

ADVANCED TECHNIQUES:

CHAPTER TWENTY-FIVE: Understanding Focal Injuries

The key information about focal injuries is explained in the self-therapy manual. This chapter contains a few notes about issues that arise for family members.

Survivors of brainstem injuries often have serious long-term physical disabilities, as well as other symptoms that can be seen or heard by others, and which place the person in the abnormal category. In the language of rehab, these injuries can be handicapping, because they incline a person to be treated as abnormal and to come to see him or herself as abnormal after a period of time. Many brainstem injuries make people slow, clumsy, hard to understand, and deformed in physical appearance. They elicit sympathy, from family members as well as from the general public. People with these symptoms are easy to underestimate. Their appearance pulls people to treat them as if they were mentally retarded, although many retain most of the abilities we think of as intelligence. Thus families affected by these injuries have to deal with the stigma of abnormality, and may need to fight to have their person taken seriously and asked to do normal things.

Frontal lobe focal injuries tend to be harder on the family than any other kind. They produce more passive behavior--not taking care of needs, responsibilities, and problems--and/or more impulsive behavior, including rude, thoughtless, dangerous, and disruptive actions, than any other injury. A frontal lobe injury can result in a constant stream of poorly-controlled, age-inappropriate behavior in a hyperactive pattern, which tries the patience of anyone. Moreover, the person does not realize that the behavior has gotten to be this way, and so makes no effort to control it or rein it in. You can get at least some help and cooperation from the person by simply describing the behavior and telling them what you want them to do about it. Describing it is very important, because without the description, the person will have no idea of what needs to be changed or fixed. But you also need to be aware that every distraction or urge can pull the person away from attempting self-control, and will require you to make a new request. As with parenting a young child, it is important not to "tolerate" the bad behavior, because that will just cause the frustration to build up inside until you explode in anger, which will only make matters worse for everyone. It is best to say something early before the frustration has built up.

Frontal lobe behaviors can also be shocking and upsetting to families that have high standards for conduct. Frontal lobe injuries tend to release profane speech and overtly sexual or aggressive actions that the family is likely to regard as shocking or unacceptable. Because these behaviors are seen as morally wrong, it is easy for family members to become critical or judgmental, and to treat the person as if the behavior was a willful act of moral disobedience. It is important to remember that frontal lobe injuries short circuit the gap between an urge and an action. When President Carter felt "lust in his heart," if he had a head injury he would have been hitting on the hottie without having formed any intention to do so. It is not that your loved one decided to do something that is wrong. The decision to act was not made--the action came out before the

decision could be made. This doesn't take away the person's responsibility to learn how to control these behaviors, which can be done, but it does make a moral interpretation of the actions unfair.

Temporal lobe focal injuries leave your loved one extremely susceptible to overload. Any kind of overload may cause the person to break into tears, a symptom called affective lability. Lability is not a sign of depression, or nervous breakdown, and there may not even be any sadness when it happens, though people are often quick to reassure and comfort the labile person and even to order anti-depressant medications. Lability is a simple brain injury symptom, not a mental health or emotional indicator. However, even the survivor can misread what it means. I have had many middle aged men confess their fear that the lability means they are having a breakdown. It means nothing of the kind. Lability goes away if you relax. Other than to deal with it that way, it should be ignored. If you are not sure about whether a bout of crying is due to sadness, depression or lability, remember that unlike sadness and depression, lability starts suddenly, full force, and stops just as abruptly. Don't play psychologist or comforter when lability happens--it has about the same psychological importance as a belch.

Temporal lobe focal injuries also tend to produce the most serious memory problems for new information. My advice to family members on dealing with forgetfulness: Don't help. Don't act as the person's memory for them. Don't give reminders of everything they have forgotten. When you do that, you delay insight into the head-injured moment and thus you delay fixing the problem. When information is obtained, suggest that your loved one write it down. When it is needed, suggest that they look it up. The less you help the more they will need to correct the problem. I will nag you about this again when we come to the chapter on memory problems.

Focal parietal injuries have several effects that are especially unfortunate for family members. One is paranoia. People who misunderstand what others say and do often come up with their own, suspicious explanations of peoples' motives. When this happens, the misunderstanding can often be corrected by a slow, simple explanation of the misunderstood material.

Parietal injuries also produce problems with excessive optimism (if the injury is on the right side) or pessimism (if the injury is on the left side). It can be helpful to do planning as an interactive activity, so that you can supply the missing anticipation of success, failure, or side-effects.

The visual perceptual problem of neglect, or lost awareness of the left half of the world, is an important practical problem. The person with right parietal injury trips over things on the left side, knocks them over, bumps into them, and can get hurt or produce a furniture crisis. The compensation strategy is simple: look all the way to the left, then bring your gaze back slowly to the right. The problem is that the very poor insight into the head-injured moment keeps the person from using the strategy when it is needed. If you see the person about to get up and walk, or trying to search for something, you should cue for the strategy. Doing that over that span of several months is usually enough to get the person to start doing it on his or her own. People with neglect usually want to do things they shouldn't do, like operate motor vehicles or other

fast-moving conveyances. Most family members realize that they need to forbid driving while there is neglect, even if it means hiding the car keys. However, some families allow the person to get into trouble with other vehicles, like an ATV, a motorized scooter or a bicycle. If you can't see half the world and forget that it is even there, you shouldn't be moving fast over the landscape in any kind of vehicle!

CHAPTER TWENTY-SIX: Setting Priorities

Adults are accustomed to setting their priorities automatically and mentally. Since that approach no longer works after a head injury, it is necessary to set them deliberately, on a schedule, and in writing. This is not a particularly easy task. Try it in your own life. I am reminded of a famous autobiography written by football star Gale Sayers. He named the book “I Am Third.” By this he meant that in his life serving God came first, then carrying out his responsibilities to family and friends. Only when he had taken care of those things did his own wishes take priority. Few people are as virtuous, but few are also so clear about their values. Sayers was respected by everyone who knew him as an outstanding person. If you haven’t seen the movie made of his book, “Brian’s Song,” check it out. You’ll be impressed with him, too.

Setting priorities is a very personal thing, so it is reasonable to offer help, but only in organizing, not in making the choices. The first step in the process is to generate a list of the major priority areas of life: spiritual, family, health, brain recovery, school, job, friendships, romantic or sexual, physical conditioning and athletics, music, attire, grooming and make-up, reputation, honor or honesty, peer popularity, entertainment, helping others, money and financial security, and so on. Then they can be set into a first-draft priority order. Then the person should look at each pair of adjacent items and make sure that they are not ordered backward. After each pair is checked and any adjustments made, the list is in its final form. You may not agree with it, and it may surprise you. You will probably find brain recovery lower on the list than you would like. Don’t rock the boat! The list should be readjusted every six months for the next year or two, and then every year after that.

The priority list then serves as a very useful tool to help set daily and weekly goals, to evaluate scheduling conflicts, and to help in making difficult life decisions. Survivors who do not do this priority setting activity tend to have lives that drift aimlessly, in which their activities are not related in any significant way to their values. Their lives go out of their own control. By paying attention to priorities and using the list where it is relevant, your loved one can retain some control over his or her destiny.

CHAPTER TWENTY-SEVEN: Remembering Telephone Messages

When the phone rings in a home in which a person with a long-term head injury lives, things work a little differently. The survivor may ignore the phone call under orders from the family, who do not trust him/her to handle it. Or the survivor may take the call, but if it comes from a friend or family member, they may ask for another family member or simply call back later if they have something important to relay. Or the survivor may take the call, but another family member may come in and take the call away if it is someone who might be providing or seeking information. In other words, the head injured person is taken out of the role of an information giver and taker. This comes from bad experiences with forgotten or botched phone messages.

The fix is as easy as cracking an egg--phone messages get written on an 8 ½ by 11 pad kept next to the phone. If there are messages that the survivor needs to give to a particular caller, they should be written down on that pad. Then when a call comes in, the person can scan the outgoing messages on the pad to see if there is one to go to the caller. If the caller has a message for the survivor or the family, the survivor takes it down in whole sentences (not abbreviations) on the pad. One sheet of paper is used for each caller. That allows the note to be filed away. If the call is nothing but personal news, the survivor probably should take notes on it. Then those notes can be filed away in a folder marked with the name of that friend or relative. That way, when it comes time to write a letter, pay a visit, or make another phone call to that person, the file can be reviewed and the survivor can show interest in the person's life in the way that an uninjured person does via mental memories of past phone calls. As long as this system is used according to these instructions, it is airtight.

Your jobs are to keep a fresh pad and a pen or pencil by every non-portable phone in your home, and to spy on your loved one when he or she answers the phone during the early training period. It is a good idea to cue the person to take notes at first, until the habit gets built up. It should take no more than a couple of months of cuing as long as the person has a good attitude toward taking the notes.

Any time the notes are not taken, or taken only because there was cuing, and any time the notes are incomplete or impossible to decipher, that calls for an Analysis Form.

CHAPTER TWENTY-EIGHT: Remembering Information

Will your person be one of those head-injured folks with a Swiss cheese for a brain, who you tell something to and it goes in one ear and out the other--someone who forgets what they learn and forgets to do things they promised to do? Failing to cope with memory problems produces a kind of public incompetence that undermines faith and trust of others. On the other hand, a survivor who has developed a strong system to record information and uses it religiously inspires trust--you quickly learn that this person never lets anything go out the other ear.

“You keep information by writing it down. You lose it too often if you put it in your head.” These statements may have to be repeated every so often. Many survivors resist taking notes. Some are cocky about being able to make themselves memorize information again. They are encouraged by their occasional successes in committing individual facts to memory. They don’t realize that hit-and-miss memory is the best they will get, and that this doesn’t make it for many practical purposes. Others hate writing things down and have since they were in school. Pen and paper bring back bad memories of prissy teachers who embarrassed them. They can often be hard cases, willing to be forgetful rather than to use this simple, perfect fix.

