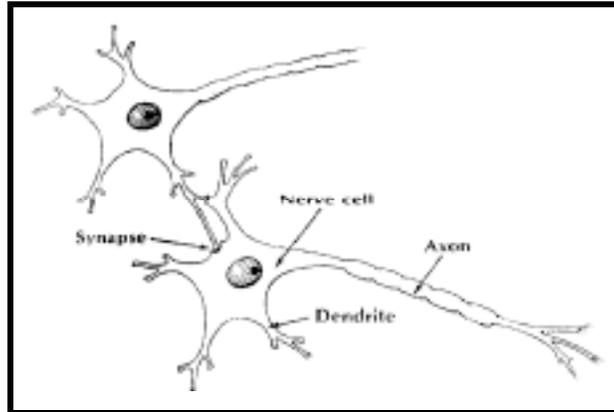
## **UNDERSTANDING HOW THE BRAIN WORKS**

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It's important to understand the complexity of the human brain. The human brain weighs only three pounds but is estimated to have about 100 billion cells. It is hard to get a handle on a number that large (or connections that small). Let's try to get an understanding of this complexity by comparing it with something humans have created--the entire phone system for the planet. If we took all the phones in the world and all the wires (there are over four billion people on the planet), the number of connections and the trillions of messages per day would NOT equal the complexity or activity of a single human brain. Now let's take a "small problem"--break every phone in Michigan and cut every wire in the state. How long would it take for the entire state (about 15 million people) to get phone service back? A week, a month, or several years? If you guessed several years, you are now beginning to see the complexity of recovering from a head injury. In the example I used, Michigan residents would be without phone service while the rest of the world had phone service that worked fine. This is also true with people who have a head injury. Some parts of the brain will work fine while others are in need of repair or are slowly being reconnected.

### **AN ELECTRICAL AND CHEMICAL MACHINE**

Let's start looking at the building blocks of the brain. As previously stated, the brain consists of about 100 billion cells. Most of these cells are called neurons. A neuron is basically an on/off switch just like the one you use to control the lights in your home. It is either in a resting state (off) or it is shooting an electrical impulse down a wire (on). It has a cell body, a long little wire (the "wire"



is called an axon), and at the very end it has a little part that shoots out a chemical. This chemical goes across a gap (synapse) where it triggers another neuron to send a message. There are a lot of these neurons sending messages down a wire (axon). By the way, each of these billions of axons is generating a small amount of electrical charge; this total power has been estimated to equal a 60 watt bulb. Doctors have learned that measuring this electrical activity can tell how the brain is working. A device that measures electrical activity in the brain is called an EEG (electroencephalograph).

Each of the billions of neurons "spit out" chemicals that trigger other neurons. Different neurons use different types of chemicals. These chemicals are called "transmitters" and are given names like epinephrine, norepinephrine, or dopamine. Pretty simple, right? Well, no. Even in the simplified model that I'm presenting, it gets more complex.

## **IS THE BRAIN ONE BIG COMPUTER?**

Is the brain like a big phone system (because it has a lot of connections) or is it one big computer with ON or OFF states (like the zeros and ones in a computer)? Neither of the above is correct.

Let's look at the brain using a different model. Let's look at the brain as an orchestra. In an orchestra, you have different musical sections. There is a percussion section, a string section, a woodwind section, and so on. Each has its own job to do and must work closely with the other sections.

When playing music, each section waits for the conductor. The conductor raises a baton and all the members of the orchestra begin playing at the same time playing on the same note. If the drum section hasn't been practicing, they don't play as well as the rest of the orchestra. The overall sound of the music seems "off" or plays poorly at certain times. This is a better model of how the brain works. We used to think of the brain as a big computer, but it's really like millions of little computers all working together.

## **GETTING INFORMATION IN AND OUT OF THE BRAIN**

How does information come into the brain? A lot of information comes in through the spinal cord at the base of the brain. Think of a spinal cord as a thick phone cable with thousands of phone lines. If you cut that spinal cord, you won't be able to move or feel anything in your body. Information goes OUT from the brain to make body parts (arms and legs) do their job. There is also a great deal of INCOMING information (hot, cold, pain, joint sensation, etc.). Vision and hearing do not go through the spinal cord but go directly into the brain. That's why people can be completely paralyzed (unable to move their arms and legs) but still see and hear with no problems.

Information enters from the spinal cord and comes up the middle of the brain. It branches out like a tree and goes to the surface of the brain. The surface of the brain is gray due to the color of the cell bodies (that's why it's called the gray matter). The wires or axons have a coating on them that's colored white (called white matter).

## **TWO BRAINS--LEFT AND RIGHT HEMISPHERE**

We have two eyes, two hands, and two legs, so why not two brains? The brain is divided in half, a right and left hemisphere. The right hemisphere does a different job than the left. The right hemisphere deals more with visual activities and plays a role in putting things together. For

example, it takes visual information, puts it together, and says "*I recognize that--that's a chair,*" or "*that's a car*" or "*that's a house.*" It organizes or groups information together. The left hemisphere tends to be the more analytical part; it analyzes information collected by the right. It takes information from the right hemisphere and applies language to it. The right hemisphere "sees" a house, but the left hemisphere says, "*Oh yeah, I know whose house that is--it's Uncle Bob's house.*"

So what happens if one side of the brain is injured? People who have an injury to the right side of the brain "don't put things together" and fail to process important information. As a result, they often develop a "denial syndrome" and say "there's nothing wrong with me." For example, I treated a person with an injury to the right side of the brain--specifically, the back part of the right brain that deals with visual information--and he lost half of his vision. Because the right side of the brain was injured, it failed to "collect" information, so the brain did not realize that something was missing. Essentially, this person was blind on one side but did not know it. What was scary was that this person had driven his car to my office. After seeing the results of the tests that I gave him, I asked, "Do you have a lot of dents on the left side of your car?" He was amazed that I magically knew this without seeing his car. Unfortunately, I had to ask him not to drive until his problems got better. But you can see how the right side puts things together.

The left side of the brain deals more with language and helps to analyze information given to the brain. If you injure the left side of the brain, you're aware that things aren't working (the right hemisphere is doing its job) but are unable to solve complex problems or do a complex activity. People with left hemisphere injuries tend to be more depressed, have more organizational problems, and have problems using language.

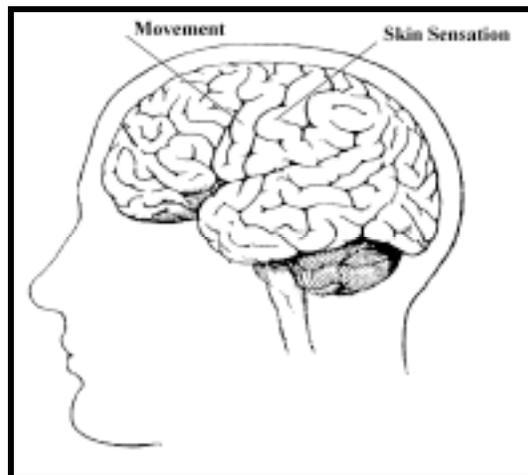
## **VISION--HOW WE SEE THINGS**

Information from our eyes goes to areas at the very back of the brain. We've all seen cartoons where the rabbit gets hit on the head and the rabbit sees stars. This can actually happen in human beings (trust me, not a good

thing to do at home!). If you take a hard enough blow to the back of the head, this brain area bangs against back of your skull. This stimulates it and you can see stars and flashing lights. Remember those two hemispheres? Each hemisphere processes half the visual information. Visual information that we see on the left gets processed by the right hemisphere. Information on the right gets processed by the left hemisphere. Remember, wires that bring in information to the brain are "crossed"--visual information from the left goes to the right brain.

## MOVEMENT

The area of the brain that controls movement is in a very narrow strip that goes from near the top of the head right down along where your ear is located. It's called the motor strip. If I injure that area, I'll have problems controlling half of my body. If I have a stroke in the left hemisphere of my brain, the right side of the body will stop working. If I have an injury to my right hemisphere in this area, the left side of my body stops working (remember, we have two brains). This is why one half of the face may droop when a person has had a stroke.



## HEARING AND LANGUAGE

In the general population, 95 percent of people are right-handed, which means that the left hemisphere is the dominant hemisphere. (For you left-handers, the right hemisphere is dominant.) With right-handed people, the ability to understand and express language is in this left temporal lobe. If I were to take a metal probe, and charge it with just a bit of electricity, and put it on the "primary" area of my left temporal lobe, I might say "*hey*,

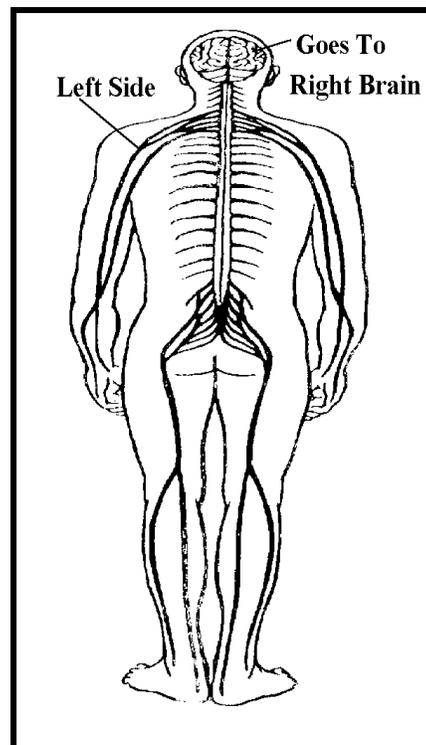
*I hear a tone.*" If I move this probe to a more complex area of the temporal lobe, I might hear a word being said. If I move the electrical probe to an even more complex area, I might hear the voice of somebody I recognize; *"I hear Uncle Bob's voice."* We have simple areas of the temporal lobe that deal with basic sounds and other areas of the temporal lobe that look at more complex hearing information.

The right temporal lobe also deals with hearing. However, its job is to process musical information or help in the identification of noises. If this area is damaged, we might not be able to appreciate music or be able to sing. Because we tend to think and express in terms of language, the left temporal lobe is more critical for day-to-day functioning.

The vision areas and the hearing areas of the brain have a boundary area where they interact. This is the area of the brain that does reading. We take the visual images and convert them into sounds. So if you injure this area (or it doesn't develop when you are very young), you get something called dyslexia. People who have dyslexia have problems that may include seeing letters backwards or have problems understanding what written words mean.

## SKIN SENSATION

If something lands on my left hand, this information will be transmitted to the right side of my brain. It goes to the area of the brain next to the area that deals with movement. The **tactile** area of the brain deals with physical sensation. Movement and feeling are closely related, so it makes sense that they are next to each other in the brain. Because movement and tactile areas are located close to each other, it is not uncommon for people with a brain injuries to lose both movement and feeling in parts of their body. Remember--tactile



information from the left side of the body goes to the right brain, just like movement and vision.

### **FRONTAL LOBES--Planning, Organizing, Controlling**

The biggest and most advanced part of the brain is the frontal lobe. (It's called the *frontal* lobe because it's in the front part of brain.) One job of the frontal lobe is **planning**. You have probably heard of "frontal lobotomies." At the turn of the century, this surgery was done on people who were very violent or who were in a psychiatric hospital because they were very agitated. Doctors used surgery to damage this area of the brain. Following this surgery, people became very passive and less violent. At first, scientists saw this as a great thing. Neurosurgery could stop behavioral problems such as violence. The problem was that the patients stopped doing a lot of other things. They didn't take care of themselves and they stopped many activities of daily living. They basically sat there. In head injury, individuals with frontal lobe impairment seem to lack motivation and have difficulty doing any task that requires multiple steps (e.g., fixing a car or planning a meal). They have problems with planning.

The frontal lobe is also involved in **organizing**. For a lot of activities, we need to do step A, then step B, then step C. We have to do things in order. That's what the frontal lobes help us do. When the frontal lobe is injured, there is a breakdown in the ability to sequence and organize. A common example is people who cook and leave out a step in the sequence. They forget to add an important ingredient or they don't turn the stove off. I've met a lot of patients who've burned or melted a lot of pans.

Additionally, the frontal lobes also play a very important role in **controlling emotions**. Deep in the middle of the brain are sections that control emotions. They're very primitive emotions that deal with hunger, aggression, and sexual drive. These areas send messages to other parts of the brain to DO SOMETHING. If you're mad, hit something or someone. If you're hungry, grab something and eat it. The frontal lobes "manage" emotions. In general, the frontal lobe has a NO or STOP function. If your

emotions tell you to punch your boss, it's the frontal lobes that say "STOP or you are going to lose your job." People have often said to me "*a little thing will set me off and I'm really mad.*" The frontal lobes failed to stop or turn off the emotional system.

On the other hand, we have talked about how the frontal lobes plan activities. The frontal lobes may fail to plan for some types of emotion. For example, sexual interest involves some level of planning or preparation. Without this planning, there is a lack of sexual interest. A lack of planning can also affect the expression of anger. I've had some family members say "*You know, the head injury actually improved him, he's not such a hot-head anymore.*" If you listen very carefully, you're also going to hear "*he's not as motivated anymore.*" Remember, the frontal lobe plans activities as well as controls emotions.

## **MEMORY**

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Impaired memory is one of the universal problems of people with head injury. All of my patients have complained about memory problems following their injury. Most people think of memory as being "good or bad." As we get older, we recognize that our memory isn't as good as it used to be. It's more complicated than that. There are several different types of memory . Let's take a look at them.

### **TYPES OF MEMORY**

First, we'll look at the different types of memory. For example, we all have memory for music. We can be listening to a song on the radio and have a very distinct feeling associated with that music. The brain processes music and puts that information in one part of the brain. We also have memories for taste and smell. We know the taste of chocolate. We know the smell of burning rubber. We have memories for the things we feel (physical). We can remember the difference between the feel of silk and the feel of sand paper. Each type of memory has a different site in the brain. Two of the more important types of memory are vision and hearing (in this case, words). Visual things are the things we see, such as a familiar place or where we've left our car. We also have memory for language, including things that we've heard or read (things we've read we translate into language). Verbal information is stored in the left hemisphere with visual information stored in the right hemisphere of the brain.