There are approximately a zillion books that have been written on memory tricks and devices. Ignore them. They can be used after a head injury, but it takes a whole lot of time and effort to memorize a single list, and the techniques are useless if the thing to be memorized is longer than a list of ten words or so. I used to teach these tricks to my patients, but I quit. What convinced me was that an expert on these tricks, and also on memory disorders, the neuropsychologist Dr. Laird Cermak, gave a major speech recommending that we quit trying to restore memory and concentrate on compensation strategies--writing the information down, and/or tape recording it. I am not the only one who agrees with Dr. Cermak. Most cognitive rehabilitation experts caution that mnemonic devices and memory-practice drills simply don’t help prevent forgetting. We all agree that writing things down is the only good answer.

Your most important part in this is to stop remembering things for your loved one. Do you have any idea how many times every day you do this? Probably not. Without even thinking, you step in to supply information missing from memory: what day it is, what was supposed to be bought at the store, what stories the survivor already told and doesn’t need to tell again, the directions to get to a certain store or home, appointments, phone calls to return, today’s weather, it just goes on and on. The survivor is glad to get the information and you are used to giving it and happy to help out. So where is the problem? The problem is that he or she will always need you to be his/her memory. Are you willing to be joined to him/her at the hip? Can we stitch the two of you together, so you go everywhere as a pair? Because then, and only then, it’s okay for you to be the memory. But if your survivor is to have a life of his/her own, and needs to be able to function, and shouldn’t look mentally crippled to others, than he/she must learn to handle information without your help. And as long as you go on helping, that will not happen. You have to quit helping first. And you have to announce that you are no longer going to be the memory. You should present your survivor with a big tablet and a nice pen, and say “Now the job is yours.”

This habit can be so hard to break, especially for mothers and mothering wives, that I have sometimes had to deputize a dad or an adolescent child to get mom to stop helping. Don't be a hard case. Stop yourself. In the end, your loved one will become more capable for it. That means when he/she is trying to remember something, and looks at you with that pleading expression, you have to bite your tongue and say "look it up" even when you know that he/she didn't write it down in the first place. And when he/she tries to look it up, and sees that it never got written down, and looks at you with that same pleading expression, you have to bite your tongue again and say "Analysis Form." In other words, you have to not bail him/her out. If it means forgetting an appointment or being frustrated about not being able to recall a name, that is a small price to pay for a learning experience (and an Analysis Form) that will help him or her to write down the necessary information upon getting it next time.

The main trick to making this work is that the person needs to stop and think when new information starts to come in. He/she needs to ask, "Is this something I'm going to need to know later on?" If the answer is yes, the habitual plan needs to be "Write it down." That is what makes the system work. But until there have been a number of frustrating experiences with not having the information because it didn't get written down, and perhaps ten to twenty Analysis Forms, that habit of writing down is not going to be there. Every time you rob him/her of that frustrating experience, or fail to cue for an Analysis Form, it is another chance to learn how to handle information competently that got wasted. Tough love, again, right?

You need to know that it is also far easier for you to just tell your loved one the information they need or want, and if you make them look for it, and then do an Analysis Form, that will take both more of your time and more of your energy. That's the cost of doing the recovery business.

CHAPTER TWENTY-NINE: Remembering to Do Things at a Certain Time

Most survivors have more trouble with remembering to do something at a particular time than with any other memory task. Make it easy on everyone. Get an alarm watch. Make sure the alarm is loud enough to be heard.

If your loved one is extremely forgetful, he/she will need to make a note about what the alarm is for, as we discuss in the survivor chapter. As in the last chapter, you can help by cuing him/her to set the alarm watch, and by not doing the remembering. Mainly the second thing.

By the way, it can be exquisitely hard for a survivor to learn to use an alarm watch. Each watch has its own quirky control procedure. And the instructions are usually written by someone who speaks only Japanese or Mandarin, and then translated by someone who has a very weird idea of how English is used. This makes the instructions hard for all of us to use. You should really help out with this part of it. Together, you and the survivor should make up a list of the procedures to set the alarm, and put them on something you can put near the watch, like a plastic covered luggage tag. You can fasten the luggage tag to the watch, which is easy to use but funky looking, or the person can put the luggage tag in a pocket or purse, and pull it out when time comes to set the watch. After a couple of months, the procedure will be well enough learned to do without the luggage tag. But if you don't do this, the watch will never get used.

CHAPTER THIRTY: Remembering Directions and Locations

If you are compulsive, you probably write out complete directions before going someplace unfamiliar. And you probably have a place for everything in your home, and you put everything away where it goes when you are done with it. My older son is like that. Michael can find anything in a heartbeat, and he can tell if anyone has been in his room and moved any of his stuff. If you watch the popular sitcom Friends, you know that Monica Geller is like that. Her place is perfectly organized and perfectly kept. On the other hand, if you're sloppy, like me or my younger son, your place probably looks like a tornado just went through--piles of this and that everywhere. I prefer to live that way. It would make me crazy to live with Monica Geller. But if you are sloppy and you live with a person with a brain injury, you have a real problem on your hands. Because a sloppy lifestyle means that your survivor is going to lose things--all the time--and be unable to find them when they are needed.

If your loved one is compulsive, or gets compulsive to combat the disorganization produced by the injury, he/she is going to get very upset with you if you move his/her things, with good reason. You might just as well give in and become compulsive yourself. There is no use fighting the tide. Your survivor is right to be compulsive, and you'll only wind up feeling guilty if you stand in the way, so you can't win unless you give in and become another neat-freak.

If your loved one is sloppy, it's a very different matter. Very few sloppy people become neat after a head injury. It has happened but it's rare. Many sloppy people become even sloppier. It can be scary. I remember a home visit my OT made on a patient who had been injured for many years and who lived alone. His house was not only a sea of dirty clothes, possessions and garbage, but he had a huge snake that slithered in and out of the piles of mess. It was awesome!

The answer for a family that is sloppy to the core is to let the Analysis Forms be your guide. There are certain things you just can't afford to lose--like your keys and a lit candle--and a snake, if you have one--and if you lose them a number of times, and do an Analysis Form each time, you will come to the conclusion that you need to be compulsive with those things--picking a certain place for them and putting them only there. The same thing goes for a wallet, and for the mail. All you have to do is lose a couple of utility bills and get your services turned off (and do an Analysis Form each time) and you realize that just putting the mail down somewhere is a strategy for cold, dark nights and no phone service. So you end up choosing a spot where all incoming mail gets put, and where it stays until it is dealt with. Through this problem-solving approach, the results teach everyone which kinds of sloppiness are harmless and can go on, and which kinds are hurtful and need to be replaced with compulsiveness.

With following directions, the issues are a little trickier. The compulsive person writes out a full set of directions in longhand, abbreviating nothing and writing neatly on lined paper. The directions are double-checked with the source person before they are folded neatly and placed in a purse or briefcase. The sloppy person uses a scrap of a pizza box or the bag your lunch came in, and writes chicken scratchings that go off in all directions, with words and phrases abbreviated by a couple of letters and then inserted hither and yon by arrows, until even a

professor of anthropology couldn't translate them back into English. Sloppy instructions lead people to Marineland in Miami or NASA in Cape Canaveral, not to their desired destination. So if your loved one makes sloppy directions, or even worse, tries to remember directions, he/she is going to get lost.

It's okay to get lost, as long as you have procedure to follow that preserves safety. People who get lost get into trouble if they freak out. So the first step when getting lost is to pull over quickly and calm down. The second step is to make a plan. If the person is lost in a familiar neighborhood, the plan may be to head for the largest street you can find, which will be one you know. If the person is lost in an unfamiliar neighborhood, the plan may be to start by back-tracing the route--by going back where you came from, and looking for the last landmark or street where you had your bearings. It is a good idea to stop in a safe manner by the side of the road and look over your directions and your city map to find the route you came in on. Many people have trouble rotating a map in their minds in order to go back the way they came--it may be necessary to turn the actual map around to see things from the opposite direction. If going back the way you came brings you to a known location, you can turn back around, stop, figure out your next move, and then continue on your route. If going back doesn't get you to a known location, then you need to find the names of the streets going both ways at the next intersection so you can get directions. Pull over. Calm down again. If you are a female, you may ask a passer-by for directions. If you are a male you would probably starve before asking anyone, so pull out your cell phone and call a friend with a good sense of direction or a set of maps, or a local police station, and get some new directions. Be sure to write the new directions down as you get them, and double check them with the source.

I recommend that you set a goal one week to deal with getting lost. Review these procedures. Then take them out and get them lost. See if they can handle finding their way back to known space. If they can use these methods, you can rest easy--they can go off with the directions they wrote down, and even if the directions are bad, they can get back home (and fill out an Analysis Form on badly written directions.) The experience of getting lost because of sloppy directions is a powerful way to learn to be more careful when writing them. It can make even the sloppiest person into a compulsive. And then, of course, the directions will always be perfectly prepared. That is how effective problem-solving fixes sloppiness!

CHAPTER THIRTY-ONE: General Tips About Record Keeping

By now, you should pretty much know the drill. If your loved one doesn't write something down that needs to be written down, Analysis Form. If it is written in the wrong place, Analysis Form. If it is written so sloppily to read when it is needed later on, Analysis Form. If it gets put someplace where it can't be found, Analysis Form. The Analysis Form will guide the person to keep records in a way that really works, and that gives full access to all needed information without difficulty. But that will happen only by diligent use of the problem-solving system.

Don't you even think about putting away a note that he or she left sitting out! That would be treason! What is the thing to do if he/she leaves a note sitting out? Right--Analysis Form!

CHAPTER THIRTY-TWO: Putting Organization Into Learning

Learning large amounts of information is a special problem for most survivors. Just reading does not make adequate memories. Just reviewing what was read is not good enough either. The material has to be pounded into the brain. And just reading the same stuff over and over again is a very poor method of pounding it in.

The best way to pound in information is *active*, *reinforcing*, and *reductive*. Information is easier to remember if you don't just repeat it but think *about* it. Try it out. When you meet someone new at a party, try repeating their full name ten times. When you meet someone else, say their name to yourself and think of ten things about them--who they look like, whose name their name sounds like, what their name rhymes with, what unusual facial feature they have, what out-of-the ordinary clothing they have on, who introduced them to you, where you might see them later, and so on. This active approach is called deep processing--it involves linking new information to other items in your mental library of knowledge. Deep processing makes stronger memories that are easier to recall later. By reinforcing, I mean that if you test yourself to see if you can remember, it will stamp the information in even harder. What was his name? Where did he say he comes from? What does he do? By passing your own memory tests you punch in the memory. Finally, a reductive approach spends study time only on the information you haven't learned. Anything you learned gets tossed aside. The more you study, the less you need to learn.

This technique takes a lot of time. The full method, described in the survivor chapter, takes even longer. But it works. Students who use these methods get top grades in high school, college, and graduate school. Using these methods gets people passing scores on trade school entrance exams and licensing exams. If your loved one is out of school, and not in line for any detailed job training, these methods may not be needed very often, but they are there when they are needed.

CHAPTER THIRTY-THREE: Putting Organization Into Actions and Speech

People with extremely severe injuries or large focal frontal injuries tend to have all kinds of trouble in performing a sequence of behaviors. People with less serious injuries may need the techniques in this chapter only on special occasions--when learning something very unfamiliar and complicated, or when doing something with many steps where an error is intolerable. For example, most people are likely to need this approach when building put-it-together-yourself furniture, equipment or major mechanical toys like a bike. Many people also need it to learn to program a VCR, both with and without a brain injury. However, only those with the most serious injuries need these methods on a daily basis.

When there is a very severe head injury, caregivers tend to give instructions for a multi-step behavior one step at a time. This can be fully effective, but it makes the person totally dependent on the caregiver. Walking a husband or daughter through the morning routine for the ten thousandth time is painful and frustrating--and totally unnecessary. If all that is needed is to follow a series of steps, almost any survivor can follow a checklist.

A good checklist breaks a task down into single steps. Each step is briefly, clearly described. Something that seems simple, like brushing teeth or shaving, might have to be spelled out in fifteen steps for a person who is extremely impaired. On the other hand, many survivors remember how to brush teeth and shave, but they don't remember to do each of those things every morning without a reminder. A checklist that includes every step of the morning routine can take care of that problem completely, and make the person fully independent for that activity in the process.

Teaching checklist use requires close supervision and patient instruction at first. The first habit that must be built is checking off the step as soon as it is completed. Most people want to skip this step, because we all use checklists without checking off the steps if we have had no brain injury. When instructed that they must check off the steps in order to stay organized and be sure which step comes next, most survivors are sloppy about it, and they need to be instructed to increase their quality control to get it done carefully. To accomplish this step, they need to be sure not to talk, respond to the talk of others, or get distracted into doing anything else, until they make their check mark. From starting a step to making the mark, there can be no interruption. Once the check mark is made, they can allow self to be pulled away momentarily, because the check mark tells them where to resume. Within a few weeks at the latest, using a list should have become a reliable habit.

The next part of the self-therapy process has to do with perfecting the checklist itself. If an instruction is not clear, when the checklist is used it will become obvious that it isn't directing the proper behavior, and it can be adjusted to make it clearer. If it asks the person to do more than one thing, you will see it cause confusion and disorganization when it is used, and you can split it up into more than one instruction. If the list has left out some steps, you will see those steps skipped when it is being followed. Always put in the missing steps--never press the person to remember anything. The list should tell all.

Sometimes a list will need to have a conditional set of rules--what to do if a certain problem crops up. For example, instructions for shaving with a blade razor need to have a section (perhaps in the margin, or possibly on another sheet) on what to do if you cut yourself. Instructions on putting on nail polish need a side-loop on what to do if you spill the bottle.

Write up the list the best way you can. Then put it to use. If there are problems with the way it is written, they will show up, and each time that happens you can fix them. A checklist may need to be correct ten times before it works completely, or it may come out perfect the first time. That depends in part on how complicated the activity is, and in part how much you can think like a robot. But once you get a checklist right, the result is pure pleasure. You can sit back and enjoy your coffee, while both you and your survivor feel proud of how well he/she can self-direct through that morning routine.

Diffuse injuries often leave the survivor a pretty good conversationalist, but not a very good speech maker. Speeches tend to be repetitive, disorganized, wandering, and hard to understand. If you are a very nice family member, you can sit through these awful monologues, which may go on and on until the cock crows for sunup the next day, and not say anything, and keep your family member blissfully ignorant of what a pain he/she is to listen to, but if you do that everyone else will avoid him/her and you will become his/her only audience for life. Or you can say something. But what should you say? You don't just want to hurt feelings--it should do some good. What I usually say is "It sounds to me like you didn't prepare your thoughts before you started talking." A comment like that is prescriptive--it helps the person to realize what he/she should have done, and could do in the future. "Do you know what I picked up on?" Always give your loved one the opportunity to be smart about deficits. In this case, he/she may know what the problem is. Defects in speech can be heard more easily than defects in behavior can be noticed. "It wasn't very organized, and I don't think you ever got to your point."

Don't ever invite me to your parties. Because if someone says something rambling to me, I'm likely to get out a pad and a pen and start writing down message units. "Here are the points you made." And I list them out. "This one probably came out too early. It seems to go better right here." And here is where you got off on a tangent about Ted Nugent. You were talking about bicycles--Ted Nugent has nothing to do with your topic! So what was the main point you were trying to get across?" And when he/she says it I write it down at the bottom. Now I number the points--1,2,3,4, and 5 for the main point or conclusion. Then I hand over the pad. "Try it again, but this time follow the numbers." Of course, a speech that is made following a topic list is likely to be short, to the point, on topic, and effective in getting the main idea across. "Perfecto!" Of course, I don't get invited to the next party, but the survivor now knows how to put a speech across.

People feel extremely strange using topic lists when they are not giving a speech at a podium, but it is a great idea when the subject is hard to explain and the stakes are high. If I had a head injury, I would never propose marriage, or ask my father-in-law for my future wife's hand, without a topic list. Nor would I try to talk my way out of a parking ticket without one. Nor

would I ask for a raise in my paycheck or allowance, or try to explain to my father why I wrecked his car. These situations cry out for a topic list.

Learning how to tell a story, give an opinion, or explain a point of view without rambling or monopolizing the conversation is important in rebuilding social skills. Using topic lists, at least during training, is a good idea. The training procedure involves role plays that are videotaped. For example, we can pretend that I am a high school graduate who wants to know how to get into the survivor's profession, and he/she is going to explain that, while being taped. Before we start the role play, we set goals, which include turn taking (letting the other person talk), following the topic list, and other practical communication behaviors (discussed further below in the section on social skills).

CHAPTER THIRTY-FOUR: Having Fair and Effective Arguments

You've probably noticed how easy it is to win an argument with your survivor. Talk fast, and he or she can't keep up. Make your point and then distract him/her, and there will be no comeback. Of course, you aren't really convincing him/her of anything, and the incredible inflexibility that accompanies most injuries makes it extremely hard to do that. But if all else fails, you can just push his/her buttons, get a fit of temper, and occupy the moral high ground as the person who didn't get upset. You can do that every time. If he/she has a younger sibling, the sib learns this very quickly, and punches the survivor's buttons mercilessly to get that dance of rage going like you might get a dance from a trained monkey. It is like bullying a crippled person--the survivor has no defense against it. On the other hand, the survivor eventually learns that arguing doesn't ever work, and may turn to sneaking or having destructive fits of temper to make a point. The end result is always ugly and never fair.

Does the idea of having an argument on paper amaze you, or put you off? Well, if you are going to have family communication and deal with peoples' complaints, you're going to have to have a procedure like that which permits exchange of views without overload. And that's very unlikely to happen when people speak their minds.

Put the shoe on the other foot. How would you feel about your family if you could never win an argument with them? There needs to be fair way to argue if the family is going to work.

Who am I kidding? Arguing with a head injury survivor is like arguing with a tree. The tree isn't going anywhere. Head injury survivors almost never change their minds in an argument. So when the argument begins, your frustration level probably goes through the roof. Here we go again, another exercise in futility! But when your frustration comes across and triggers an angry reaction, the two things together put the survivor in total overload, and nothing happens after that but primitive yelling and name calling. So when the argument starts, you *will* get emotional. Fine. That's the perfect time to cut off the angry exchange of words and get out the tablet. If you explain yourself in writing, in the least angry words you can find, there is actually a chance that the survivor will see your point, if you keep at it for about half a page. And then you might actually win one of these exchanges every once in a blue moon. In any case, having the verbal argument is a lose-lose proposition. You don't ever get your point across, and the survivor winds up acting like an emotional child. A civilized exchange on a tablet is a far better choice for both of you. You just need to cultivate the habit of picking up and using the tablet when you feel like throwing it.

CHAPTER THIRTY-FIVE: Sensitivity to Loud Noises and Bright Lights

It is very hard to imagine what stimulation is like to a person whose brain can't turn it down. Imagine being blinded by twenty mirrors and deafened by hammers beating on a trash can above your head. That gives a little of the flavor of it. Overstimulation penetrates the brain, shocks the mind into silence, and blasts up the level of emotions. It is an ordeal.