## **IMMEDIATE MEMORY**

Information going into the brain is processed at several stages. I'm going to simplify at this point and discuss what I call immediate memory. Immediate memory really doesn't last very long--perhaps minutes. When do you use immediate memory? When you call information for a phone number, the operator will tell you a seven digit number. If you're pretty good, you can remember those seven digits long enough to dial the phone. That's immediate memory--information that is briefly saved. With people who have a head injury, immediate memory can be "good" or it can be "bad." The problem for most head-injured people, however, is with short-term memory.

## **SHORT-TERM MEMORY**

There's some variation in how people define short-term memory. I define it as the ability to remember something after 30 minutes. In a head injury, someone's immediate memory may be good, yet they may still have problems with short-term memory. For example, a nurse in the hospital asked a head-injured patient to get up and take a shower and get breakfast. The patient said that he would, but the nurse came back 30 minutes later and the patient was still sitting in bed. When the nurse asked him why he didn't get up and take a shower, he said that the nurse never told him. So immediate memory is something you quickly "spit back", but the problem rests more with short-term memory. For example, someone may tell you to go to the store and get some milk, some eggs, a newspaper, and some dish soap. By the time you get to the store, all that you remember is the milk. In head injury, impaired short-term memory is a very significant problem.

## **LONG-TERM MEMORY**

Long-term memory is information that we recall after a day, two weeks, or ten years. For most head-injured people, their long-term memory tends to be good. One patient told me "*I can tell you what happened 10 years ago with great detail; I just can't tell you what happened 10 minutes ago.*" After you get a head injury, short-term memory isn't working, so

information has a hard time getting to long-term memory. For example, head-injured people may double or triple their usual study time in preparing for a test the next day. By the time they get to the exam, they are completely blank on the material. People with head injuries have also told me "*you know, time just seems to fly by.*" The little events of the day are sometimes forgotten, making life "fly by" when you look back at events that have happened since the injury.

## **LOST MEMORIES--TWO TYPES OF AMNESIA**

Before we go on with memory, let's talk about two common things that happen with people with head injuries: **retrograde** and **anterior** grade amnesia. Amnesia means you lost a memory that you once had. It's as if someone has erased part of your past. Retrograde amnesia means you have lost memories for events **PRIOR** to the accident. For some people, retrograde amnesia can cover just a minute or even a few seconds. In other words, they'll recall the car coming right at them but are unable to recall the moment of impact. For other people, retrograde amnesia may affect longer periods of time. The last three or four hours prior to the accident are gone. I had one individual who had lost the last year of his life. As people get better from their head injuries, long-term memories tend to return. However, memories tend to return like pieces of a jigsaw puzzle; these bits and pieces return in random order. In general, the smaller the degree of retrograde amnesia, the less significant the head injury.

Another form of memory loss is called **anterior** grade amnesia. In this case, events **FOLLOWING** the accident have been erased. A good part of that is due to the brain injury itself. Complex systems in the brain are injured. The chemical balance in the brain is upset. As brain chemistry normalizes and brain systems begin working, memory also starts to work. I've had patients who have spent several months in the hospital but are only able to recall the last to two to three weeks of their stay.

## **WHY IS MEMORY IMPAIRED?**

Why doesn't my short-term memory work? Well, let's quickly review how the brain works. We know the information flows in through the middle of our brain and branches out like a tree. Before that information goes to different areas, it goes through a channeling/filtering system. It's almost like a mail room--this information goes into this box, and that letter goes into that box. When the brain is injured, these middle areas get pressed upon because of swelling (pressure pushes down on the brain). The middle sections of the brain are also resting on the bone of the skull. Because of forward and backward movement of the brain in an accident, they get sheered or torn. A problem develops when there is a large flow of information coming in which the brain can't process, or when information is not being sent to the right place. So the mail room of the brain is not doing its job.

There is also a second type of memory problem. Once information is stored in the brain, the brain has a hard time finding it. For example, you saw a movie but you can't recall the name of the actor in the movie. You can visualize who the actor is, but can't come up with his name. People typically describe a "*tip of the tongue*" type of thing--"*I know what I want to say but I just can't get it out*". It's almost as if the brain is saying, "searching, searching" and not finding. Several minutes later, it just comes to you. So think of it as a library in some sense. If I take a book on history and I just put it anywhere in the library, I'm going to have to search that whole library to get that one book. So there are basically two kinds of memory problems: storage problems and retrieval problems.

## **WHAT CAN I DO TO IMPROVE MY MEMORY?**

**Work with a Specialist in Memory**--One of the most important things is to get help from people who specialize in head injury. Every head injury program has a specialist who teaches memory strategies. In most cases, this is a Speech Therapist (they don't just help people who have slurred speech). In the Neuro-Recovery program, our Speech Therapist teaches 15 different memory strategies and helps you to pick the 2 or 3 that work best for you. There is often a fair amount of testing in order to figure out the best memory strategy for each head-injured person. For some

people, one type of memory may be impaired (verbal recall) but another type be intact (remembering visual information). If I know that my verbal memory is not very good, I write things down and encourage visual memory systems to work. Specialists can help you pick out the best memory strategies to help you. Once you find an effective strategy, keep working on it. Think of memory like a muscle. The more you use it, the stronger it gets.

**Get Organized**--We learn better if we are organized. Many people have told me that, prior to their head injury, they had incredibly messy desks with papers all over. But if someone came in and said, "*I need this particular paper*", they could pull it out of a big pile and say "*here it is.*" After a head injury, though, the ability to organize gets really messed up. One symptom of not being organized is when someone says, "*I've started 50 projects and haven't finished one of them.*" If you organize information, it tends to help you recall it. For example, if you are constantly losing your car keys or constantly forgetting where you put your wallet, there's one simple technique to use. **Put things in the same place.** Always put your car keys in one spot on the dresser. Always put your purse in one spot in the house and nowhere else. Being organized helps your memory and you will be less likely to lose things.

**Break It Down**--Another thing that we can do to help memory is to break it into small bits. If you have something really tough to learn, try to break it down into small bits and then learn each one little bit at a time. Some people call this "chunking;" you are memorizing little "chunks" of information. For example, your brand new VCR has a remote control with 50 buttons on it. Reading the entire manual in one sitting to learn what all of the 50 buttons do is very hard. So, learn one function and then play with that feature for awhile. Once you've learned that, go on to the next button. We've been using this technique for years to learn simple information like a phone number. The wonderful folks at Bell Labs (they invented the phone) figured out that people will learn a 7 digit phone number if you group 3 digits together and then group 4 digits together (a "chunk" of 3 numbers and a "chunk" of 4 numbers).

**Using Association--** Association is really important for retrieving important information. For example, you are taking a literature course and you need to remember a famous essayist--Francis Bacon. You might associate the image of a piece of bacon with the name of this person. So if you're trying to think of this explorer, an image of a piece of bacon will come to you. This approach is particularly helpful with learning names. Remembering names is a difficult task for most people in the world; it is especially hard for most people with a head injury.

**Get a Daily Planner--**Probably one of the best things you can do to help your memory is to use a daily planner. This brings up two important points:

- ◆ **The First Rule of Memory--**write everything down in one spot (your daily planner).
  
- ◆ **The Second Rule of Memory--**write it down when it's fresh in your mind.

For example, you go to your doctor's office and you are asked to return for another appointment. Many people have a calendar stuck on their refrigerator or on a wall at home. By the time you get back home, you've forgotten the date or lost the appointment card. Next time, bring a planner to the doctor's office and write your appointment in it just after the doctor tells you the date. Get a medium size planner or something called an organizer. Don't get something that's too small--you're going to be doing a lot of writing. **Write complete notes!** Some people make notes so short that they later can't figure out what the note means.

**Make A "To Do" List--**In addition to a planner, make a "to do" list. For example, you may have a number of chores to do around the house but none of them in any particular order. What you can do is get a small pad of paper and write down the things that they have to do. Once you have this list, decide which task to do first, second, third, and so on. This will work if your list doesn't get too long. If the list gets too long, you're going to run into problems.

**Make a "Modified To Do" List**--I commonly hear the same problem, *"I've got 50 projects going but I haven't finished any of them."* This is a combined problem of memory deficits and organizational deficits. One solution is to buy a small dry-erase board and put it up in the home (or office). On the board, you are only allowed to list five items on the "To Do" list. You cannot add another item to the board until you have completed one of the items already on the board. Make a "Modified To Do List" and put it somewhere in your house where the whole family can see it. Family can also offer suggestions to help you to get projects organized. This will in turn help family members get a better understanding of what the head-injured person has to deal with. When you get organized and use the Planner/To Do List, you'll feel better about yourself because you will be getting things accomplished.

## **THINGS THAT CAN AFFECT MEMORY**

**Fatigue and Sleep**--Memory can be affected by a number of things. Some of these influences can affect even people without a head injury. If you do have a head injury, these effects are multiplied. For example, if you're tired, your memory tends to be poor. If you have to learn something really important, it's best to learn it when you're fresh. Generally, most people with head injuries learn better in the morning than in the late afternoon. So if you've got something really important (a test for school), studying the night before the exam may not be very useful. The best time to study is in the morning. In addition, people with head injuries commonly have sleep disorders. It's very important that you talk with your doctor about getting your sleep pattern back to normal. If you wake up tired, you're going to make memory problems worse. (See the sections of this book on Sleep Disorders and Fatigue.)

**Strong Emotions**--Very emotional situations will distort your memory. If someone comes into a bank and waves a gun at you, this will create a very emotional situation (intense fear). Even though there are five people looking at the same person, you will get five different descriptions of the robber (that's one reason why they have cameras in banks). Being afraid, mad, or anxious will alter your memories. What should you do in

emotional situations? You can't always control your emotions, but there are situations where you will need to recall important information. For example, going to a doctor's office can be a very emotional experience (many people are afraid or anxious). Most head-injured people find this a very stressful situation. One approach is to bring a family member or friend along. Another approach is to tell your doctor of your memory problems and ask the doctor if you can write down important information.

I have included a Memory Sheet for Doctors' Appointments. When you get to the doctor's office, you may be so nervous that you forget to tell your doctor ALL of your problems. The next time you see your doctor, you may recall some of the old problems that you forgot on the first visit. A common complaint of doctors who work with head-injured patients is, "*Every time I see this person, I hear a new problem.*" Using the sheet of paper at the back of this book can help you organize your thoughts. Doctors deal better with information when it is presented in a quick and organized form. For each problem, I left a little space for you to write down what the doctor recommends. In this way, you can bring your memory sheet to future appointments and keep track of your progress. For example, maybe you're not sleeping and one medication approach is being tried. If that approach doesn't work or has a limited effectiveness, you will want to keep track of that and bring it up the next time you see your doctor. If you don't write these problems down and monitor them, you'll be less likely to make progress with them.

Certain types of medications (pain killers, for example) can affect memory. In the hospital, people can be on fairly significant amounts of pain killers because they have broken bones or other injuries. Some medications can make you tired, which in turn makes your memory worse. It is important to have an ongoing dialogue with your doctor about your medications. People have told me, "*I'd rather be in a little bit pain so I can be more alert.*" Sometimes the goal of pain medication is not to get rid of all the pain, but to control it. Talk with your doctor about your medications and the possible effect of medications on memory.

## HEADACHES

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Headaches can be a serious problem with a head injury. If you are in pain every day (headaches can also wake you in the middle of the night), headaches will wear you down mentally and emotionally. How common are headaches in head injury? In one study of head-injured people, 50% reported having a headache when they were discharged from the hospital. After one year, 33% of this same group of people said "*my head still hurts.*" That's a long time to have a headache. I'm going to describe three common types of headaches that people with a head injury get. There are many other variations on the types of headaches that can develop, but most head-injured people will have one (or more) of the following:

### **PAIN IN THE BACK OF THE HEAD/NECK/SHOULDER**

This type of head pain is described as a pain that starts at the base of the head/neck area. The pain commonly gets worse as the day goes on and it may spread over the top of the head to the front part of the head. What is causing this? You have to remember that when you were in a car accident, your head was traveling at a high rate of speed. For example, a car is traveling 50 mph and it suddenly stops. Everything in the car goes from 50 mph to zero in an instant, and your head is thrown forward. The only thing holding your head on the top of your body is a bunch of muscles, some bones, and some cartilage. Your neck consists of bones, rubbery disks (bones don't bend--the disks help the neck to bend), and muscles so you can move your neck and head. When your head is thrown forward in the accident, the disks that are between the bones can get squished. These

squished disks may press on nerves in the neck. Pressing on the nerve can make parts of the body numb or decrease strength in parts of the body. Another problem that can happen at the same time is stretched muscles. If you take a rubber band and stretched it almost to the breaking point, then let it come back, you may have noticed a change in the rubber band. A similar thing happens with muscles. If you really yank on them, they come back in knots. Sometimes, you can actually feel the knots. This stretched muscle problem is called myofascial pain disorder by doctors. The pain at the back of the head can go on for a long period of time (possibly for years, especially if you keep re-injuring or stressing the sore muscles). So, the first type of head pain is due to muscle tension and/or nerve problems. Unfortunately, this type of headache can trigger a migraine-type of headache following a head injury.

## **MIGRAINE-LIKE HEADACHES**

The second type of headache is much tougher. Following a head injury, you can develop a headache that resembles a migraine headache. Pain tends to be in the front of the head. Many complain that their forehead or temples throb. It is commonly described as a "pounding" pain. Emotional stress or intense concentration tends to bring on or make these headaches worse. One possible explanation of this problem is a change in the vascular system of the brain. The brain has veins and arteries that supply blood to it. The brain weighs only about three pounds but uses 30% of the oxygen and energy in your body. So there's a lot of blood flowing to the brain. Think of this blood flowing through a hollow tube, like the water flowing through pipes in your home. These pipes, however, can change their diameter. If the veins and arteries couldn't change shape, all the blood would run down to our feet. The heart is pumping the blood around the body and veins constrict to keep a constant pressure. If I make the diameter smaller and put more pressure on the system, I develop high blood pressure. If my blood pressure is too low, I'll faint because there's not enough pressure to make things work. With head injury, these very finely tuned little pipes get stretched or injured. Remember, the brain is yanked forward and backward in an accident. Things get stretched and don't work the way they normally do. In a classic migraine headache, blood is flowing at a

normal rate and the tubes (veins/arteries) suddenly get much smaller. During this constriction phase, some people get a warning sign. They may become very sensitive to light, or they may lose their peripheral vision (the outside of their vision goes black and they just see the middle part). That's just the start. The veins go from being very small to "giving up", in which they suddenly open wide. When this happens, the pounding or throbbing headache begins.