Everyone around a patient with a focal temporal lobe injury has an obligation to become aware of the loudness of his or her voice, and the sounds he or she is making by manipulating objects or playing audio-visual equipment. If a family member likes loud music, it needs to be under headphones. The same goes for loud TV. There needs to be a quiet place for the person, and it should not be that person's own bedroom. Having to go to your room to keep from being bombarded by stimulation is like being an exile in your own home. The loud noise people need to take their noise to their own rooms and have it there.

The survivor also has an obligation to let people know when there is a problem. Even the most considerate person will forget or fail to notice sometimes. And a home can't be kept as quiet as a monastery, so using earplugs is often a necessary fix. Whenever earplugs are used, they should be powerful enough to reduce the painful noise, but not so powerful that the person cannot hear anything, because total noise isolation is unsafe in an emergency, not to mention anti-social.

You may notice that the survivor sometimes puts him/herself in a situation in which he/she is being blasted by noise and lights. For example, some of my patients with this problem went to rave clubs, and got deafened by the music and blinded by the light show and disco ball. Don't look at that as evidence that your family member actually doesn't mind light and noise. He/she is suffering at the club. Look at it for what it is--bad judgment.

CHAPTER THIRTY-SIX: Doing Calculations

Calculation deficits are quite common in head injury, not because math ability itself is lost, but because of poor quality control, disorganization, distractibility, and problems with keeping figures in the proper column when borrowing or carrying. Thus the problem is a symptom of carelessness and insufficient attention to detail, one that is easy to work with because the training materials are so easy to come by or make.

The first step in Self-Therapy is recognition of the problem. Calculation problems are easy to demonstrate. You can use a math test from the internet, or from your local school, or you can make your own math test. The proof of the problem is your results after doing the problem on a calculator. Your loved one may make excuses for a single poor performance. To establish a clear understanding of the presence of a deficit, it may be necessary to give several tests. If necessary, one method which gets the point across with devastating certainty is to give a math test that is scored by grade equivalent level. An adult or adolescent who scores at a low grade school level is going to have great difficulty finding an excuse. More likely, he/she will admit the problem and try to deny that the skill is important, or will claim to have always had the problem. If possible, the latter claim should be countered, because when the problem is seen as an old one, the person is unlikely to work on improving it. If you have school records, or get them from the school district, you can probably prove what his/her math abilities were before the injury. The goal is simply to have the person recognize that there is a new problem.

If he/she wants to do something about it, the second step is to structure therapy sessions. The usual structure is used. A pretask preparation session includes a review of the Seven Techniques, setting a goal for the session, and predicting performance on the training exercises. For this therapy, ordinary math problems are fine. If you can get an old math book--the schools often keep warehouses of old textbooks that you can buy for a buck apiece--that is the easiest way to get sets of problems that already have answers. Start with relatively easy problems--addition of two two-digit is a reasonable level at which to start. More complex addition problems--adding three or more numbers of three or more digits--are fertile ground for errors due to rushing, fluctuating attention, and visual errors. You can go on to subtraction, then multiplication, then division, and so on. Use only the kinds of problems the person had mastered before the injury--don't go into math that was iffy or not working before. If you run out of problems at a particular level, don't re-use problems you already gave. Either get another math book, or make up your own problems. The final goal for the problems at each level of difficulty is at least 90% accuracy. 100% is possible and desirable. Your loved one may protest that he/she didn't get 90% or 100% on math in school, but the response is that this is not math therapy, it's quality control therapy, and how many brain injured mistakes does the person want to make?

If the goal is not being met, and the scores have leveled off or fluctuate or have even gone down, it is probably because the Seven Techniques are not being used. If you can't be there in person to supervise the therapy, arrange to have it videotaped and watch for problems in being slow, cautious and careful. Another big source of trouble is trying to borrow and carry mentally,

without writing down the numbers. Everything needs to be written down. Perhaps it is being done with the TV or music playing in the background. Maybe he/she is not double-checking the answers. It's always something, as Roseanne Rosannadanna used to say. So if progress is not being made, look for the cause of the trouble in how the work is being done. When the answers have been scored, you ask the survivor what he/she thinks he/she did well, and what things could have been done better. Then you give your feedback about any part of the plan that got skipped or done improperly. If something was skipped or done wrong, you wait to see if he/she goes for an Analysis Form, and if not, you cue it. If that doesn't get the Analysis Form filled out, you write it up in your own Error Notebook. Easy as one-two-three, no?

The final step is watching to see if he/she carries the techniques that worked in the therapy sessions over to the real world situations in which calculation is done. Is he/she slow and careful in checking totals at the cash register, or filling in the check register? Look for the "carry-over" or "generalization," and if it doesn't happen that becomes the subject for another Analysis Form. Eventually, the goal is to get calculation with good quality control done at his/her initiative whenever it is needed.

CHAPTER THIRTY-SEVEN: Making a Plan

Should I buy a new Lexus, on time payments of course? Should I marry this man twenty-five years older than me? Should I move to Belize? Should I invest all my money in this really great taco stand? Should I let these two homeless guys move in with me and pay me rent when they can panhandle some cash? Should I invest in this pound of high-grade marijuana which I could re-sell for much more than I paid for it? Can I buy another Harley? Is suicide the answer? These are some of the kinds of major life decisions that adults whose lives have been dumped upside down ask themselves to make. These are not daily issues, but they are issues that sometimes arise in the lives of people who feel desperate about their options.

People with un-fixed head injuries are famous for handling these decisions poorly. They tend to max out their credit cards when they have no income to pay them off. They make impulse buys they can't afford. They take up with people who use them or are dangerous to them. They get into trouble with the law. In every case, the person takes the action without realizing the risks they are facing, the odds against success, and/or how intolerable the eventual failure is for them. Of course there are other people who make these same mistakes without benefit of a head injury, but that just shows that there is more than one way to ruin your life.

After completing the largest follow up study of "natural" recovery (i.e., without benefit of advanced rehab methods) that has ever been done, the Los Angeles Head Injury Survey, Dr. Harvey Jacobs concluded that nearly 100% of the survivors were either receiving distant supervision from their parents or spouses, or if they did not have them, were living out-of-control lives marked by major judgment errors, and as such, in need of that supervision. Distant supervision does not necessarily refer to watching the person. It can be checking up on them with a regular phone call, and discussing their plans and ideas, to prevent them from acting on some foolish notion. These survivors were so many years post onset that their defective problem solving judgment represents a permanent deficit. And Jacobs' conclusion was that they were not able to handle the complexities of modern life on their own. This outcome is every parent's nightmare: my kid will never be able to make it on his own.

The core problem caused by these injuries is a lack of think-through when analyzing a problem. When an uninjured brain does problem solving, it comes up with a crude idea about what to do and then tests it, to see how well it will work. When it fails that test, it gets revised and tested again. That process of revising and retesting goes on, at a rate of about five cycles per second, until a well-put-together idea is built that passes the test. If a person takes twenty seconds to think about what to do, they can make 100 progressive upgrades of their plan in that time. Give me a hundred upgrades and I can make a plan to conquer the world. A German dictator almost did exactly that thing--he called his plan Mein Kampf.

After a head injury, the cycling device is broken. A plan gets crafted one time. When it is tested the broken device says it is perfect. That is the plan that gets used. It works just fine for routine tasks, because they only need a simple plan and that plan is already on file. But it produces terrible plans for complicated situations, new issues or situations, or for social

problems. The solution to the problem is to instruct the brain to carry out the plan-test-plan-test sequence deliberately, one step at a time. This method of planning is much slower, and it's more work to write down each step and to carefully visualize each outcome. But it pays off in producing better, more thought-through plans and thus better decisions.

Try it out yourself. Look over the instructions in the survivor's manual. Then use it to decide whether you should get long term care (nursing home) insurance for yourself. Use it to decide whether you should fill out an organ donor card. Use it to decide about buying into a time share. Sure, you can probably make all those decisions the easy way, in ten seconds, without putting pencil to paper. Then try it the way your loved one would have to do it--step by deliberate step. You can see that it takes patience to do, but also how it tightens up the thinking process and gives the person control over the extent of think-through.

Self-therapy in this area follows the general format described in detail in Chapter 33. However, it is usually pretty hard to convince a survivor that there is a planning problem. You can pull out your mistake book and point out a series of poorly-planned behaviors, but expect to get an argument. Unlike math, with planning there isn't a single, universally accepted correct answer. So you should discuss the issue, but don't expect the therapy to begin with a person who is fully aware of having a problem. In the rehab setting, I often have to refer to my neuropsychological test results as evidence of the planning deficit.

You can use the list of questions at the end of this chapter in the Survivor book as the training tasks, or you can make up your own. To score the survivor's work, you need to have the task done by a person who is not brain injured (It could be you.) Scoring is something that you and your loved one do together. You look at the plans the uninjured person came up with that your survivor did not, and discuss how many of them indicate a planning error by the survivor. The score is the total number of plans the survivor made divided by the total number that should have been made. A score of 80% is good. A score of 90% is what I am usually looking for. When the score is low, the reason is usually rushing, making assumptions, overlooking issues (because of a disorganized approach to planning) and/or failing to double check the final solution.

Remember that using this system depends on being able to use mental pictures to imagine the outcome of a plan. If there is parietal damage, you may need to help out with walking the person through a complete mental picture of each outcome.

CHAPTER THIRTY-EIGHT: Visual Search Strategies

Like math, it is fairly easy to demonstrate that a person has a visual search deficit. He/she starts looking for something, spends a certain number of minutes searching, then somebody else (who doesn't know where it is) goes right to the thing being searched for. You keep records on this sort of thing, and after you have five or six examples, your point should be pretty well made. Another way to do this is to have a search competition using the Where's Waldo books. There is likely to be a big difference between how long it takes your loved one to find the Waldos and how long it takes his little brother.

The format in Chapter 33 should be followed for this therapy. Special attention needs to be given to making the plan. Different kinds of search tasks are likely to need different search strategies. For example, when looking for numbers on a printed page, it is usually a good idea to run an index finger across the page to guide the entire search. When searching a room, it is a good idea to break up the search areas into sections, and to search slowly through areas that are crowded with objects or clutter.

It's a good idea to supervise these exercises closely. They have no benefit unless the search is being done in the correct, careful, quality controlled way. A search that is helter-skelter accomplishes nothing and teaches nothing except that there is a search deficit--it needs to be organized. A search done too quickly is of poor quality, and fails to teach the most important lesson--don't outrun your own brain. When I do visual search training, I often use a number search puzzle where the person is searching for a specific target embedded in a field of numbers. Since I know where that number is, I can see if the person locates it or just runs past it, rushing too fast to find it. Once he or she gets to the bottom of the page, we both know that the target got missed. I have instructed him/her to slow down whenever the end is reached without finding the target, because that means the search was rushed. If it is not found the second time, I consider the task failed and will stop it and re-instruct the person that the purpose of the exercise is pacing.

Once a visual search program is started, you have wonderful opportunities to link the training to real-world needs when your loved one is looking for something on his/her own. You should watch to see how this self-initiated search is conducted--again, probably, too fast and far too disorganized. If you see that--you guessed it--Analysis Form time! Then the search can be tried again, this time doing it the right way, and if that makes it successful, an excellent lesson has been learned.

Remember to point out that searching skills are important because searches take place in all parts of our world. Search is a big part of shopping trips, looking through closets and drawers, getting ready to do the laundry, using a map, and many other things.

CHAPTER THIRTY-NINE: What to Do About Visual Neglect

Neglect is an issue for your attention. As discussed earlier, neglect tends to be a problem about which your loved one has very little awareness. So you will have to play a more active part in cuing him/her to deal with it.

The compensation strategy for neglect is always the same, no matter what visual task you are performing: swing your head around to the far left, so that your gaze has swung past the edge of your target area, and then slowly scan back to the right. It works for seeing obstacles in your path, for looking for clothes in the closet, shoes on the floor, a can in the cupboard, a leftover in the refrigerator, the words on a printed page, the beard you need to shave or the face you need to paint with make-up. In other words, whenever you are taking a wide look at anything, this strategy is needed to avoid missing the left edge of it.

Visual search tasks work fine as therapy for neglect. The task is first used as a test, without any special preparation or discussion of any strategies. Thus searching for certain words or pictures in a newspaper, certain letters on a page of print, or people with certain features in large group pictures are all effective test tasks. An even better way to test neglect is to have the person sit down and search a cluttered area in front of the chair. It is easy to demonstrate that the items on the left side are being missed every time. Looking for cities on a map can show the problem well also. You can even use the TV as a therapy tool. The person can be assigned to call out as soon as someone enters the picture from either side, and you can score how many seconds it takes to see the person coming in from the right versus from the left. Be sure to videotape the show, so that you can play it back in slow motion and show the people who did not get seen, or got seen late.

Once there is some acceptance that the neglect problem is there, the same set of tasks can be used in the Chapter 33 therapy format, with the neglect strategy being the main feature of the corrective plan. You can compare the scores earned without the strategy to the ones that are earned with it, to demonstrate how useful it is.

The final step in the therapy is to cue using the neglect strategy in real life situations--when rising to walk, to check the pathway ahead, when approaching doorways or entering new rooms, when searching for something, when grooming, and so on.

CHAPTER FORTY: Problems with Handwriting

Problems with your loved one's handwriting come in three forms: writing too messily or distorted for most people to read, writing that you can't read, and writing even your loved one can't read. I believe that when a person is making notes to him/herself, it doesn't make a bit of difference how messy they are, so long as he/she can read them. After a head injury, handwriting can change in many ways. It can get tiny, huge, shaky, letter shapes can get distorted, letters can run together and lines run off the end of the paper, and so on. Often the survivor can read this chicken scratching when I'm not sure it is even writing.

Injury also tends to make the writer less careful about writing in a way that can be read by others, so this can be a major problem. Sometimes the person's spouse or parent has learned to read the survivor's hieroglyphics, and the family member steps in to translate. This is not recommended. When this happens, the writing deficit is not fixed, and the survivor is dependent for help. Don't rescue your family member from bad writing. The answer is usually to write it again, but more slowly and carefully. If it was written on a poor surface, you should find a tabletop or desktop. Having to rewrite a note because others can't read it is a reality check. Combined with an Analysis Form, a few of these experiences can prompt changes in how the person tries to write.

A second problem is wildly disorganized notes. Patients with reduced impulse control, visual deficits, and particularly those with both, tend to write all over a sheet of note paper, with several unrelated notes being written at different angles, running into, over, and under one another until you can't tell which words go with which note. These survivors are also prone to add words and phrases with arrows. Pretty soon, the note looks like a relief map of Bosnia. These fragmented, disorganized notes are virtually useless. Survivors need to write their notes one-subject-to-a-sheet, and stay on the lines. If much material needs to be inserted, the note needs to be rewritten.

There are universal strategies for note taking that always improve writing. These include writing more slowly and carefully, writing in a sitting position with good posture, making sure to have good lighting. It is a good idea to sample pens looking for one that fits the hand well and gives a sure grip. People who have trouble controlling their hand movements often do better with a larger diameter pen with a rubber-coated gripping surface. Some people write better with a free-writing pen that gives a strong line with little pressure. Those with poor motor control may do better with a pen that has some resistance in the writing tip, as with an old-fashioned ballpoint pen.

Some survivors who have extreme problems shift to keyboarding. Keyboarding is a good solution but a limited one, since most people don't travel with a keyboard and printer and so can't leave notes on someone's door or windshield. However, they do make hand-held keyboards with printers, so if your loved one gets sick of struggling with writing and is able to buy and willing to carry a portable word processor, it is a reasonable strategy.

CHAPTER FORTY-ONE: Passivity and Reactivity

Your survivor may be overactive--if so, this is not the chapter for you. He/she may be underactive. Or he/she may be unresponsive until a situation reaches a certain level of urgency, and then may respond strongly to it. This chapter is for both of the latter patterns.

General passivity is a consequence of damage to the planning mechanism of the frontal lobes. An approaching opportunity or catastrophe doesn't seem important, or doesn't trigger a reaction, at least not until the last minute. The brain's action system is uninvolved and sluggish to react.

What this confronts you with is a family member who doesn't initiate anything, who just sits around or does passive activities like TV-viewing constantly. To the untrained eye, it looks like the person has lost all motivation and no longer cares--is treating life like a summer vacation. This is not the case--all the old motivations are there, but cut off from the action system. The person would care--if he/she were mobilized enough to raise his/her feeling level to a normal range. This is not a problem of attitude, or laziness, or taking advantage of an easy ride, or anything of the kind. But the sad truth is that the person is left on his/her own turns into the ultimate couch potato every time and stays that way until somebody says to get up.

This can all be changed by taking the role of the initiator. You mothers out there probably remember doing this during summer vacations in grade school. "Go out and play. Find something to do." Once you get your loved one started doing something, you see that there is interest and motivation. Your loved one gets up; you command taking a shower. The shower is completed; you order getting dressed. A fully dressed person appears; you direct eating breakfast. When that is done, you issue instructions for yard work. Things are now getting done, instead of two hours of reruns of *The Love Boat* every morning. And now you realize that if you play PE coach or drill instructor for the rest of your loved one's life, his/her activity pattern will return to pretty much a normal level. But only as long as the activating signals from outside continue. Is this progress? Yes, but certainly that isn't the recovery goal.

One way some family members can get from being a drill sergeant into living a more normal life is by transitioning from a period of constant oral orders into a set of written work orders. A couple of wives have adopted the suggestion of mounting a dry-erase board ("white board") in the living room or kitchen, and listing off the tasks that have to be accomplished. This works well enough if it is done after the oral orders have been fully in place for at least a month. If it is done too early, the person finishes a meal or task and winds up back at *The Love Boat*. The habit of moving from one ordered task to another has to be built up for this to work. It is also good to build the habit of having each completed task checked off or struck through to prevent raking the yard or vacuuming the rugs three times in the same afternoon.

A still stronger solution is to have the survivor create the work orders that he/she follows. This is done with the day planner system (Chapter 18).

Even if these methods are fully successful, they don't fix the problem of passive reactions to unexpected events in the situation. Remember, this could be a person who would watch a snake crawling up his/her leg, or stare at a fire starting in your drapes. As quiet and cooperative as your loved one appears to be, you may have a false sense of security that he/she is safe when left alone. Nothing could be farther from the truth. Emergency situations that could be handled by a second grader might have tragic results because of the passivity. You can try to develop some protection against the risk by role playing different kinds of emergency situations, though these role plays don't really show much unless you can simulate the problem starting with no warning of any kind from you. For example, I once simulated a heart attack during a role play that was ostensibly intended to demonstrate handling an angry customer. The patient, an assistant manager of a pharmacy, stood and watched with open mouth for several minutes as I "died" on the floor.

The best protection against catastrophe is to never leave the person with extreme passivity alone.

CHAPTER FORTY-TWO: Achieving Insight Into Head-Injured Moments

Welcome back to the Issue from Hell. You know how important and difficult this issue is (Chapter 2) and how much work has been recommended to go into it (Chapter 11). Now we need to talk about completing the task.

What we want is to have the person not only understand that there are cognitive problems and what they are, but to target specific ones for action. People don't fight back well against an invisible enemy. It needs a name and a face. That's what the label for the deficit is all about.

There is a powerful truth in this. Here are a couple of examples from history. People have known for thousands of years that women are not treated as men's equals in this society, and that their role is not fair. However, the fight against this problem picked up a great deal of momentum after the term "sexism" was coined. People have known even longer what "stress" is all about, but there was no common word for it until recently. Now people are much quicker to understand and deal with their stress-related problems. People have been hotheads since people were invented, but only recently did we get the concept of "anger management" do fix it.