### **THE "STABBING" HEADACHE**

The third type of headache is described as a sudden, sharp pain. One person described this as *"I'm walking along and all of a sudden I feel like someone is jamming a hot metal rod through my skull."* It is a severe pain that will nearly bring some people to their knees by its intensity. The pain may last from a few seconds to a minute or two. Most doctors don't treat it because it lasts for a very short period of time. There are some drugs (typically of the anti-seizure variety) that can help with this problem. Some of my patients have reported improvement when a physical therapist or massage therapist works on the neck area. If you are thinking about this option, ALWAYS talk with your physician first!

### **COPING WITH HEAD PAIN**

If you have one or more of these headaches, what should you do about them? Let's start with the neck/back of head pain. After an accident, your doctor may send you to a physical therapist. It is important to find a physical therapist who is familiar with this problem. The first time a physical therapist works on your neck, the pain may get much worse. I've even had one or two people say the pain was so bad that they passed out. And this was just from simple moving or stretching. Many people say *"I went to this physical therapist and it made me worse so I'm not going back."* Tell your physical therapist that you hurt. **But remember, it gets worse before it gets better.** Physical therapy alone may not be enough. You may have to continue loosening these muscles up by exercising. Of all the exercise approaches, most of my patients feel that swimming is a big benefit. A warm water pool is probably one of the very best ways of

preventing these headaches. Its also very helpful for a lot of people who have back pain.

Migraine-like headaches are a lot tougher to deal with. These headaches will generally require some form of medication. Medications that doctors use to treat headaches tend to generate a lot of questions. There are two medication approaches: **controlling pain** that already exists and **preventing headaches** from getting started. To control pain, many people use drugs like Motrin, Darvocet, and Tylenol. One problem with pain medications is that you have to take them every 4 to 6 hours. They can interfere with your thinking and memory as well. In using pain killers, be aware of the following:

- ◆ If you use pain medications more than three days per week, you need to be aware of something called “**analgesic rebound headache**”. Chronic use of pain killers can cause you to have MORE headaches (an increase in the number of headaches).
- ◆ **Don’t assume that all over-the-counter medications are safe!** For example, long term or intensive use of Tylenol can produce liver damage. People also seem to feel free to take extra amounts of over-the-counter pain killers (if two pills work, six must be better). If you have chronic head pain, ALWAYS talk with your doctor about over-the-counter medications.

There are some very effective preventative types of medications. These tend to be “unusual” types of drugs. For example, some anti-depressant medications can help with headaches. Why? Did you ever notice that when you're depressed you feel more achy? Burn victims, people who have intense pain, often use anti-depressant medications. These medications help decrease both depression and pain. Some of these anti-depressant medications may also help normalize sleep. Without a good night's sleep, you're going to be more prone to headaches. Another medication approach to headaches is to stop them just as they are starting. In this approach, a medication (i.e., Imitrex, Zomig) is used in the very early phase of a headache. Timing of taking the drug is critical with this

approach. One of the best ways to deal with headaches is to prevent them. In a new use for a drug that's been around awhile, the anti-seizure drug Depakote has been approved by the FDA to treat migraine headaches. This drug works very well in about 70 percent of head-injured patients. However, many people have problems with the side effects of this drug. It's hard on the stomach, so many people have to take this drug with food.

I have one warning about vascular headaches--they tend not to have a "quick fix" with medications and there is a lot of trial and error in finding the medication that works. For many, medication may reduce, but not eliminate, head pain. You need to be very patient in working with your doctor. **TAKE MEDICATIONS EXACTLY AS YOUR DOCTOR DIRECTS!** Doctors who feel that you are taking medications improperly will hesitate to use more powerful medications that might benefit you. Read the section of this book on Dealing with Doctors. This chapter will help you to establish a positive relationship with your doctor. If you have frequent headaches, a solid relationship with your doctor is essential.

What can you do for vascular headaches on your own? The most common way people deal with a headache is to go to sleep or lie down. Try to lie down early before the headache gets bad. When you lie down, find a dark and/or quiet place. Most of my patients also avoid eating--largely because they report that their headaches make them sick to their stomachs. This next approach may help to prevent this type of headache: **Wear dark sunglasses!** I have people who go from a dark building out into the bright sunlight and have instant headaches. You can get these headaches especially in the early fall or in the summer when the sun is very low, and when you're looking at or driving into the sun. In general, the cheaper and darker the sun glasses, the better. Some people have used photo gray glasses; they tend to be not dark enough.

Some of the things that you eat and drink may affect the vascular type of headache. For example, some people who drink red wine will get an instant headache. There is an amino acid in red wine that can trigger a headache. In general, it's a good idea to avoid drinking alcohol following a head injury (a hangover is the brain's way of reminding you that you are

hurting it). The same amino acid in red wine is also found in some foods (such as hard cheeses). An allergic reaction may also cause a headache. If you have these nasty pounding headaches, pay close attention to your diet to see if food is triggering a headache.

Another important strategy for vascular headaches and muscular headaches is to manage your stress level. Involvement in something very stressful or something that makes you very nervous will often trigger a headache. If you have to do something stressful, it's better to deal with it early in the day when your thinking is better. If you deal with something late in the day when you are really tired, you're more likely to get a headache.

Sleep has an indirect role with headaches. When it's too warm in the house or you have too many covers on the bed, the body heats up and you'll have less restful sleep, which in turn increases headaches. A lot of people do something called "turtling," in which they pull the covers over their face if it's too cold in the house (like a turtle hiding in a shell). If you do this, you're breathing the same air over and over. The problem is that you're breathing carbon dioxide. There is less oxygen going into your brain, which may trigger a headache. The temperature of food can also trigger a headache. Remember taking large bites of really cold ice cream and remember those ice cream headaches? If you get headaches easily, you might have to take smaller bites of ice cream or make sure you warm up your mouth before you take another bite.

Keep a headache journal. Get a monthly calendar and each day rate your headaches on a 1 to 10 scale with "1" being no headache and "10" being the worst headache you've ever had. You can also note what events in your life tend to trigger a headache. A lot of people start to realize how important stress is when they look through the entire month and see the relationship between their bad headaches and the activities of the same time period. They may notice a pattern developing. Some people get more headaches toward the end of the week because stress tends to build up over time. You can get more headaches on the weekends due to family and friends visiting.

It is very helpful to bring this journal to your doctor. If the two of you are struggling with the best drug or a combination of drugs to use, the doctor is going to need some method of rating how they're doing. If your doctor asks "how's your headaches?" after trying a medication and you say "the same," the doctor may stop the medication. Because of the way you reported it, this may have been a mistake. For example, you bring in your headache journal sheet and you had 7's before the medication and now after the medication you have 5's. Your doctor may have been onto something, but you asked to stop it too early. So make a headache journal if you get headaches.

It is important to take medications for headaches (and other medical conditions) at the same time every day (no more than plus or minus 15 minutes). This is a big problem for many people with head injuries because they tend to be forgetful and may be missing important medications. For under \$40, Casio makes a watch that can be programmed for five events during the day. The beeping of the watch will remind you when to take medications. A lot of people don't want to carry all the jars of medications with them at once. You can buy little plastic holders for medications that you fill once a day (cost under \$10). Another nice thing about these pill holders is that you can double check to see whether or not you took your medication.

## **PROBLEMS GETTING ORGANIZED**

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A lot of people complain that following a head injury they have difficulty getting organized. I commonly hear, "*I've got 50 projects going, but I've completed none of them,*" or "*I start on something, but I just can't seem to finish it.*" These problems involve organization.

Why do people have a problem with organization? The front part of the brain is called the frontal lobe. We have a left frontal lobe and a right frontal lobe. Each is involved in planning activities, getting things in the right sequence, and evaluating possible errors. There are two types of processes that occur in the front of the brain: **language** and **visual analysis**. The left frontal lobe helps us with language. This is important because the majority of things that we do in our day-to-day life is language-related. The right frontal lobe generally involves visual organization. For example, if you're going to take a lawnmower apart, you've got to make sure all the parts go back together in the right order. Having a few "extra parts" after putting a lawnmower together is not a good thing. This problem happens very frequently in head injury.

Can you get a frontal lobe injury from hitting the back of your head? Yes. If you've ever watched the seat belt commercials on cars, you'll notice that in a head-on collision, the people are thrown forward in the car, then go flying backward. In a car that's been rear-ended, the brain is thrown backward, then bounces forward. The medical term for this is *contra-coup* injury. That's a French word meaning "other side". In this type of injury, the brain essentially rattles back and forth.

Many of my patients complain that they used to be able to handle 10 things at one time but now can only handle one or two. Secretaries, for example, often have to do multiple activities. They have to type, answer phones, talk with customers, and do filing, all at the same time. In your home, you cook dinner, watch television, and maybe have a load of laundry going at the same time. But if you have problems organizing and sequencing, you may lose track of one or more tasks. You may be watching TV or doing the laundry only to realize that you're also burning the food.

### **SO WHAT CAN I DO?**

Getting help in a head injury program is very important. These programs have a number of activities aimed at improving various skills. At Neuro-Recovery, we will give people two tasks, then throw in something to distract them. For example, we may have some noise going on in the room while the other tasks are being completed. The brain has to process many things at once. This is a gradual process, requiring a working knowledge of what the head-injured person can handle at one time.

If you're not involved in a head injury program, what can you do for yourself? Start simple--do one thing at a time. This may sound easy, but it's hard to do in the real world. For example, if you're home cooking a meal, family members can't be in the kitchen bugging you. You should not be doing other tasks at the same time (like the laundry or watching TV). Limit yourself to one activity at a time until you've mastered that task. Once you feel confident, start adding a second task. Be patient--this process can take many months.

One of the most important things to help with organization is writing things down. Get a daily planner and write things down in the order you're going to do them. Let's look at a common problem. Someone with a head injury may go into town because they need to get groceries. Afterwards, they realize that they needed to go to the post office; and now a second trip into town is needed. That's extra work and very frustrating if it happens to you enough. Sit down at the beginning of every day or the night before

(actually, you should do both) and look at your schedule. Plan what you are going to do. I know that people have very busy schedules, but taking that extra 10 minutes to organize is going to save you a lot of time and frustration.

Let's look at another common problem. Planning a meal each day is difficult even if you *don't* have a head injury; it can become a nightmare if you *do* have one. One solution is to sit down on Saturday or Sunday and plan out meals for the entire week. Just plan one main meal for each day. Once you have the main meal, go back and add dishes. Make a list of what you need and do your shopping in one visit. This will save both time and the daily frustration of making a decision. I know this sounds like a lot of work, but it will help stop the "brain lock" problem of not being able to make a decision.

Secondly, use a "Modified To-Do List" (This is also discussed in the *Memory* section of this book). Get a dry marker board (2x3 feet) and put it up somewhere in your house. Write on it the things that you have to do and then erase them as you complete them. Sometimes people will list 50 projects and none of them will get done. If you have this problem, create a list of 5 projects that you want to do and write them on the dry marker board. Don't add another project to the list until you completed one of the 5 items. As you add one, you have to subtract one. You may want to limit it to only 3 projects on the board; sometimes looking at even 5 things can be overwhelming.

Practice organization skills early in the day. Remember, fatigue will make your ability to organize worse. Do it when you are fresh.

## Getting Overloaded

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I call this problem the "Meijers Effect." In Michigan, we have a chain of large stores called "Meijers". They have a hardware department, grocery department, clothes department, photo department, and so on--all in one giant building. When people with head injuries go into one, they often find they can't stay for more than 10 or 15 minutes. There's just too much information to process. The reason that I call it the "Meijers Effect" is that even people without a head injury will say "on a busy day, I find Meijers too much to handle." But when my head-injured patients go into a store like this, they tell me "*I go into this place and I feel I'm going to jump out of my skin . . . I just can't handle all the noise . . . I JUST HAVE TO GET OUT.*" It doesn't happen only when going shopping, either. It can happen in noisy situations (playing loud music) or crowded settings (busy restaurants). I have many patients that say being around young children can also overwhelm them.

What is happening in the brain? Think of a tree with information flowing out to its branches. In the middle of the trunk (brain) is an area where information is sorted and sent to other areas. It is not by coincidence that the areas that process short-term memory and control sleep are in the same neighborhood. In previous sections of this book, I've talked about how these middle areas get squished or pressed on. In terms of getting overloaded, let's make another analogy. I want to drink out of a straw in a glass. I can get a drink because there is a small amount for water traveling at an even rate. If I try to drink from a fire hose going at full blast, I can't get a drink from it because there is too much water moving too fast. Think of information flowing like water in a pipe. If the brain can't handle the

flow of information, it gets overloaded. People with head injuries frequently have to cope with situations where there is too much information. When overloaded, some people become irritable or develop headaches. In large groups, some people with head injuries can't filter out one conversation from the next and become overloaded (they can only handle one conversation at a time).

What to do about this problem? In the early stages of recovery, many people have to change their lifestyle. For example, many of my patients find themselves not going to bars or noisy restaurants anymore. Many people now go to quieter restaurants or choose activities that are not as noisy. The problem is, you can't always choose quiet situations. For example, New Year's Day or Thanksgiving is very stressful for people with head injuries. There may be many people in the house talking, the football game may be on the TV, and the kids may be running around. If you have to handle overload situations, TAKE BREAKS! Find a quiet place and take a nap for an hour. You may have to go out to your car or go for a long walk by yourself. Inform your family members about this problem; they can try to help you cope with this. Some people have resorted to wearing ear plugs (for a noisy work environment or going to a basketball games). If you can't use ear plugs, try limiting your exposure to overload situations.

It's not always overload from sound; some people have visual overload. Typically, very bright lights will cause overload. When you go from a dark building to the bright light outside; you may be briefly shocked. With a head injury, the shock is 10 times greater and you may not adjust. What to do? Buy the darkest sunglasses you can find. Most often, the cheapest sunglasses work the best. This will also help those who get headaches from bright lights.

Visual overload can also occur from having to process too much information. For some people, finding their favorite breakfast cereal in a grocery store lane that has over 50 different cereals can cause the same overload. One suggestion is to try shopping at a smaller store and stick with that store.

## Sleep Disorders

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Nearly all of my head-injured patients have some form of a sleep disorder. This is rather confusing because people with head injuries can also have a fatigue disorder. You would think people with a fatigue disorder would want to sleep all the time or would sleep like rocks. You can, however, have both problems.

First, let's recognize what happens with a typical sleep disorder caused by a head injury. Typically, you may go to sleep fairly easily, although sometimes people can't stop their thoughts in the evening and have difficulty getting to sleep. Once you have fallen asleep, you may feel that you're waking up as often as every hour. By about 4 or 5 in the morning, you're wide awake, even though you are dead tired. In addition, many people who have head injuries are easily awakened by small noises. I've had patients who would sleep through a fire alarm prior to their head injuries, but who now wake up when a cat walks by.

Sleep is very important to the healing process. If you don't sleep, you're going to be tired throughout the day. If you're tired throughout the day, your memory will get worse and you'll be more cranky and irritable. Lack of sleep makes the other head injury symptoms much worse. Sleep also has an important role in physical healing. People may sustain muscle strain as well as head injuries. Muscles may be pulled due to the violent nature of a car accident. You can feel the "knots" caused by these muscle pulls. One of the things that happens when you sleep (in particular, when you dream) is that you become paralyzed. If you didn't do that, you would act out your dreams. Did you know that an EEG (which measures electrical

activity in the brain) taken when you're dreaming is identical to one taken when you're awake? The brain is going full blast when you dream. When you were young and your brain was not fully developed, you may have done things like sleepwalking. In other words, the part of the brain that kept you from acting out your dreams wasn't fully developed. As you got older, your brain developed and that paralysis prevented the sleepwalking.

When you're fully paralyzed in sleep, it allows your muscles to relax. When you're awake, you may think your muscles are relaxed when they're really not. When your muscles get tense, they can stay tense. Someone may massage your neck and it's painful because you've been tense without even knowing it. If you're sleeping poorly, you're not allowing those muscles to relax and heal. They're chronically in knots. One of the tough things about a muscle injury is that you can easily keep aggravating it. This can go on for years because you never allow it to heal.

There are medications that can help you with sleep problems. Although some medications are specifically designed to promote sleep (i.e. "Sleepers"), they are typically avoided by physicians who treat head injury. Many physicians use small doses of anti-depressant medications (e.g., Elavil or Desyrel) with their head-injured patients and have found it to be very effective. Typically, you take this medication a half hour before bedtime and you will sleep straight through the night. Sometimes this medication works too well and people sleep for 12 to 15 hours for the first 2 or 3 days. This is normal; your brain is trying to "catch up" on the sleep that it's missed. However, some people report side effects. They may report that it's hard to wake up in the mornings. But once you get going in the morning, you will feel a lot better. You need to talk to your doctor about any side effects. Some of them are temporary and go away with time. After about a month or two of working great, the medication may seem to stop doing its job, and may need readjustment. See your doctor--most patients with head injuries can get effective relief from this problem.

There are things you can do to promote what's called "sleep hygiene." For example, go to bed at exactly the same time every night--even on the weekend. Do not vary more than 15 minutes. That may sound

extreme, but if you go to bed at the same time and get up at the same time each day, your body will adjust to that pattern. Avoid caffeine. Caffeine has a negative effect on the brain, and for some people it may increase the likelihood of seizures. Avoid it especially in the evening. Try not to exercise late in the evening. If your room is too hot, that can interfere with the normal pattern of sleep through the night. If your room is too cold, you may do something called "turtling"--pulling the covers over your face and breathing the same air over and over again. That increases the carbon dioxide and may cause headaches or interfere with sleep. Make sure the room is very dark. This can be very important because light plays a critical role in your sleep pattern. Make sure it's quiet as well. Talk with family members about respecting your need to have quiet so you can sleep.

Is it good to take a nap during the day? If you're extremely fatigued, you may not have a choice. In general, *resting* is a good idea, but *sleeping* during the day tends to disrupt your evening sleep. For example, some people come home from school, sleep from 4:00 to 7:00, have dinner, and then can't sleep in the evening. It might be better to lie down and rest without allowing yourself to sleep. This will help to normalize your sleep pattern.



# FATIGUE

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A nearly universal complaint that people have with head injury is fatigue. Although fatigue decreases over time, it is a very persistent problem. Many patients recover from nearly all of their other deficits, only to have fatigue prevent them from returning to work full time (they go back, but at a part-time level). A lot of people are used to working 50, sometimes even 60, hours a week. In addition to a 9 to 5 job, they come home and work in the home, or they have a second job. Fatigue from a head injury drastically alters their lifestyle.

## **Mental versus Physical Fatigue**

There are two types of fatigue: physical fatigue and mental fatigue. "Physical" refers to doing some sort of physical labor such as mowing the lawn or working in a flower garden. Just after a head injury, physical fatigue may be troublesome. For example, if you're relearning to walk, the amount of effort it requires to relearn to coordinate the muscles and build up strength is going to be substantial. For most people, physical fatigue tends to go away after 6 months. What surprises people with a head injury is the mental fatigue. For example, you could spend all day in your yard pulling out weeds and not feel tired from it, but an hour of balancing the checkbook will leave you exhausted. This is mental fatigue, and tends to go on for long periods of time. Let's use another analogy. Think of owning a car that you can only fill with half a tank of gas. You can now only go half as far as you used to. When you run out of gas, the engine stops. With mental fatigue, it's as if the brain runs out of chemicals and just shuts down.

Why does this occur? Let's look at the brain as a big phone line system. We make a daily call from Chicago to New York City and it's a direct line. If the line breaks, you lose the connection. The phone company is prepared, however; they realize that phone lines break, so they've programmed their computers to reroute phone calls. As a result, a phone call from Chicago to New York may have to go to St. Louis, Pittsburgh, and then to New York. It's no longer a direct call--we've added 3 more

connections. More time and energy is needed to send the same information. This analogy seems to make sense. People with a head injury tell me that it takes much more effort to get the same answer.

Does fatigue get better over time? For most, it does. Does it go away completely? For most, it does not. At first, people may work for 3 hours and then they're beat. Eventually, they work for 4 hours, then 5 hours, then 6. I have many people who finally work 8 hours a day, but are extremely tired in the evenings and need the weekend to recover. If you become physically ill with a cold, or have surgery, this fatigue disorder briefly comes back with a vengeance.

### **What Can I Do?**

Most people tend to get fatigued in the afternoon, generally around 2:00 or 3:00. One suggestion--if you're going to do something that is stressful or hard, do it in the morning. Your mind will be a lot clearer in the morning and less prone to making mistakes. Realize that fatigue will affect your memory. If you learn information when you are fresh, it is more likely to stay with you. If you stay up late studying for a big exam, you will have more problems trying to recall this information the next day.

Exercise improves your ability to think. This seems pretty obvious, but for individuals with head injury, it becomes crucial. If your doctor has cleared you to do exercise, you should make a conscious effort to do it. Why? Even though the brain weighs less than 5% of the entire body, it uses 30% of the oxygen in the body, and probably the same amount of glucose (which is the energy that runs your body). If we use a car analogy, a clogged air filter and gunked up carburetor will not allow full power. With exercise, you get more oxygen into your blood system. Also, for people who have chronic pain syndromes, some types of exercise are very beneficial. For example, swimming is a very good exercise for people who have neck or back pain. Always talk with your doctor about what exercise works best for you.

Diet is another important consideration. When I say "diet", I don't necessarily mean to lose weight. It's important to eat 3 good meals a day. In our rushed society, we'll eat a doughnut, have some coffee, and run off to work. That's not a very good diet. The sugar that you get from a doughnut or the caffeine from coffee gives you a brief burst of energy, but that energy doesn't last. We've all heard of a "sugar buzz." Children are very prone to this. The same thing occurs in adults. The problem with sugar is that you "roller coaster"--you get that burst of energy but you come crashing down. The trick is to have a constant supply of energy to the brain.

You need to gradually increase your stamina. Going from not working to working 40 hours a week is very stressful. For the head-injured individual, this is nearly impossible. You must give the brain time to build a tolerance to fatigue. A common approach to this problem is by having people gradually return to work. You might start off with part-time, beginning with 1 to 3 hours on returning to work. Gradually, add hours only as you can tolerate it. What's the problem with this? Most employers only want you 100%. They want you there 40 hours or they don't want you there at all. Many employers are beginning to realize that this is a discriminatory policy. A head injury program will work with the employer. Businesses are beginning to see that good employees are hard to come by. If you can't return to work, however, volunteering is a good means of building job skills. This will also help to decrease fatigue and will improve self-esteem.

## ANGER AND DEPRESSION

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People will accept that head injury can change your thoughts and memories, but have difficulty understanding that it also changes your emotions. Your emotions don't exist in some cloud that follows behind your head. They're in your head just like everything else. Two of the more common changes in emotion are anger and depression. Someone may have been a "hot-head" or an angry individual before their accident. Since the head injury, this person's anger is multiplied 2 or 3 times. For example, a dog may pee on the carpet. This might be an angering situation for most people. But following a head injury, the anger is so extreme that the person may want to harm the dog. Anger after a head injury is quite different from "normal" anger. Anger following a head injury tends to have a **"quick on" and a "quick off."** Basically you can be in a good mood until some small thing irritates you and you suddenly get very angry. But this anger doesn't seem to last; you're angry for a few minutes, someone changes the topic of conversation, and you quickly stop being angry. In another variation of anger problems, some little thing sets you off and then the "whole day is ruined" (you're not mad but seem to be in a bad mood).

Many people say, following a head injury, *"I cry real easily, sometimes over the dumbest things."* This is especially tough for men in our society because men have been taught not to cry. I've had many male patients say to me, *"I've never cried as an adult; now I'll watch some silly movie on television and have tears running down my face."* Many people begin to feel that they're losing their mind because of this emotional roller coaster.

Why is this happening? We know that the middle sections of the brain are pretty primitive. Rage, fear, and sexual feelings all come from very primitive emotional areas of the brain. If you have animals at home, you'll see the same primitive emotions in them. Humans also have primitive systems in the brain that says "yes" or "DO IT". If you're mad, hit something. If you get hungry, let's eat. Don't wait, do it right now. In contrast, the front part of the brain helps plan and control behavior. The

front part of our brain is involved in saying "NO". For example, your boss says something to you that gets you really mad. Your first impulse is to hit him. The "NO" part of your brain says "*Don't do that--you're going to be fired--you're going to go to jail.*" So the frontal lobes and the primitive parts of the brain act like a thermostat and a furnace. If the "NO" part of the system isn't working so well, the primitive functions tend to be more prominent.

This change in emotion may cause your family members and friends to start avoiding you. With family members, they're going to learn to walk around you as if on "eggshells". If it's your friends, your yelling at them will result in a lot fewer friends. They may be afraid of the changes that they see in you.

What can you do to deal with the anger problem? One very helpful approach is the Time-Out procedure. Before you get to the point where you are going to explode (throw something, break something, or punch a hole in the wall), you **MUST** walk away. You have to get away from the thing that's really irritating you. **I ask people to walk away for a minimum of 15 minutes.** Get out of the house; go for a long walk. But don't stay in the situation that's making you angry. Why 15 minutes? People will say, "*I'm pretty calm after 5 minutes.*" But they go right back into the situation and they're instantly angry again. It takes quite a while for your emotional system to calm down. Time-Out must be at least 15 minutes. **The more you do Time-Out, the more you learn to control your feelings, or hold back the flood of emotion.** It's basically practice, practice, and more practice; just like learning to hit a ball with a bat. The more you try, the more likely you are to get better at it the next time. You can't just say, "*Okay, I've got the principle on swinging a bat; now I'll go out and play major league baseball.*" You have to keep at it--so practicing "Time Out" is a good thing.

One of the problems with Time-Out is that people don't realize that they are angry until it's too late. For example, I had one patient who was waiting in a check-out lane in the store and there was a little child being a brat; picking things up, throwing them on the ground, yelling, screaming,

and basically driving everybody in line crazy. The family member who was with the patient could see the anger starting to build. The jaw was tightening; the fists were clenching; the feet were tapping. The head-injured person didn't recognize the anger. This person finally "exploded" at the parent and said, "*Shut your kid up!*" There are cues that anger is building in us, and we've got to learn to pick them up. It may be tightening in the jaw; it may be clenching in the hands; it may be sweating more or breathing heavily. It depends on the person. I often request that family members help with Time-Out. (In fact, the family member is most often the target of the anger.)

I also have a rule for the time-out procedure: **No matter who calls time-out (whether you feel it's fair or not), you've got to do it.** If you're the head-injured person and someone calls time-out on you, you have to do the 15 minute Time-Out, even if you don't think you need it. You may get mad because someone's called a Time-Out procedure. You still need to do it. Family members, however, have to "play fair" with the time-out procedure--they can't chase after you with an ongoing argument (the No-Nagging rule). If you're trying to get out of the situation, family members must not run after you and say "*Oh yeah, and here's another rotten thing you do.*" They've got to do their part by "shutting up" during Time-Out.

It helps if you have a signal for time-out. It might be like the referees in a football game, where they make a "T" with their hands. If it's in a crowd and you don't want to be obvious, you might pull on your earlobe or touch your nose. Whatever the cue that you and your family use, you've got to do it. The more you practice this technique, the more it works. The first few weeks, it may not seem like it's working. But keep at it; it will work over time.

## WORD-FINDING

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Word-finding is a common, and often annoying, problem. Almost every head-injured person has this problem to some degree. Head-injured people may talk normally; speech flows evenly and it's easy to understand. But they'll have this very odd problem--they'll know the word they want to say but just can't come up with it. Professionals call this "anomia," which means "can't name". Everyone has an occasional anomia; those with a head injury have it frequently. It is particularly annoying if you are dealing with people all day long. For example, it will stand out if you've got to give a lecture to 100 people and you stumble over words. You develop poor self-esteem because you're just not sure of what you're saying anymore. A variation on this problem is that you say the wrong word. Instead of saying, "pass me the spoon", you might say "pass me the noon." Or, instead of using a similar sounding word, you may use an entirely wrong word. Instead of "pass me the spoon," you may say, "pass me the car." You may not even recognize that you said the wrong word until people point it out to you.