The same thing is true for brain deficits. When patients are taught to talk about and look for a particular deficit by name, they become more aware of it and handle it better. In therapy, I force the issue for a key deficit like "impulsivity," talking about it at every opportunity along with the other members of the treatment team. Not surprisingly, my former patients are still talking about it, and being careful of it, ten years later.

The best way you can encourage this kind of learning is by changing your own vocabulary to incorporate the words and concepts of the Seven Techniques and other key deficit terms. The more you use the words "quality control," "overload," "preparation," "multi-tasking," "neglect," and so on, the more real these deficits are likely to become for your loved one.

I also like to encourage deficit awareness by challenging it. When I notice a problem, I am likely not to label it myself before asking the person who did it if he/she can beat me to the punch. "Do you know the name for what just happened?" Sometimes I encourage couples who have a frisky relationship to compete at home to be the first one to name the deficit when it occurs.

CHAPTER FORTY-THREE: Energy Management

It is extremely easy to wind up in energy debt after a brain injury. Stay up too late, and tomorrow is shot. Have coffee or a cola at dinner, and you will stay up too late. Watch a crime drama just before going to bed, and three hours later you are lying in bed awake.

It is just as easy to wind up in trouble after a good night's sleep. Make your best effort at any task, concentrate fully, and a minute or a few minutes later, you are exhausted. Work under tension and you get tired much, much quicker. Bear down, try to push through the fatigue, and the bottom drops out.

Learning to manage energy is learning to put getting a good night's sleep ahead of a family of habits like using caffeine and late-night entertainment. It's learning to budget your energy checkbook, to hoard and carefully spend your energy so that you can get through a task. It's learning to do things so that you have time to rest and refresh your energy supply properly before tackling anything else.

If you have ever tried to wean a long-term survivor away from excessive use of caffeine, you would swear you had a cocaine addict on your hands. What is the great attraction to caffeine? To put it simply, caffeine gives a sense of energy, vitality and optimism that makes a survivor feel more fully normal. It may take quite a bit of caffeine to get that feeling, and a lot of refills to keep it going. But that's what makes it so attractive.

Unfortunately, a caffeinated person with a head injury dumps out their energy reserve in a short time, leaving a depleted, fatigued person to finish out most of the day. It may feel good to get really juiced, but it comes at quite a cost.

One way to provide environmental support for a person who does not acknowledge the issue is to brew up only decaf. If decaf is in the pot, that's what the person is going to drink. Having a pot full of caffeinated coffee is like an invitation to drink to excess, spill out all the energy in the morning, and need a nap by after lunchtime. The same issue holds for soft drinks. If you have Coke, Pepsi, or most other soft drinks you are providing a good hit of caffeine, leave alone the Mountain Dew (horrors!), Jolt, or Red Bull. If all you have in the house is Seven-Up, and caffeine-free colas and orange drinks, that's what will he/she will drink.

If you are not willing to keep the problem beverages away from the household, the next best move you can make is to have a little bulletin board or blackboard on which the number of cups or cans of soda gets charted. You may be shocked to see how high that number goes each day.

Energy management also depends on careful planning when the day planner is filled out. You can help by asking your survivor to look at a completed day plan in terms of how much energy gets used up by each activity. How much is left for the afternoon activities? How well will they get done if you are tired by that time? The majority of survivors learn to schedule the hardest and most critical activities in the morning.

Survivors may also need some cuing to take rest breaks. They do not notice the early signs of fatigue, and tend to discount what they do notice. It is not hard to train someone to notice fatigue and to take proper rest breaks. It just takes persistent attention on your part, and discussion of the issue during therapy sessions and other tasks that deplete energy strongly. Remember, your goal is not to get the break taken, but to have your survivor learn to initiate taking a break. That means relying on cuing only at the start, and switching to preparation and Analysis Forms as the training tools as soon as possible.

CHAPTER FORTY-FOUR: Impulsive and Inappropriate Behavior

Impulsive behavior--actions not thought through--probably impacts your life and your loved one's more than any other deficit. Impulsive behavior is what embarrasses the family in public places and social gatherings. It is why adolescent siblings and old friends don't want to be seen with the survivor. It is the source of so many kinds of inconsiderate behavior, words or actions produced without any awareness of how you will feel or be affected. This is the behavior of the husband who sold his wife's car because he thought it was time for her to have a new one, but didn't mention it to her until it was a done deed. Or the wife who laundered all of her husband's dress shirts when he needed one of them to wear to work that morning. Or the son who came in the front door, saw clothing he had left in the living room, and immediately put it away, leaving the front door wide open for the rest of the afternoon.

If this is not a self-therapy target for your loved one, you have a hard row to hoe. But there are things you can do. Most family members use a lot of cuing to handle impulsive actions, encouraging reconsideration of foolish ideas and repair of blurted, inappropriate remarks. It is often a good idea to try to discuss an upcoming interaction, outing or project, and try to talk through the plan of action. The more you discuss, the less he/she will be improvising, and it's improvising that brings out the highest level of impulsivity. Emotional overload can produce a massive tendency to act impulsively, so if you notice that state, you may have some methods for calming your person down. One classic way to do it is with a snack. Eating activates the calming system. Another is by distracting the person from whatever it is that is producing the emotion.

Here is my most dramatic case of using a distraction technique to block impulsive behavior. A young man with a very severe diffuse injury and a left temporal focal injury had extreme emotional outbursts of anger and yelling immediately after coming home from the hospital. The outbursts were caused by a combination of very low self-control and sharp emotional discharges. He indicated some desire to control himself, though when he got angry he did not have the presence of mind to do so. His wife was working closely with us, attending every therapy session. She had tried every trick in her bag, and had found nothing that even helped a little bit. His angry behavior was loud and intense enough to stop traffic in a mall. I suggested to them that they try using "Red Hot" cinnamon candies to stop the episodes. He was willing to do it. When he had his next bout of loud ranting, she approached him, held up the candy, and with his consent popped it into his mouth. The overwhelming taste sensation stopped the ranting immediately. He sat and chewed on his candy, growing calmer by the minute, and his wife thanked her lucky stars. They used this procedure a number of times, with success every time. I believe they still have a few candies left in the box, as the "treatment" conditioned him to stop having the episodes after a few weeks.

Later on, he developed a resentful attitude and began to get loud and argumentative again. This time, it was not the same sudden, explosive anger, but it was still inappropriately loud and intense. He did it in my office, and I told him that he would have to leave if he did not control himself in my office. He was downstairs and halfway out of the building when he realized that

he didn't want to foul up his relationship with me. He came back, apologized, and never did it again in my presence. In a manner of speaking, he found out that I required him to be careful about controlling his angry impulses, and as a consequence he became as careful as he was expected to be. Don't try this at home, not unless you still have a very strong bond. This young man was very fond of me, or I would never have used the approach I chose. I knew I could get him to use adequate control because he could harness his high motivation (to get along with me) to get it done.

If impulse control is a goal selected for his/her self-therapy program, your role is very much the same as for any other deficit under treatment. The most important input you can provide is help in anticipating the situations that are most likely to bring out impulsive behavior, so that he/she can be well prepared, and much vigilance and cuing to notice impulsive acts and do Analysis Forms, since most of the Analysis Forms that patients write are about impulsive behaviors. Remember, you or I could stop almost all of the impulsive acts if we simply said, "Stop and think," before the act was performed, but the goal of the therapy is for your loved one to say it to him/herself, uncued, independently.

Impulses are managed by pre-planning an activity carefully, and then sticking to the plan, and by reining in any urge to do or say anything that is not within the plan until time can be taken to plan out the added response. For example, a young man may arrive at a party given by neighbors with a plan to introduce himself formally to the hosts. When he sees his hostess in a lovely party gown, he feels tempted to compliment her on her appearance ("Your breasts look beautiful in that gown, if you don't mind my saying so.") but because it was not planned out already, it is his job to hold off.

When a self-therapist has begun to make progress with the treatment, and can stop single impulsive acts well when thinking about impulsivity, the next hurdle is trying to maintain control over long periods of time, as in during social events. A particularly good therapy for this kind of sustained control is mazes. Even better is the jigsaw puzzle exercise (where an impulse point is earned every time two pieces that don't belong together are brought together to touch.)

Once good progress has been made on controlling impulses on therapy exercises, the next step is to apply the same strategy to real-world activities. Here family members can be extremely valuable by monitoring for the impulsive behavior at family get-togethers, on shopping trips, on vacations, and so on.

CHAPTER FORTY-FIVE: Getting Stuck on a Thought or Action

When your loved one gets stuck, and keeps talking about or doing the same thing over and over again, it is annoying and can be infuriating if you think he/she is doing it deliberately. But if there has been focal injury to the frontal lobes or basal ganglia, it probably isn't deliberate. In fact, it may be virtually beyond his/her control to stop the reaction once it gets started.

When I run into stuckness, I always label it, telling the person "It looks like you're stuck on that. Can we try something to break you out of it?" If you just try to interrupt the activity pattern without this introduction, the person may resist what you are doing.

Anything that shifts attention can break stuckness--a break, a change of setting, a change of topic, background music. The more severe the injury, the more stuck the person becomes. With the most severe injuries, it is extremely difficult for me, or anyone, to get someone unstuck.

A nifty trick I have not tried is to give the person who is stuck on a word or phrase delayed auditory feedback--to pick up what he/she is saying with a microphone and play it back at full conversational volume on a stereo or karaoke machine. Delayed auditory feedback breaks up activity patterns like a battering ram.

The short-range goal with stuckness is to use training to make the person easier to cue. After some training, a simple "I think you're stuck" or a special hand gesture (of your choice) used during training may be enough to get him/her to break out of it. Of course, the ultimate goal is for him/her to notice the stuckness independently and stop it without your, or anyone's, help.