A speech/language pathologist is a professional who commonly works with this type of problem. This person can teach you techniques to decrease this problem. For example, you can use a technique called "circumlocution." Basically, you "talk around" the word. If you can't come up with the word "telephone," you might say "you dial it, you can put a quarter in it, you can call people." People eventually get what you were trying to say. Another technique that people sometimes use is to go through the alphabet and try to get the first letter of the word. (The word "telephone" begins with a T--which is near the end of the alphabet--so that might take a while.) Or you can visualize spelling the word. Visualize a blackboard and try to "see" someone writing the word on the blackboard. Then read the word off the blackboard. Depending on the type of injury you have, one of these techniques may be helpful to you. Seeing a Speech Language Pathologist or other head injury specialist is a way to get help for this problem.

## Dealing with Doctors

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It's important to understand that your relationship with your doctor is absolutely going to effect the quality of care that you receive. Doctors tend to put patients into two categories: the good ones and the bad ones. Patients that are likable fall into the "good" category. They get more effort from hospital staff and they often make more progress. But patients are never told what it takes to be a good patient. Although getting along with your doctor is just "common sense," few people know how to do it.

Diagnosing a head injury is not a simple thing. If your doctor does not believe that you have a head injury, you will not get the treatment you need. Why doesn't the doctor believe you? From the doctor's perspective, standard medical tests to diagnose head injury are often negative. In nearly 85 percent of the patients that I see, the CT Scan or MRI (these are very expensive machines that take a picture of the brain) results are "negative"—in other words, normal. People can have significant head injuries and still not have a positive finding on these tests (medicine is strange, a positive finding means they found something--it's not "positive" in the sense of being good for the patient). In fact, all the medical tests can be negative on a person who still has a significant head injury. For example, the blood work may be fine, and the patient may be able to stand, walk, and talk without difficulty. But the head-injured person may have significant problems with memory, fatigue, and headaches. You have to remember that doctors are trained to rely on medical tests to give them direction on what to do next. If all of the medical tests are negative, what is the next step?

Many doctors rely on neuropsychological testing. Neuropsychological testing is probably one of the best vehicles for diagnosing head injury. It's between 90 and 95 percent correct in accurately diagnosing someone who has a head injury. Right now, it is the best technique available. But not everyone has access to a neuropsychologist. Often there's not one available or people don't have

insurance coverage to pay for this very expensive service. Without good documentation, it is easy to see why your doctor doesn't believe you.

How do I get my doctor to believe me? When you meet with your doctor, **bring a complete list of your problems.** Now this sounds pretty obvious. But for the head-injured person, it is actually difficult. Head-injured people typically have memory disorders. In other words, they forget. So one day they go to the doctor and say, "*my back hurts and my memory is not good.*" They go in the next week and say, "*By the way, I'm not sleeping very well.*" They go in another week and say "*Oh, I have headaches.*" A doctor might begin to think "*This person is just a complainer and comes up with a new problem every week*". In reality, the head-injured person just forgets to tell their doctor the full story. They often kick themselves when they get home, because a family member asks, "*Well, did you ask about your headaches?*" The patient says, "*I forgot*", and doesn't get any help until the next appointment (that can be one to two months for some people).

I highly recommend that you write your complaints down. Get them all on paper. Spend some time thinking about it. Maybe put that list up on your refrigerator, and as you are reminded of a problem, write it on that piece of paper. I've included a sheet at the end of this book; it's called a Memory Sheet for Doctors' Appointments, where you can write down your appointment time and a list of your problems. When you go to your doctor, take the list of all your complaints. By the way, your doctor writes down all your complaints and keeps a written record. Insurance companies commonly review these notes when they are thinking about paying for services.

Not all complaints can be solved in one appointment. Back pain, headaches, and memory problems are not going to be cured by a simple pill. Identifying all your problems is a good start on a long journey with your doctor. One of the hallmarks of a good patient is communication with the doctor and talking openly and honestly about problems. The good patient also needs to realize that the doctor has no miracle cure.

It is most important that you take medications the way your doctor told you to. For example, a doctor gives a medication to help with headaches and the patient thinks, "*I took one of those pills and my stomach got really upset; I'll stop taking them,*" then doesn't tell the doctor about stopping the medication until the next appointment. If you have a side-effect, call the doctor's office and tell them. It could be something as simple as the need to take your medication with food. If it is the wrong medication, the doctor might be able to call in another prescription to your drug store. If you don't talk with your doctor and you start changing treatment without the doctor's input, you're going to quickly fall into the "bad patient" category. Why is this a problem? The doctor may not use more powerful medications that might have helped you. Why? Some of these powerful medications can be dangerous if not taken properly. If the doctor can't trust you, you won't get the medication. In the end, you will suffer. **Moral of the story--take medications exactly as your doctor tells you to.**

Sometimes people buy a medication holder (divides pills by times of the day) to help them take their medication. You can buy them for probably under ten dollars and put all your daily medications in them (you can also buy weekly sizes). Take your medications at exactly at the same time every day. Why is this smart? It makes the medications work better because your system adjusts to them better. Also, it ensures that you're not taking too much or too little of the medication. If you forgot whether you took your medication, you can open the medication holder to see if the medication is still there. Don't self-adjust the amount of medication. If your doctor gives you a prescription that is supposed to last a month, and in three weeks you call and say you've run out, the doctor will quickly figure out that you didn't take the medication the way you were supposed to. Using a medication holder and properly taking your medications sends a message to your doctor; it shows that you're serious about your medical care.

It is important to realize that physicians need to see a large number of patients to cover costs. Their expenses are extremely high. In order to cover these expenses, they have to see a lot of patients quickly. You can

help your doctor by listing your complaints in a brief manner. For the return office visit (you come back to tell them how you are doing), try to give a 3 to 5 minute report. Even if your doctor is well aware of your complaints, develop a common language in reviewing your problems. For example, in dealing with headaches, it's good to develop a numbering system. Use a pain journal (get a monthly calendar) and rate your pain each day from "1," meaning no headache, to "10," meaning the worse headache you've had in your life. Now when you go to your doctor, you can say, "*I was having "7" headaches before the Darvocet, but I'm now having "5" headaches.*" Show the doctor the journal each time you visit. This is quick, short, and conveys a lot of information. Even if there is no progress, still use this system--"*I started at "7"but they remained at "7" even after the medication"*.

One more important thing about doctors--they like to hear progress. They like to see people get better. Although it's important to talk about your problems, it's also important to acknowledge your progress. For example, someone may continue to have neck pain, but the doctor's efforts helped make the pain half of what it was three months ago. Reporting progress is also the sign of a "good patient." I love to hear when my patients do better. It makes my day. I'm sure other doctors feel the same way.

## **FAMILY MEMBERS: What You Can Do In the Hospital Setting**

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Most family members find the hospital experience a "roller coaster ride through hell." Their lives are going along fine when suddenly they are told to come to the hospital. The worst thoughts go through their heads and they are very afraid. This is the place where bad things happen--people get very sick, or die. Making this more frightening is that physicians and nurses often speak in another language. They speak in what I call "medicalese" (like Chinese). For example, people don't have a bruise, they have a "hematoma"--which is exactly the same thing as a bruise. Doctors and nurses are very busy and may be impatient with family members who are not sure of what questions to ask. Doctors tend to give quick, short news with lots of medical terms. When family members calm down enough to be rational, getting questions answered is not so easy. No wonder dealing with the hospital can be a very frustrating experience. It doesn't have to be this way.

First of all, I think it's important for family members to get educated. You need to read as much as you can about head injury. Most often, medical pamphlets tend to be too technical. They explain medical terms in a format that most people don't understand. The goal of this book is to improve your knowledge. Once you've read enough material, then what?

The typical thing that family members go through is what I call "the vigilance." If someone is hurt, family members want to be there 24 hours a day. What's wrong with that? Medical staff know that treating a head injury is like running a long race. You don't sprint a 26-mile marathon. You may start out intensely, but you have to pace yourself for the long race. There are some phases that head-injured patients go through. If you understand them, you will be better able to pace yourself.

Most people who have a head injury have little or very vague recall of their hospitalization. Even though they have extensive conversations with nurses and staff, they have few memories of what happened in the

hospital. When they are in the hospital, the head-injured person may go through what I call the "**confused and agitated phase.**" They are confused in the sense that they are not sure where they are. They may not know they're in the hospital or don't know the city they are in. They are not sure of the year, month, or day. They generally know who they are, but they may not be too clear who's visiting them. There's also the agitated or restless phase. Sometimes they have to pace up and down the floor of the hospital. If a nurse wants them to do something (such as go to the bathroom), the patients may strike out at the nurse. This is a very tough time for family members. Family members are trying to give the head-injured person a lot of love and caring, but the head-injured person may not respond well to this. For some people with head injury, this "confused and agitated phase" can last minutes. For others, this phase can go on for months. If you have a family member in this phase now, remember this important fact: *Nearly 99% of all patients eventually get out of this confused/agitated phase.* That's a good statistic. Be careful not to burn yourself out during this phase. The head-injured person will need you more further down the road.

Family burn-out is very common. How do you know if you are getting burned out? When you go to the hospital, do you start feeling sick to your stomach? Do you start getting anxious when you get close to the hospital? Do you avoid going to the hospital or feel guilty about these feelings? Don't be ashamed if you feel this way--everybody does. It is important to talk to others about your feelings. Every hospital has a social worker who can help you to understand what's going on, and to make plans for medical care. The social worker can also help you connect with other family members in the hospital who are going through the same thing. Sometimes talking with other family members who have similar experiences can be very helpful. If there are no other families in the hospital, ask the hospital social worker if there is a family who's recently gone through this stage. The social worker might be able to contact that person for you. Meeting with people who have been through this is VERY helpful.

## WHAT CAN I DO IN THE HOSPITAL?

Is there anything you can do to help with the confusion and agitation phase? One thing is to reduce stimulation. In the early recovery period, someone who gets a lot of stimulation during the day will often become agitated or confused in the late afternoons or evenings. Some stimulation is an unavoidable part of the normal hospital business. For example, there is speech therapy, occupational therapy, and physical therapy during the day. The head-injured person can become very tired by these activities. By the evening (or even earlier), it only takes little stimulation to get someone agitated. Try to decrease stimulation in the person's room. Close the blinds and keep the TV off. People will send the patient hundreds of cards, letters, stuffed animals, pictures, and so on. Family members should try to limit this to a few things because it can be visually distracting and overwhelming.

It's not what you say, but the tone of your voice that's important. If you speak calmly and slowly, people will tend to listen to you. Make your speech in short sentences, even in single words, such as, "*Hungry?*" "*Are you in pain?*" "*Show me where you are in pain.*" Very simple speech helps someone in the early stages. The head-injured person may have problems understanding long sentences. Although the patient may speak in long sentences, the ability to understand may be limited (talk to the patient's speech therapist about this). Should you correct people who say something silly in the early confusion/agitation phase? For example, the person may be saying, "*I want out of this hospital so I can go skiing.*" Many family members may debate with that person saying, "*No, it's not winter,*" or "*No, you need medical care.*" Patients who are confused or agitated, won't really understand your logic or reasoning. When someone is really confused, it's better to change the topic of conversation. You might distract them by saying "*How about a walk? You want something to drink?*" Talk about their favorite hobbies or things they enjoyed doing. In general, people with head injuries have good long-term memory (things that happened years ago) but their memory of recent history may not be good. Using old information may be comforting to some people.

When visiting a confused patient in the hospital, physically touching the patient is not always a good thing. Many times in our culture, we use touch as a reassuring gesture. When people are crying or upset, we may put our hand on theirs, or we may give them a big hug to reassure them. Normally, that's a good thing. In the early phase of a head injury, that may not be a good idea, however. You can make them very agitated by invading their space or grabbing them. There is even a condition that head-injured people can get where simple touch is often perceived as pain. You need to test the waters with touch, and you need to be very careful about it. In general, less is better in the early phases. Often the patient gets plenty of touching in therapies, such as physical therapy. The person can come back from physical therapy highly agitated. It's important that the physical therapist does their job. The price is often agitation. But if you or a guest are visiting, be careful about touch if the patient is agitated.

One of the things that overwhelm family members is the constant reporting to other family members. Many people come to the hospital and spend the day or evening with the patient only to go home and have 50 people call them to ask, "*Well, what happened in therapy today?*" They don't get to bed until midnight or one o'clock just because they have all these people calling them. I would suggest that one or two main family members who visit the hospital give this information to another family member who can make all the calls. Another thing that I recommend is that every family member get an answering machine. As a family member, count on being extremely tired from all the stress of the injury. Adequate sleep is very important for coping with stress. Sometimes it's better that you just use the answering machine rather than answer phone calls and wear yourself down.

## **WHAT TO DO AFTER LEAVING THE HOSPITAL**

Now let's talk about what to do when the head-injured person gets home. Often this is a very big event for family members. It's a great occasion. But unfortunately, it's just the beginning of the recovery process. The medical injuries (basically the bruises and broken bones) heal very quickly. But healing from a head injury can take years. When someone

goes home, many family members think, it will just be just a couple more months. In truth, it's usually a lot longer.

In the months following discharge from the hospital, it's important to be aware that the head-injured person may have a fatigue problem. In other words, they get very tired quickly. When head-injured people get home from the hospital, they may have only 3 or 4 good hours in the day before they're wiped out. They may easily fall asleep, or they may not be able to concentrate. In general, the person is better in the mornings and has tougher times in the afternoons. It's important for family members to remember this. Often the evening comes around and family members want to bring relatives over to see them. Those evenings are often tough on the head-injured person. In the early weeks, one of the things that I would suggest is to try to limit "welcome home parties" and visitors. Have them scaled down and shorter in length. For example, try a welcome home party that lasts for about a hour, then have everyone leave. The head-injured person may want to see friends right away. You may need to limit it to just one hour or two hours, depending on how much the person can tolerate. At the same time, you don't want to limit it too much, because the person may become depressed and feel isolated from friends. It is always a very careful balancing act in terms of how much the person needs versus what can be dealt with.

I think another thing that families find difficult is treating the person normally. Often, family members unknowingly will talk down to the patients, or treat them with pity. The head-injured person wants to be treated like everyone else. It's also important to note that many friends of the patient will be very uncomfortable talking about the injury. For most people, this is very frightening. Many people harbor thoughts of "*this could have been me*," and talking about it scares them. Visitors often feel that they have to get into this very deep discussion about the injury, but are afraid the head-injured person will be too upset by it. For visitor or guests, a very brief acknowledgment of the person's injury is best. If the head-injured person wants to talk about it, fine, but they usually want to get on with life and have normal conversations about how things are going. For example, most people diagnosed with a serious illness, such as cancer, don't

want to talk about their illness all the time. They also like to talk about the things they love to do, their work, their friends, what's happened since they've been away. It's important to try to normalize conversations.

Family members have difficulty dealing with someone who looks the same but is different. Head-injured people may talk the same and walk the same, but will be emotionally or behaviorally different. For example, they may be more irritable, or more cranky, and perhaps more impulsive. For family members, it's very hard to deal with this. It's almost if someone has come in and stolen their personality. This leads to a loss of a lot of friends. In general, I have what's called **The 90% Rule**. Over a one to two year period, the head-injured person may lose 90% of their friends. In the early phases of the hospital stay, their friends are there a great deal. They send a lot of cards and there's a lot of sympathy. But as time goes on, those friends seem to fade away. Although this is not true of everybody, it is a very common problem. Family members get very angry at those people who tend to fade away. It's important to understand that those who are not around may often have difficulty dealing with serious illness. Most people want to live a happy, carefree life. They don't want to think of things like head injury or cancer or someone dying terribly. People don't want to handle that level of reality. Family members can get very upset and may wish to confront friends about why they aren't around. What a family should do is encourage new relationships. New people who meet head-injured patients will like them the way they are. They don't know how they used to act before they were injured.

As I work with head-injured patients, I find it very common that the new friendships are very solid friendships, but they take time to develop. This often means that family members have to let go a little bit. When the head-injured person is with friends, the friends may not be as cautious. For example, someone may fall easily, or friends don't make transfers in and out of cars as well as family members. There is always some risk that the person may fall or be injured. It is important to understand the concept of acceptable risk. Although family members want to prevent any further harm to the injured person, nothing in life is risk-free. For family members, it's very difficult to come to terms with this concept. The head-injured

person needs to get out and be with friends, away from the sometimes protective cocoon of families. It's a difficult balancing act, but new activities must be encouraged.

## SEIZURES

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Most of my head-injured patients don't have seizure disorders (studies suggest this happens in 5 percent of head-injured people). However, it happens with enough frequency that people should be aware of it. When most people think of someone having a seizure, they think of someone who may fall to the ground and shake all over. When we see that happen in a store or restaurant, many people are frightened by it. In a head injury, a seizure tends to happen at two periods in time (but it can also happen at any time). It happens sometimes within hours or days of the accident itself. You may be in a hospital when this first occurs. A second point in time is nine months to one year following the accident.

What is a seizure? Let's think about the brain again. We know that the brain can get a scar or bruise on it because it's been jolted. With time, the bruise will go away and a scar will start to heal. Do you have any old scars on your body? If you feel them, you may notice that they're a little bit more solid or firm than the rest of the skin. The scar is always a little bit thicker and tougher than normal skin. In order to close a wound, the body sends resources to seal it. It's kind of like glue that holds your skin together. The same type of thing happens with the brain. When the brain gets a scar, the scar tends to harden over time. Some of the scars are actually rather soft at first, and with time they start to harden up a bit. The brain doesn't like that hardening and the scar starts to irritate the cells (neurons) around it. Neurons are these tiny wires that make the brain work. These are like wires in a computer, except the wires in a computer are like giant pipes compared to these small neurons. Remember we have 100 billion of these neurons in our brain. It takes a microscope to see them. Imagine a room full of electrical wires. Although most wires are coated with insulation, imagine having a room full of uncoated wires. If I were to throw a wrench in a room with uncoated wires, there'd be kind of a short in the wiring. Basically this scar tissue is like putting a metal rod across open wires. That scar tissue takes six to nine months to build.

We talked about a short in the wire, but it's a little bit more complicated than that. Visualize a room full of mouse traps. Instead of putting cheese in the mouse trap, we put a ping-pong ball on each trap, and there's not a bit of space in this entire floor where I haven't put a mouse trap and a ping-pong ball. What if I just throw one ping-pong ball into that room? What's going to happen? It's going to hit one, which will bounce, hit two, which will hit four, which will hit eight and before long, the entire room has got ping-pong balls flying in it. That's a little bit like what happens with a seizure. Irritation in the brain may start at one area of the brain and then spread until it eventually takes over the entire brain.

Let's talk about different kinds of seizures. Probably the one that we're most aware of is called a Grand Mal seizure. This is the one that affects the whole body. The person begins to shake all over and may fall to the ground. This can cause injuries, including even a second head injury just from falling and hitting the head on a desk, table, or the hard ground. What if you're driving and you have a Grand Mal seizure? You're not going to be able to control your movements and your car will run into something. In the state of Michigan, you cannot drive a car unless you have been seizure-free for six months.

Seizures sometimes give off a warning sign before they start. Sometimes it'll feel like a tingling sensation in the stomach. Some people may begin to see bright lights or stars. Some people may smell something (like the smell of burning rubber). Suddenly, they just find themselves lying on the floor. The warning signs of a seizure are called "auras." Not everybody gets a warning sign. Sometimes, you're just walking along and—bang!--the seizure hits you.

Some of my patients develop what are called simple or partial seizures. A simple seizure can be just a simple movement. A hand can begin to move uncontrollably for a few seconds to a minute. It's important to note that not all of these movements are seizures. For example, we've all had moments when we're tired or sick, when part of our face starts to twitch. That's not a seizure, it is just a spasm of a muscle. That's not a bad thing; it happens to a lot of people. Following an accident, you may start to

get abnormal twitching. You must tell your doctor, who can figure out whether it's a muscle twitch or a seizure disorder.

There's also what's called complex partial seizures. They involve short but complicated activity. I'll give you an example. There was a college professor whose entire seizure involved him saying the words "class dismissed." He would walk into his lecture hall, and five minutes into his lecture, would suddenly say "class dismissed"--then he'd realize there was no one in his classroom. This is a seizure that involves a more complex activity.

What's a common sign of a seizure? For the majority of people who have seizures, there's one symptom that follows having a seizure--a very intense feeling of fatigue. They could be just waking up in the morning, have a little movement with their arm, and minutes later they are asleep. Some people who've had Grand Mal seizures or even partial seizures will literally lie down on the floor and be asleep within minutes.

A doctor who suspects that you have a seizure disorder will order a test called an EEG (electroencephalogram). They glue little wires over your head and connect them to a machine that measures electrical activity in your brain. Each of the wires measures little tiny bits of electricity generated by the brain. If you look at an EEG while it's recording, there'll be a bunch of needles jumping up and down over a long piece of paper. Remember all those billions of neurons? They all generate a little bit of electricity. Put a few billion together and you start to get some voltage (estimated to equal a 60 watt light bulb).

Getting an EEG is not a lot of fun. It's not painful, but it's basically annoying. Why is it annoying? Many doctors want you to stay up the entire night before. They won't let you sleep or they let you sleep for just a few hours before you go in for the test. Why do they want you to do that? Ever bring your car into a mechanic when it's been making a really nasty noise, only to have it not make the noise when the mechanic is looking at it? The EEG has the same problem. The abnormal activity may not be going on when it is recording. So if you're really tired, you're more likely

to have some abnormal electrical activity. One of the problems in detecting a seizure with an EEG is that the brain may be behaving itself while the recording is going on. An EEG is really a device that only tells us something if the brain is being abnormal during the test. **A normal EEG does not eliminate the possibility of a seizure disorder.** Another annoying part of the EEG is the glue used to attach wires to the head during the test. In order to get a good contact between the wire and your head, they use a glue that holds the wire in place. Many complain that the EEG glue takes a couple of days to wash out of their hair .

What do you do if suspect you have a seizure disorder? Approximately one million people in America have some form of seizure disorder. That's a large number of people. Doctors may prescribe anti-seizure medications. How do they work? Let's try to use another image or picture of how these chemicals work. Have you ever seen an oil lamp work? It has a wick and a knob that controls the wick. If you turn the wick way up, it burns more oil and the light gets brighter. What if I turn the wick down a little bit? I'm still getting light, but I'm not getting as much light. To some degree, anti-seizure medications work on the same principle. They calm the brain down. Seizures tend to happen when there is a lot of activity in the brain. Calming the brain down a little bit decreases the odds of having a seizure. That sounds great, so why isn't everyone with a head injury on anti-seizure medications? Remember when we turned down the flame in the lamp example? Other brain activities are also "turned down." Some seizure medications tend to produce fatigue in people. In general, all seizure medications have an influence on your thinking to one degree or another.

In the early days of head injury treatment, neurologists were typically giving nearly all head-injured people anti-seizure medications. We know that 5% of head-injured people have a seizure; if I give anti-seizure medications to everybody, I'm going to control those seizures, right? What's the problem? The majority of people don't *need* the medication and they have side effects. If you have a seizure in the hospital, you can pretty well bet you're going to be on anti-seizure medications for a while. But if you've never had a seizure while you were in the hospital

following your head injury, it's unlikely that you will start off with that medication.

## **EMOTIONAL STAGES OF RECOVERY**

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We are all different. We all have different family situations, different jobs, different strengths, and different weaknesses. Despite all these differences, there are a number of very common emotional stages that people with a head injury go through. This is based upon my own experience treating patients, but many investigators note similar findings.

### **Confusion and Agitation**

The first phase that I see people going through is a **confusion/agitation** phase. This can last minutes or it can last for months. I've had people get in a car accident and be somewhat dazed for a few minutes, but then direct traffic around their car. Others had been brought into the hospital in a coma requiring intensive medical efforts. When they wake up, they may go through the confusion/agitation phase. In the hospital setting, this is very difficult for family members. Someone who is very meek and mild, for example, can be physically aggressive. They may punch the nurses, or swear and curse at family members. It's very frightening for family members, and it feels like it is going to last forever. For 99% of the patients that I've worked with, this confusion/agitation phase goes away. It may take a while, but people eventually come out of it.

### **Denial**

The next emotional phase that I see people typically go through is **denial**. The patient says, "*There's nothing wrong with me.*" For example, they're in a motor vehicle accident, they're briefly seen in an emergency room, and they go home. Suddenly, they're having difficulties. They're forgetting things or burning food. Family members may say, "*you seem different.*" But the head-injured person says "*No, there's nothing wrong with me.*" Often the medical system unknowingly supports denial. Many doctors will say, "*Go home, relax for two weeks, and everything will be better.*" For some people, things don't get better. They wonder why they're doing some silly things. For example, why did they put their shoes in the

refrigerator? Or why did they put the milk in the closet? They have these odd events and they keep rationalizing them away. Denial can be very difficult for both family members and medical staff. For example, the head-injured person may say, "*Yes, I can drive,*" but family members who have been with the person know that it would be dangerous. This can stir up huge arguments. The person in denial says there's nothing wrong, even when directly confronted by family members. When someone is in denial, you must give consistent feedback that everything is not "okay." Generally, very direct feedback is necessary. However, some people get really angry when they're constantly being told "NO". I often find that distraction, such as changing the topic of conversation, is better than getting into long-winded or violent arguments. For example, the head-injured person may want to drive when it's not safe to do so. Instead of arguing, it might be better to say, "*Your doctor has not cleared you to drive*" and move on with the conversation.

There are two types of denial. The first type of denial is an emotional one. Something has happened that is so terrible, or so frightening that they just don't want to deal with it. The second type of denial comes from changes to the brain. The brain literally refuses to process certain types of information. For example, there is one type of injury to the brain where the patient cannot receive visual information on the left side. Their vision is gone on the entire left side—but they don't know it. They may bump into walls, or, if driving a car, they may run into things. If drawing a picture, they may leave out half the drawing. The brain doesn't like missing information, so it tends to fill in that information. You may be thinking that you don't know anyone who has part of their vision missing. Think again! Did you know that part of your vision has a hole in it? Where the optic nerve comes through on the eyeball, there are no visual receptors. The brain doesn't like missing information and "fills in" that little hole. If you close your left eye, hold a pencil about one foot from the eye (down and to the right), the eraser will just disappear when you find this small hole. So, now you see how the brain can contribute to "denial."

## Anger and Depression

Denial is a very common problem, but eventually it breaks down. Head injury problems just don't go away. The same problems happen over and over and over again. This leads to the next phase, in which the person has a limited awareness of the head injury, beginning what I call the **depression/anger phase**. When you realize you are different and can't do things like you used to, you may become angry or depressed. In many ways, anger and depression share a lot in common. Some people think of depression as anger at oneself, a kind of anger turned inward. A lot of people who are depressed will say to themselves, "*I'm a failure. I can't do this. I'm no good.*" On the other hand, people who are struggling to deal with the vast changes produced by a head injury may get angry at people around them. They may see people as not being supportive of them or not understanding their head injury. Some of this anger may also be due to the head injury. They'll notice that this anger comes on extremely quickly and also goes away just as quickly. That's due to the head injury. The sections of the brain that control those emotions have been injured.

Not all of this anger or depression is due to physical changes in the brain. Instead, we're talking about an emotional way of coping with things. Virtually all people who go through a serious illness or injury will have some anger and depression. If it is a car accident, they may be angry at the person who ran into them. They may be angry at themselves for getting into an accident. Sometimes it is justified, such as in a case where a person has been drinking and driving, resulting in a head injury. Sometimes they unreasonably blame themselves--"*If I had only left my house five minutes later or five minutes earlier, I wouldn't be in this mess.*" There was no way of knowing that an accident would happen. When we have difficulty dealing with overwhelming situations, we often go back and blame ourselves. That's a very common reaction. Many religious people become angry at God--"*Why would God want me to suffer?*" They may question their faith, or wonder why God is so vindictive. Just about everybody goes through this cycling pattern, becoming depressed or angry. This can go back and forth; some people never move on to the next phase.