REAL WORLD ISSUES: SOCIAL GOALS

CHAPTER FORTY-SIX: Is He/She the Same or Different?

Bear with me on this topic. Family members have a wider range of different reactions than on any other. If what I say at the start doesn't fit for you, read on to find your part.

The change in the behavior of a spouse is one of the most painful, disturbing, upsetting effects of head injury. Some spouses say that the survivor has become a stranger to them. They no longer see nor feel the old person at all. And the stranger is not a very attractive person to them. Instead, it is a person who is high maintenance, demanding, childish and child-like, and lacking in the sense of humor, coolness, poise, confidence, caring manner, capability and conversational skills that were the person's attractive features before. It is like somebody came in the night and stole their wonderful husband/wife and left instead this awful person who has a similar face and voice. This person is not a partner anymore, not someone who can be relied upon, not someone who can do the things both of you used to enjoy, not even someone to chat with. This person has lost all sex appeal--is no hotter now than a picnic cooler. And perhaps this person now shows no interest in sex either, or perhaps he/she demands it insensitively all the time. In either case, sex is nothing more than a painful reminder of what you once had and have lost. Spouses in this situation may even come to hate the survivor, because they feel chained up to this person by obligation. If it were up to them to do what they want to do, they would leave this person today. But in our culture, to leave someone who has been disabled by an injury is something only a scummy person would do, or at least so says society. So the marriage has become empty of anything good and filled with unpleasant feelings for these spouses. Moreover, the increasing realization that things are not improving over time multiplies the bad feelings, as it now appears that this trap is a permanent one. When the survivor's parents are still alive and capable, many spouses drop the survivor at their doorstep and head for the hills. However, for those who choose this path, the burden of guilt may last a lifetime. Others stay and suffer a nightmarish life that, according to the long-term research, usually does not improve over time and often leads to clinical depression and other mental health complications. Those who find themselves in this situation are in one of life's great lose-lose predicaments.

Some of the most embittered spouses who remain in the caregiver role for years, or on a permanent basis, lash out and say very hurtful things about the survivor in his/her presence. Perhaps the most hurtful of those things is the truth: "This is not the same person anymore. This is an awful person. I would never have married anyone like this."

The change in the behavior of an adult child is perhaps the second worst nightmare for a parent. But the saving grace for it is that it stands in place of the worst one--the death of your child. At least the survivor is still with you. But as the protective scales fall from your eyes, probably gradually, and you see that many of the strengths and skills he/she was equipped with by birthright, upbringing, education, and many years of experience are damaged or shattered, you begin to fear for the future. Sure, this person acts very differently, and doesn't treat you as well, and has lost some of the things you enjoy, but a parent is accustomed to being maltreated

by his/her child--we call it adolescence--and to get substandard treatment again is neither a great shock nor a great burden for most parents. So parents, more often than not, take the behavior changes in stride and see the survivor as being the same basic person, the same self, as before, no matter how much behavior may have changed. Think of it in this way: Head injury makes most survivors much poorer at playing the role of somebody's spouse, while leaving them fully able to play the role of somebody's child. Thus while parenting an adult with a head injury has very significant burdens, the relationship often remains alive to the parent, and this in some measure compensates for the burdens. In fact, one legendary reaction of some parents of young adults with severe injuries is to parent the survivor with great gusto, as if the injury were the antidote to empty nest syndrome. This reaction is a somewhat hazardous one, in that parents in this situation unintentionally can make the survivor overly dependent because the dependence is comfortable for the parent.

The viewpoint of the parent who is extremely accepting of the new behaviors and still sees the survivor as exactly the same person dovetails with the view of the survivor. Thus the parent's viewpoint is comforting and reassuring. It is also a kind of co-dependent behavior on the part of the parent, because the truth is that the person is not the same. By seeing the donut (the things that have not changed) and ignoring the hole (the things that have changed), these caregivers block recovery because they stand in the way of insight. A parent who is truly committed to recovery must force himself/herself to see the whole truth, and the help their child, painfully, to see that he/she is different now.

The viewpoint of the spouse who is extremely rejecting of the new behaviors and sees the survivor as a completely different person is a self-protective reaction that blocks recovery every bit as much as the overly accepting parent. The truth is that this is not a completely different person. This person has the same beliefs and values--the core of the self--as before. All of the old memories are still in there, and if you explore them, you will find that all of the old emotional reactions to those memories are also still in there. And from behind the survivor's eyes, he/she sees the same old me. To deny the fact that this is the same person is to insist on seeing things only in terms of your own wants and needs.

Isn't this chapter a total contradiction? It's the same person, but it's a different person? Yes. If you see that, you've got the point. The reality is a contradiction. It *is* the same person, and it *is* a totally different person. Both are equally and totally true. And as impossible as that contradiction is to deal with, as impossible as it is to live with, if you want to cope with what has happened, you have to deal with it and live with it. You have to help your loved one realize it and come to terms with it. The reality is bizarre, it's crazy, it's confusing, and that's just how things are. Unless you deal with both sides of this dilemma, you do yourself and your loved one an awful disservice.

If you find this hard to accept, it means you are a human being. Nobody has ever accepted this quickly or easily. Nobody ever will. This is one of those life catastrophes that takes years to swallow and digest. There is no shortcut. If you are a real psychological warrior--someone who knows how to grieve and adapt--in short, a survivor yourself--then you will probably take this

mess in stride and come to terms with it over the years in the best way possible. If you are new to personal tragedy, or not built for it, get some help from a counselor or therapist. Don't hesitate--this is something that they never put in the instruction manual they gave you when you became a parent/spouse. It's a wise person who knows when they can use some help.

CHAPTER FORTY-SEVEN: Egocentricity

Me, me, me. Everything he/she talks about. Everything he/she thinks about. You? He/she doesn't think about you. We all know what this is all about. As young children we have all gone through phases of being very egocentric, and if our own parents have lived to an old enough age, we have probably seen this egocentricity come on them. We also know people who grew up but never stopped focusing on themselves and themselves alone. That adult kind of egocentricity is a character flaw--a second-rate personal quality: Better to find friends and lovers who have room in their minds to care about you.

As parents, we expect our kids to be self-centered, and it's always a joy when they're not. But as spouses, we expect a certain amount of attention, concern, help, compassion, consideration, and empathy from someone we love. If we don't get it, we tend to question the love. The less we get, the more unloved we feel. And if we are giving a lot, and getting very little back, we feel taken advantage of. These feelings, although they are totally natural, are also totally bogus. The most loving head injured person in the world would be very egocentric. Take Ronald and Nancy Reagan as an example. In their younger days, they always gave the impression of being a close, loving couple. But as Ronnie got deeper into Alzheimer's disease, he gave less and less thought to Nancy, until he essentially ignored her. It wasn't because he loved her any less. It was because his mind skipped over her.

Egocentricity is partly a perceptual problem--out of sight, out of mind. It's also partly a side effect of having your life ruined, since the painful changes tend to fill a person's mind with thoughts of self.

You see how much the egocentricity is a head and not a heart problem when you make a special effort to call your own problems to your loved one's attention. If you make your needs known very clearly, you will probably see that there is real concern for you--the old feelings are still there, though they fade fast because of distractibility.

If you could be objective about your needs, the smart way to handle egocentricity would be to help your loved one to think of you--by writing in your birthday and anniversary on his/her day planner, and by sitting him/her down and asking for some focus on your life when you need it. Of course, to do that, you would have to break out of your own customary way of looking at things. Most people feel that if they have to push for empathy or support, it isn't worth anything. You'd have to be very careful not to take the egocentricity personally, not to get hurt feelings over not being noticed. You'd have to remind yourself that if you were the most wonderful wife in the world (a heart like Oprah in a body by Britney Spears) or the greatest husband (Patrick Swayze with a brain), he/she wouldn't pay any more attention to you than you get right now.

Of course, cuing your loved one to pay proper attention to people other than self would only be the first step. The second step, if egocentricity became a goal in his/her program, would be to transfer the cuing over to self-cuing, supported by generous filling out of Analysis Forms.

CHAPTER FORTY-EIGHT: Social Life and Activity Limits

Some survivors are given an extra burden because their medical condition prevents them from engaging in the activities they once enjoyed, and by doing that, places a wedge between them and their friends. Perhaps the most common of these problems is abstinence from alcohol. Some people live in an alcohol culture, socializing in bars, pool halls, or bowling alleys where the sport and bending an elbow go hand in glove. Their friends and/or sexual conquests may be drawn from these settings, and be heavy drinkers. To keep socializing with these people and frequenting these settings means to resume drinking, regardless of what good intentions the survivor and friends may avow. If abstinence is a priority, the survivor needs to lose the old friends and the old haunts. For some people, this is their whole social world. Other survivors are part of an alcohol-oriented tailgating group, or fishing group. To continue these activities is flirting with disaster.

Another very common source of social isolation is the permanent loss of the driving privilege. People who can no longer drive are often forced out of their social world. Sometimes this effect is gradual, as old friends may be willing to provide rides at first, but they drift away in part because all the picking up and dropping off becomes a pain in the neck eventually. Others are excluded from active, dangerous hobbies like surfing, four-wheeling, sky diving, martial arts or motor sports, all activities that tend to be done in groups.

While the loss of these activities is inevitable and necessary for safety reasons, it is usually hard for the survivor to accept (since he/she is unlikely to recognize and accept the safety problem) and may be an area of bitter resentment and complaint for months or even years afterward. It can also become a bone of contention between caregiver and survivor if the survivor tries to resume the activities on the sly. As a caregiver, if you value your loved one's safety, you have no choice but to be the bad guy.

You can try to compensate or make up for what has been lost by aiding your loved on to find new activities and friends, but both are quite hard to do and seldom as satisfying as what has been lost. Rehab has no easy answers for this painful problem.