## Testing Phase

The next phase almost always follows after a period of recovery and improvement in thinking abilities. When people eventually realize they are improving, they go through the **testing phase**. Basically, they test themselves to see their limits. To some degree, there's a little bit of denial in this. The person feels, *"I'm really close to the way I was, so I'll just act the way I was. I'll do things as I always did."* For example, many people with a head injury have a fatigue disorder. They know they get tired easily. But during this testing phase, they "forget" they have a head injury and say, *"Well, I've got a lot of friends visiting this weekend. I'm just going to stay up really late. I'm going to see if I just can't be the way I used to be."* When you overdo and go beyond your abilities, you may spend the next several days paying for it. Sometimes, people will test themselves and fail. For example, they previously may have been an A or B student. They take a class and come out with a C or D, even though they put in twice the effort for that C. For many people, getting a C is a failure. There's a period of time when the head-injured person says, *"Why can't I be the way I used to?"* This a very painful stage.

## Uneasy Acceptance

The next phase is what I call **uneasy acceptance**. This is when head-injured people learn where they stand and what their limits are. They've learned after many failings and many times of paying for it, that they can only handle a limited number of hours of work or play. They've learned to keep a consistent schedule and will stick to that schedule. For example, they can work six hours a day, but realize that 8 hours is too much. They've learned to say, *"I have to deal with this head injury."* Does this mean they like it? NO. They're not happy about it, but they've learned to accept it. Often individuals in this phase begin to use words like the "old" me and the "new" me. Many of their old friends are no longer with them, but they've found new friends. They've moved on to new relationships, maybe even new work, and they've basically said, *"People have to like me for what I am."* That's "uneasy acceptance".

Now you will notice that I haven't talked about the level of injury (or how bad off the person is). I have many patients who have no scars, no physical problems, and have largely returned to their own job, yet they're different. Sometimes those people have the greatest difficulty with acceptance. Often people who "seem fine" have greater emotional problems than those who have obvious disabilities. These emotional phases really don't correlate with how physically impaired they are, or whether they return to their own job or not. It varies with the person.

### **Factors in Emotional Adjustment**

Some people tend to handle the stress of a head injury better than others. In general, people who do well emotionally tend to have a very strong work ethic. They tend to believe that it's important to contribute to society and to people around them. It's important to help others. They look outside of themselves to see what they can do to make the world around them better. In my experience, these people tend to do better. On the other hand, people who are extremely self-centered and who have poor social relationships before their injury tend not to do well. One important predictor of how well people do is a sense of humor. I believe that humor is an essential component to getting better. I like to joke with the people that I work with, but not in a hostile way or to make fun of them. Sometimes people can make jokes about themselves; that's a very positive sign. One of my patients told me, "*Sometimes laughing keeps me from crying.*" Another factor is people's avoidance of drug and alcohol problems. Some people cope with their personal failures or personal problems through alcohol or drugs. If you return to alcohol or drugs and don't see the destruction it causes, you will have a hard time coping with this injury. That doesn't mean that people who abuse alcohol or drugs are *always* going to have negative outcomes. The question is, have those people learned that using alcohol or drugs will make their brain worse?

Another factor in head injury is whether or not people freely admit to others that they have a head injury. Many of my patients at first didn't want anybody to know about their injury. People are afraid that others might think they are "dumb" or "retarded." But after a while, these same patients

realize that there are a lot of people in this world who have had head injuries. People who have dealt with a head injury over a long period tend to “reach out” to those who are just starting the process of recovery. Some of my patients have gone beyond just talking with someone on a one-to-one basis. Some have even lectured, have gone to schools and talked about wearing helmets; or talked about drinking and driving. People who have suffered a head injury somehow move beyond their suffering to help others.

People who go to support groups often get a lot of positive feeling from being with other head-injured people. They want to openly talk about their frustrations or fatigue or forgetting things. Those people do better. On the other hand, people who avoid talking about their accident, avoid telling people they have a head injury, and avoid being with other head-injured patients tend to have a poorer adjustment. In every state in the United States, there is a brain injury association with some type of support group. Don't be afraid to check one out.

## RETURNING TO SCHOOL

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For many people who have a head injury, going back to school is one of the toughest things they are going to face. A number of head injury factors will make this difficult. First of all, short-term memory will make it very hard to learn new material. School is nothing but learning new things. Second, school has a fair amount of fatigue associated with it. With head injury, people have limited energy. They may be good in the morning, but fade early in the afternoon. Third, returning to school involves a social dimension--people very desperately want to fit in with their peers. For some people, having some friends that you can hang out with is their number one priority in college or high school. Often, they put more effort into being social than into studying.

### RETURNING TO COLLEGE

Many universities will help you learn new material if you let them know that you have a disability. If you are blind, colleges will help you get books in braille or get a reader for you. A head injury is also a disability. Colleges are willing to help you, but you have to ask for help. In each college, there will be a "student services" or "special needs" department; the name of the department will vary with each college. You need to have your doctor or neuropsychologist write a letter to document that you have a valid disability.

The college is then going to ask you, "*What do you want? What sort of accommodations or special help are you looking for?*" One of the things you could ask for is extra time taking a test. Many people who have a head injury don't think as fast as they used to, and they need longer to think about some of the items. Ask to take exams without time limits. In other words, you would be allowed to just keep working on it until you are done. Ask to take the exam in a quiet room so you won't be distracted by other students. Many people who take a test are distracted by people rattling their chairs, moving papers, or people walking by in the hall. If you are

taking a test and you can't filter out noise, you are not going to do well. Ask if you can take the exam in one of the counseling offices.

Ask if you can get help with notes. Sometimes you can get the teacher's notes or you can get another student's notes. Why should you ask for notes? Many people with a head injury have a hard time concentrating on what is being said and writing at the same time, particularly if the material is very hard. For some people, doing two things at once makes learning impossible. In addition, getting another student's notes will also help you separate what is important from what is not important. Basically, the question that you may need to ask in every class is, "*What is going to be on the exam?*" That is not always easy, but if you have another person to work with, you are more likely to figure that out. Try to get an "A" student's notes. Also try to get someone who has good handwriting. If you set this up ahead of time, most people won't mind doing this. In the college level environment, most people are happy to help.

## **RETURNING TO HIGH SCHOOL**

If you are returning to high school, the procedure is a little different. In Michigan, you are going to need to schedule a meeting called an IEPC (the letters stand for Individual Educational Planning Committee). If you have a disability, you need to have this IEPC, or the school will not give you any special help. The committee will determine if you qualify for services. Before this meeting, the school may need to do some testing. If you already have a neuropsychologist, speech therapist, or other person who has done some type of testing, it would be helpful to submit the results to the school. But if you don't have that, you can request that the school provide testing for you. Under Michigan law, they are required to provide assessment for you.

To request an IEPC, you have to notify the school in writing. There is a certain time limit in which they can schedule this meeting. If you wait for this meeting in the middle of summer, you are out of luck. Why? Because there are no teachers in the school. The beginning of school is often a very busy time. You need to start planning this as early as possible

(sometimes, you might start this process while the head-injured person is in the hospital).

At the IEPC meeting, the school has to "classify" you so that you can receive services. For example, many people have a classification called "Learning Disability" (often called "LD" for short). This classification requires that people are at least 2 to 3 years behind in their studies. There is also a classification called "EMI" which stands for "Emotionally Mentally Impaired." There is a third classification called "POHI" (standing for "Physically or Other Health Impaired"). In the past, most people who had a head injury fell into this category, but head injuries don't really belong in any of the above categories. There is a new category in the Michigan school system appropriately called "Traumatic Brain Injury." In order to receive this classification, you will need documentation from medical doctors or other specialists such as neuropsychologists. Does this mean you have to be in a "special" classroom with very impaired people? No. In fact, you can attend regular education classes even with this head injury diagnosis. The Traumatic Brain Injury classification allows you to receive available services. For example, you can ask for speech therapy if the school has a speech therapist available. You may also be able to get some counseling through the school system. But you have to justify why you need each of these services within the school system. That's why the IEPC meeting is so important. In general, if you know what you want, they are more likely to give it to you.

If you are returning to high school, what help do you need? Some of the things we have already talked about are no time limits on tests, and getting notes (maybe even teachers' notes). I would also recommend someone to help you review your progress in your classes (someone from the special education department). You would meet once every week or every other week to review how you are doing in each of your classes. They might need to meet with your teachers if you start to develop a problem in one of your classes.

I would also highly recommend an academic journal. Make a folder that lists each class with the homework and upcoming tests for the next

couple of weeks. If you have a test in a history class, you need to prepare in advance. Short-term memory is impaired in head injury and it takes many repetitions of the material to learn it. You need to plan ahead and not wait until the last minute.

You should avoid studying in the evening. I have many people who do better studying in the morning, because they are alert and the brain works better then. Getting up in the morning to study is much better. If you can't do that, my suggestion is to plan it for early in the evening. The other thing that I would suggest is to study at the same time every evening. You are going to commit yourself to studying from 5:00--7:00 every night, only breaking for dinner. My suggestion is to set a time, whether you need to study or not, just to keep reviewing your materials. Get in the habit of making yourself study for 2 hours per night. Some people may have to increase that amount. In general, 2 hours is about the maximum that most people can handle. During that 2 hours, you will need to take occasional breaks, so you don't burn yourself out.

You can ask the school system to give you copies of your books. Most high schools only lend out the books. Normally, you cannot make any marks in the books, and you have to return them at the end of the class. I suggest that you ask the school to give you the books outright so that you can use a highlighter in the book. Highlighting is necessary to help you figure out what is the important material (in other words, what's going to be on the test). After you have highlighted, you may want to go back and reread it. Some school materials have questions at the back of the chapter. Most people avoid them. My suggestion is to answer everyone of them. Go back and go through the material and keep trying to do the questions as best as you can.

I strongly recommend getting a study group or a "study buddy." Get with a partner or group and try to figure out what is the most important material to learn. If you study the wrong material for an exam, you're going to get a bad grade even though you worked hard. This is particularly true with tests that have essays. A study partner will give you a new perspective by saying, *"No, I think this is really important and this is why I think the*

*teacher is going to ask this.*" So you cover what you think is important and cover what they think is important. Nine times out of ten, you are going to get it.

Lets talk about some test strategies. Most tests these days use multiple choice formats. Go through the test the first time and answer the questions you are sure you know. For any question you are not absolutely confident with, try to narrow down answers to two possibilities. If you think the answer is A or C, put little dashes by them and go on--don't answer those. Now go through the test a second time and start trying to answer the items with 2 or 3 possibilities. In general, don't go back a third time to change your answers. Your first guess is usually your best one; stick with it.

Many people make a common mistake of not turning over the page or not fully looking at the page to see if there are more items. They got a "C" or "D" because they didn't answer a third of the test. Always double-check every page and make sure every mark is filled in. If you can get it down to 2 or 3 items and haven't a clue, guess anyway. Don't leave it blank. Most tests don't penalize you for guessing. If it's a multiple choice and there are four items, you at least have a 1 in 4 chance. If you put nothing down, it's automatically wrong.

Watch the wording of the items. There may be "trick" questions. Words like "always" and "never" are trick items. An item that says "which is the best answer" is a trick item, because they may give you 4 correct answers but only 1 of them is the very best answer. Watch for key words. Sometimes teachers don't realize that they are giving away the test item by the words they use. Most teachers are pretty good about this, but occasionally they will slip up. Watch if words are singular or plural (i.e., group or groups). Watch the wording of the test.

Essay exams are the world's toughest tests. When I was a teaching assistant, I was basically looking for key words when grading papers. If an essay needed three separate elements to get full credit, I would look for the key word or phrase as I was reading the essay. Before you even start

answering the essay, try to outline the main points by scribbling them on the side of the paper. Once you are organized, start writing. Always start the first line of the paragraph with the main point you are going to cover.

One of the difficulties for most people is that they learn their material in the order that it was presented in class. The mid-term or final exam will not ask questions in that order. The problem is that you have memorized the material in order and you are going to have a hard time retrieving that information. Invest \$2.00 or \$3.00 and buy yourself a deck of blank file cards. Put a test question on one side of the card, then flip it over and put the answer on the back. First, learn the cards in order. Once you have gotten all the answers and questions correct, shuffle the cards and try to answer them again. In this way, the order of information will not be a factor. The other thing you can do is review every card one or two days before the exam. Sort every card you got right in one pile and every card that you got wrong in another pile. Keep working on the wrong pile until there are no more cards left in the wrong pile. If you are serious about getting good grades, this technique will work.

The social part of school is very important, and it probably is one of the things that people like the most. The problem is that socializing can get out of control if you don't spend the time on your classes. You have to set your own limits and apply discipline. Don't get behind. This is a fatal mistake for most head-injured people in school. If you need help with discipline, ask family members or friends to push you to study. Turn off the radio and the television when you are studying. Avoid distractions or get out of the house to study. When I was in college and lived in the dorm, there was something happening every minute. I made myself go to the library. I was in an environment where people were studying, and that gave me motivation to keep going. When at the library, I couldn't just go turn on the television or go to the refrigerator for a snack. But if the television or refrigerator is there, I'm going to be tempted to do it. Self-discipline is tough to come by. But it is something that can be learned. Using these techniques, you can be a better student.

## WHEN WILL I GET BETTER?

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This is the most common question asked of head injury professionals. Unfortunately, the best answer to "*How long it takes to get better?*" is, "**I don't know.**" In the first six months following a head injury, professionals tend to be poor at long range predictions. I put this chapter at the end of this book because it is the least useful bit of information. If you want to know why this is a problem or have symptoms that go beyond six months, read on.

Let's talk a little about why we can't predict results and some general statistics about recovering from a head injury. In the very early stages of a head injury, it is impossible to predict the long road ahead. Obvious physical injuries (ones that we can see) are an unreliable predictor of the future. For example, some people have "minor" medical problems and are discharged from a hospital within hours of the car accident. In the long run, however, they may never be the same. On the other hand, I've had people who were in a lengthy coma and had multiple physical injuries. These people not only got out of the coma, but are doing extremely well.

Let's look at it from a wider perspective. If we can't predict individuals, can we predict groups? I may not be able to predict the behavior of one person at a football game, but I can reliably predict the behavior of a large group of people (especially when someone scores a touchdown!).

Let's start looking at some of the things that make a head injury prediction complicated. First of all, a positive CT Scan or MRI (machines that take pictures of the brain) doesn't always predict how severe an injury is. (*Remember, "positive" means they found something abnormal in the brain; Positive doesn't always mean "good".*) CT's or MRI's are very good at picking up bleeding in the brain. There are people who have significant bleeding in the brain (requiring neurosurgery), yet have a very good recovery. At the same time, I have seen people with negative CT

Scans and MRI's who are in a deep coma. This highlights the problem that medical tests are not always the best predictors of long-range outcome.

People bring different strengths and weaknesses to the recovery process. One way of looking at differences in people is to look at their ability to solve problems. Psychologists use IQ tests to measure this ability. A 100 score is an average score. What happens if I drop 15 IQ points following a head injury? If someone has a 130 IQ score (smarter than 99 out of 100 people), then drops to an IQ of 115 (smarter than 85 out of 100 people), that's still pretty good. But if I have a 100 IQ (smarter than 50 out of 100 people) and I drop the same 15 points, I'm now smarter than only 16 out of 100. In general, having a higher IQ tends to help. However, there is a common problem that I have found with people who have a high IQ who get a head injury. They realize they're "different" and often have a harder time dealing with it emotionally. They're used to thinking quickly, having answers come to them quickly, and doing things easily. This is true for anyone with a head injury, but can be a greater problem for very bright people.

Another positive factor is how people do in the school system. In general, good performance in the educational system is a good predictor. A college diploma is great. A high school diploma is also great, particularly if someone has done well. Now, here is a common problem. Many people were not motivated when they went to high school. They were lazy, found school boring, or they just never applied their skills. Some of these people did poorly in the education system, but became very successful later in life. In other words, they worked hard and were able to get ahead. Academic skills can be, but are not always, a predictor of recovery.

A lot of studies have found that use of drugs and alcohol is a negative predictor. If you've been abusing alcohol for many years (10 to 20 years), you have already killed off large numbers of brain cells. Alcohol is one of the most deadly drugs (yes--alcohol is a drug) that we have. Alcohol kills more than any other drug. Of the 50,000 traffic deaths per year in America, half are alcohol-related. It is clearly important to stop using alcohol and drugs following the injury. Alcohol especially tends to attack

areas of the brain dealing with short-term memory. Those who continue to use drugs following a head injury have a poor outcome.

## **HOW LONG DOES IT TAKE TO RECOVER?**

Each doctor you talk to is likely to give a different estimate of how long it takes to recover. Some physicians may say that recovery from head injury is 6 to 9 months. This may stem from a "medical" point of view, as they commonly look at how long it takes to relearn to walk or use parts of the body. As a neuropsychologist, I look at complex thinking and very subtle changes in behavior. I use psychological tests that look for changes in thinking or memory. Research on these tests indicate that for two years following a head injury, there is evidence of improving scores. After this two year period in time, I can no longer see large changes in scores. Does that mean people stop getting better at two years? No. I have many patients in a long-term support group that I run who continue to report progress. However, these changes tend to be very subtle. For example, fatigue tends to be a long-term problem. From the second to the third year following the injury, they report that their fatigue has decreased.

Some people want to know, "How long will I be in treatment?" Once you leave the hospital, you may be lucky enough to be in a head injury program (I would estimate that only 25% of head-injured people have insurance coverage for this type of programming). Using the Neuro-Recovery head injury program as an estimator, the average individual will be in the program between 3 and 6 months (normal variation). Depending upon the services provided and the type of injury you have, the length of treatment will vary.

Does this mean you will be "all better" when you are discharged from a head injury program? Unfortunately, no. When people leave the Neuro-Recovery program, it is my expectation that they will continue to improve on their own. A lot of what a head injury program will do is improve what skills they can and teach you coping approaches for what can't be improved. This may include memory techniques and

organizational strategies. Basically, no one ever really "graduates." They learn the tools to continue with their own recovery.

Is it better to get therapy early on? Yes. There were some studies that compared individuals who had a stroke and got treatment with individuals who didn't get treatment. Those who did not receive treatment did improve on their own. The brain will spontaneously heal on its own. But individuals who did get treatment healed faster and did better on tests. What if there is a delay in getting treatment? Sometimes it takes a while to get into a head injury program. I've had people enter a program after a year and still make large gains. On test scores, people have sometimes improved 5 or 6 years in terms of their academic abilities (e.g., reading abilities, comprehension abilities, etc.) in just a few months. However, not everyone makes this level of gain.

### **WILL I EVER BE "100 PERCENT" AGAIN?**

*Am I ever going to be "100 percent" following my head injury?* In working with patients over a long periods of time, I find that they almost universally say "no". People will report being at 99% or 98 or 95% of their former abilities; I've never really met anybody who's claimed to have recovered 100 %. I've had people who've had significant head injuries, yet returned to work, regained a normal family life, and seemed to be doing great. They appeared to be doing well socially, got promotions, and made money. Yet they still say, "*I just feel different.*" Often family members will argue, saying that the head-injured person is fine ("*You just want sympathy*"). It is very hard for family members to deal with this type of change.

Change is a hard part of life. But in reality, we are always changing. If you have your appendix out, the scar from surgery never completely goes away. It's going to be there forever. It's become part of you. As we get older, some of our skills diminish over time. We know that we're not as strong or as quick; our stamina is not as good as when we were younger. If you ask, "Am I 100% of what I was at 18?", no one is. The aging process

is gradual and happens over time. We learn to accept this as part of life. The unfairness of the head injury is that change happens so suddenly.

### **HEY, THIS PREDICTION STUFF IS DEPRESSING!**

For most people who hear this information, it can be very depressing. In the hospital, medical recovery seems so quick. You can have major heart surgery and be out of the hospital in a week. With some surgeries, you are in and out of the hospital in one day. If I have a broken leg, I'm going to be in a cast for a month or two. Why does this head injury take so long? The brain is the most complex machine in the world. Fixing it is not easy. That's the bad news. **The good news is that people *do* get better.** I think you have to keep in mind that, "*With time, I will get better.*" You have to keep having faith. You have to keep working hard. Keep using the memory and organizational strategies. Head injury is like running a marathon. A marathon is 26 miles; you can't sprint 26 miles. You have to pace yourself for the long race and keep as positive an attitude as you can along the way.

## WHO ARE ALL THESE PROFESSIONALS?

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By the time I see a patient, it is not uncommon that they've seen between 10 and 15 physicians. In addition, they've also seen a lot of other treatment specialists. In this next section, I will try to explain the what each specialist does and how that relates to head injury. Each discipline is listed alphabetically.

**Dietitian--** A dietitian or nutritionist may sometimes get involved in your case. Following a head injury, you may not be as physically active as you used to be. It is not uncommon for people to gain weight following a head injury. The dietitian or nutritionist will help you to a more healthier diet and the means to lose those extra pounds.

**Ear, Nose and Throat Doctor (ENT)--** In a car accident, you may smash your nose or take a blow to the front part of your head. Many people experience difficulty breathing because the cartilage in the nose has been crushed; they may snore a lot more, or they may have multiple sinus infections. Some of these sinus infections can go on and off for a long period of time. As a result, you may be sent to an ear, nose and throat physician.

**Insurance Adjuster--** This is someone who is not in the medical system directly, but who has a great deal of impact on your care. This is someone from the insurance company who has the responsibility to figure out what medical bills they will pay for. They will not pay for treatments that are unrelated to your accident or for pre-existing illnesses. Because many insurance adjusters have hundreds of other claims, they may hire a **case manager**. Generally this is a nurse who has prior experience in dealing with head injury. A case manager may come to your home to take a lengthy history from you and discuss your injuries with your doctor. The case manager functions as an advisor to the insurance company; however, it is the insurance adjuster who finally authorizes or denies treatment.

**Internal Medicine--** A good way of thinking about this physician is to look at what is inside or "internal" to your body (dealing with your guts and organs). Internal medicine deals with the complex interaction of systems inside your body. This doctor is usually a consultant rather than someone who follows your care from start to finish.

**Neurologist--** This is a physician that you're likely to see following a head injury. A neurologist deals with the brain and nerves. The neurologist is usually a consultant rather than a primary doctor for head-injured patients. The most common problem that neurologists deal with is headaches. Neurologists also deal with seizures. The neurologist may give you a test called an EEG. This measures electrical activity in your brain to see if something abnormal is going on. If you do have a seizure, the neurologist is likely to give you anti-seizure medications to help control seizures.

**Neuropsychologist--** A neuropsychologist is a psychologist (See Psychologist) with advanced training in how brain injuries can effect behavior. The neuropsychologist gives tests that are very sensitive to the effects of a brain injury. This testing will locate areas of the brain that may be damaged. Many neuropsychologists are also involved in planning treatment strategies to improve thinking in damaged areas of the brain. Because recovering from a head injury is extremely stressful, some neuropsychologists also do counseling to help the head-injured person and family members to deal with the recovery process.

**Neurosurgeon--** This is a surgeon who does surgery on your brain or nerves. In the early stages, you may have a bruise on your brain. If you put pressure on the brain, you can stop important parts of the brain from working (e.g., parts that control breathing or being awake). In the early phases of a head injury, a neurosurgeon may be needed to stop bleeding in the brain. Because they are surgically oriented, they tend not to follow brain-injured people over long periods of time. You may be referred to another doctor for your long-term care.

**Nurses--** Nurses are there to carry out medical orders and apply medical treatments. They interact with you daily. They get you up, they give you

medications, and they'll chart how you are doing. Nurses cannot prescribe medications; that must be done by a physician. There are nurses who have gone for additional training. They are often called clinical nurse practitioners. Doctors come to rely heavily on their input.

**Occupational Therapist (Also called OT)--** When many people hear the word "occupation", they think that means "getting a job." Although occupational therapists can help with returning to work, they tend to deal with activities you do every day. In the hospital, they call this "ADL's" (activities of daily living). For example, we all brush our teeth, comb our hair, get dressed, and generally use our hands in a coordinated and smooth manor. With the head-injured patient, the occupational therapist also works on high-level thinking skills necessary to return home and work successfully.

**Ophthalmologist (also, Neuro-ophthalmologist)--** This is an eye doctor. Following an accident, some people will have a change in their vision. Vision can become blurry, doubled (seeing two of everything), or have missing areas. The neuro-ophthalmologist has more advanced training in vision problems caused by a brain injury. If your vision has changed, you may go to an optometrist (the person that gives you eyeglasses). A blow to the head can produce changes in your vision. Following a head injury, some people go through 2 or 3 pairs of glasses in one year. Right after the accident, their vision is very bad, then improves with time, and improves again.

**Physical Therapist (Also called PT)--** Walking and movement means freedom. The physical therapist is a key person in returning physical ability. This is often very painful work. Re-learning movement, or getting your arm or leg to fully extend (called "range of movement"), is often very difficult and can take long periods of time. When people are in the early stages of an injury, they tend to focus on walking. For most of my head-injured patients, the ability to walk and move seems fine. The physical therapist may be called in for common problems like neck or back pain.

**Plastic Surgeon--** This doctor will work on removing scars. If you are lucky, a plastic surgeon may be in the ER when you come into the hospital. They may sew up your face or other areas on your skin. For most of my head-injured patients, doctors like to wait for 6 to 9 months before they send you to a plastic surgeon to remove scars that may have developed. Plastic surgeons can do some remarkably good work at removing scars. For example, some scars may be red or slightly raised or bumpy. The surgeon can go in and lighten or diminish the scar so that it's nearly invisible. I have seen some really amazing work by these specialists.

**Psychiatrist--** A psychiatrist is a physician who works with people who have emotional or behavioral problems. They often give medications to help assist people in dealing with intense emotions or behavior. In the early phases of hospitalization, the head-injured person can be very confused and agitated. If someone is confused to point of hitting the nurses or being threatening, medications may be prescribed to help calm the patient down. Later in the recovery process, people can become depressed and a psychiatrist may also use medications to help cope with depression.

**Psychologist--** A psychologist is not a physician; so does not prescribe medications. A psychologist works with behavior and coping. In the hospital environment, the psychologist has several roles. One role is testing. Psychologists have developed standardized tests to measure things like intelligence. The psychologist may also be called in to help the head-injured person cope with emotions or control behavior, or to help the family deal with different aspects of the recovery process.

**Radiologist--** This is a physician who specializes in looking at X-rays, CT Scans or MRI's. He or she is involved with diagnosing problems using X-ray or other imaging equipment. They look at the X-ray or CT Scan and then send a report to your physician.

**Recreation Therapist--** A recreational therapist looks at a lot of the important things we do in life--recreation and fun. In the hospital, you may be involved with a recreational therapist who may ask you about your interests and hobbies. I've known some people who are in a wheelchair but

loved bowling before the injury. With the aid of a recreational therapist, there are ways that you can continue to bowl, even in a wheelchair. A recreational therapist often helps people to reclaim the enjoyable parts of their life.

**Rehabilitation Medicine Physician (also known as a physiatrist)--** This is a physician who treats individuals who have multiple medical problems. If you are in a car accident, you may have a number of injuries, including broken bones, bruises, infections, and so on. Your recovery may take a long time and involve multiple doctors. The rehab medicine doctor commonly takes the role of the primary physician. The medical system has realized that we need one doctor to coordinate treatment when multiple doctors are involved. This responsibility is typically given to the rehab medicine physician.

**Social Worker--** In a hospital, you're likely to be involved with a social worker. For some individuals, a social worker helps provide discharge plans for leaving the hospital. In other hospitals, social workers also help the patient and family members to cope with their medical problems.

**Speech/Language Pathologist (Speech Therapist)--** Helping people improve their speech is just one area the speech pathologist works with. They also help people with all sorts of language and cognitive problems. With a head-injured individual, the speech therapist may work on attention, memory, organization, planning, and sequencing, as well as things like reading comprehension and writing skills. They also specialize in teaching memory strategies (one of the classic problems in head injury).

**Vocational Rehabilitation Counselor--**This is a counselor who will assist you with a successful return to work, school, or volunteering. They will help support you by setting up job coaching, job strategies, and school strategies. The counselor will locate jobs, school programs, and volunteer sites that best match your individual needs.