CHAPTER FORTY-NINE: Thinking of Things to Talk About

You may be an extremely valuable source of help and support for this problem area. The inability to make small talk might seem like a trivial deficit, but it interferes with socializing of all kinds and virtually destroys the ability to make new friends.

The problem works in this way. As you go through your day, you accumulate a pile of “mental junk mail” consisting of information you did not try to learn, but that got stuck in your head anyway. This includes things like the news headlines, sports results, the weather, the traffic problems on the major highways in your area, gossip, jokes somebody told you, and so on, yatta yatta yatta. When you get stuck in an elevator, or at a bus stop, or at a party full of strangers, and strike up a conversation you effortlessly pull out this crud and toss it into the conversation. If you’re a skilled conversationalist, you may also draw out the person you’re talking with, and connect with something he/she says to get into a less-than-mindless discussion of some idea or issue, but nobody expects you to do that unless you’re a high-society hostess, a businessman or a politician. The problem is that your loved one’s junk file is empty--all the time. Casual contact with information doesn’t make memories anymore. The things he/she knows about are only the things that got thought about, and that doesn’t include the things people chit-chat about.

The same problem takes place when it comes to making conversation with friends and acquaintances he/she doesn’t see every day. When you talk with Uncle Filbert, you automatically store away his droning nonsense about his hemorrhoid surgery, his new Pontiac station wagon, and his philodendron collection. The next time he calls, you dutifully ask about each of those dizzyingly dull topics, and Uncle Filbert rings off after what he thinks of as a lively chat feeling cared about. But your loved one barely remembers that Uncle Filbert lives in Cleveland and wears a toupee. Your loved one has nothing to ask about and nothing to talk about, except me me me. And Uncle Filbert is sick of hearing your loved one complain about not being allowed to drive and wanting to buy a new X-Box, because that has been the sum and total of their conversation the last ten times he called.

Since the problem is that there is nothing in the junk file, the answer is to put things into it. So if you are doing all the work for your loved one, you need to engineer a heart-felt discussion of two or three headlines every morning. You need to work up a joke. You need to load in a handful of things for your survivor to talk about. When you are waiting for Uncle Filbert’s 7 p.m. call on Tuesday night, you need to give your loved one a file card with a short blurb on Uncle Fil’s recent life. Once there is information in the junk file, chatting happens.

Of course, this is a half-baked solution. It’s far better if your loved one recognizes this problem, includes it in his/her Self-Therapy Program, and makes the effort independent of you to pull some things to talk about out of the newspaper or a TV news broadcast. And it’s far better if he/she decides to keep her own “tickler file” on all of the major people in his/her life, so as to be ready to chat when they call or visit. This kind of program can make the difference between seeming indifferent to others and having relationships with them.

CHAPTER FIFTY: Reading Social Signals and Empathy

Most survivors are capable of empathy, but most use that ability sparingly. Empathy is another one of those mental processes which takes place virtually effortlessly in an intact brain, and only with considerable effort in a damaged one. When we empathize, we “step into the shoes” of another person with our imagination, first picturing self in the other’s situation, then feeling what it would be like to be there. It works well for most people, spectacularly well for some. Empathy is not automatic--it takes a decision to go there. But because of egocentricity and tunnel vision, a survivor rarely tries to go there. If an effort is made, it is difficult to get and hold the picture in mind. And the survivor rarely makes enough of an effort to see things in the way the other person would see them if the other person has a different viewpoint. Thus if a mother asks her head-injured son to imagine what it must be like for her to get yelled at by him, he thinks about what it would be like for a young man to get yelled at, not the feeling a mother would get to receive verbal abuse from her own son.

It is not particularly difficult to guide a survivor to have effective empathy. The cuing is easy: “Imagine what he/she would be feeling.” Then the caregiver can shape the picture the survivor is making in his/her mind with some instructions to make it fit the situation better.

It is harder to help a survivor to deliberately rebuild empathy for him/herself. I usually discuss the issue, raising these key questions: Was empathy a part of your old make-up? Was it important to you to be an empathic person? Do you realize how rarely you use your empathy now? When should you be using it and aren’t? How could you cue yourself to use it? Is that important enough to add to your Self-Therapy treatment plan?

To be of most help, you then need to watch for situations that call for empathy, see if it gets initiated, and cue for an Analysis Form if it doesn’t. It is often a good idea to start this treatment focusing on a relationship which is particularly positive and important to the survivor. For example, patients who are parents are horrified to realize how little empathy they use with their kids, which in turn creates a lot of motivation to work on empathy in those relationships.

CHAPTER FIFTY-ONE: Other Conversational Speech Problems

By far the best way to handle issues of conversational ability is to tape record some conversations, and then play the tape back while the two of you are listening to it. Allow your loved one the first chance to identify the problems, but if he/she doesn't see them, you should offer your opinion.

Monopolizing conversation is one of the biggest and baddest of the problems. I like to keep a word tally: how many words he/she said, and how many the conversation partner was allowed to say. Another good issue is "length of utterance," or how many words he/she says without pausing to let someone else speak. Some survivors, when they are excited or aroused, might speak for three or four minutes straight, saying hundreds of words before letting the conversation partner say anything. Once a problem like this is identified, it is easy to do therapy on by role-playing conversations on various topics into the tape recorder. The goal is to have an even amount of air time for both partners, with no more than a couple of sentences spoken without pausing for the other person.

Another very common problem is talking too fast. Again, tape recording is the best way to show the person how serious the problem is. Often rapid speech is also slurred or mis-spoken such that it is somewhat hard to understand. Here, the therapy should begin by reading single sentences, trying to slow them down to a proper talking pace. Then the therapy can shift from reading to exchanging one-sentence remarks in a role-played conversation. Each time a sentence is spoken too quickly and/or pronounced badly, it should be repeated into the tape recorder more carefully until it is done well. Once single-sentence "conversations" are going well, the training can shift to more natural, multiple sentence exchanges.

Patients who have suffered right brain focal injuries often have a flat voice tone, a problem sometimes called "affective dysprosodia" in the rehab world. Most patients can fix this problem by practicing saying sentences into the tape recorder while making a deliberate attempt to put more melody into their speech. In some cases, it may be necessary for you to give an example of how to say a sentence in the proper melody, followed by practicing that melody. At first, the melody "forced" into speech sounds odd and unnatural and may even sound stranger than the flat speech, but with lots of practice on the tape recorder, it usually gets more natural and effective. Since some patients' voice tone has become so flat they almost sound like robots, this therapy is very helpful in teaching them to make a good impression again.

Sometimes patients develop weird mannerisms of speech, usually exaggerated versions of their old speech patterns. For example, a few patients kept using a catch phrase like "so to say" over and over again, sentence after sentence. A few also inserted "uh" or "um" in between their phrases way too often. Occasionally an adolescent will throw in "like" too many times. All of these stereotyped mannerisms can be broken by giving feedback comments and then tape recording speech and counting the offending insertions. In one therapy group, we had a patient who said "um" so many times and stuck with it so long that we assigned one member of the group to serve as the "um catcher" by tallying the "ums." This bright spotlight eliminated the

problem almost immediately. At home, you may find that you can use a younger sibling to play this part. Older siblings often are extremely motivated to get rid of things their younger counterparts can use against them.

Remember, these home practice exercises are no substitute for professional speech therapy. If a conversational speech problem is serious, or if it does not respond to these training approaches, you should consider consulting a speech therapist. It is recommended that you try to find someone who is experienced with head injury. If you need a referral for this therapy, you should contact the Brain Injury Association, who have a directory of local therapy providers who treat head injury, or the American Speech-Hearing Association.

CHAPTER FIFTY-TWO: Reliability

If a person with a head injury gives you his/her word that he/she will do something, it might get done. Maybe. Or not. Probably not. This is not good.

Of course, the biggest problem with reliability is remembering what got promised, and remembering to do it at the promised time. And those problems are completely and effectively solved by the habits of writing down the promises that are made into the day planner, and following the day planner with the help of an alarm watch. A survivor who does those two things is going to try to come through every time a commitment gets made.

What should you do if the commitment is broken? Cut the person some slack? He/she *is* head injured after all . . . SURELY YOU'RE NOT TAKING THIS SERIOUSLY! If you excuse irresponsible actions, your loved one will become and remain an irresponsible person. A person who makes promises and does not keep them--because the person did not bother writing them down--was making empty promises. Society looks down on people who make empty promises. That kind of thing needs to be discouraged. And the way to discourage it is with the natural consequence: disappointment. "I'm disappointed that you made that promise and then didn't write it down. You want to be reliable, but if you don't write your promises down, you're not."

The second problem with reliability happens when the person changes his/her mind. Suppose he/she agrees to pick you up at the airport, but then hears about a really great sale at Burdines, and strands you instead. What do you say? No problem--I just caught a cab home. NO!!!! What you say is "You made a promise to me, and then you broke it. I feel let down by you. Is that the kind of thing you want to do?" Remember, your loved one probably doesn't know how his/her failure to come through made you feel if you don't explain it in plain language.

CHAPTER FIFTY-THREE: Give and Take

Ever get involved in a relationship in which the other person used and exploited you? In which you gave and they took? That's the way relationships tend to work after a head injury, also. But the reasons for the uneven balance of give and take are different. When you are being exploited, the imbalance is deliberate. In head injury, it's not.

Survivors are acutely aware of doing something nice for you, because to do so requires going out of their way, which always draws attention. They are not aware of you doing something nice for them, because that is a background event, and background events tend to get overlooked.

You could say that people who are well brought-up keep a tally in the back of their minds-- favors asked versus favors done, dinners shared versus dinners mooched, gifts bought versus gifts received, and so on. A decent person tries to repay kindness in kind. A friend not only is careful to do that, but is willing to give a good bit more than he/she has recently gotten in the good faith expectation that things will even out in the long run. After a head injury, that tally is not carefully kept up. It may get ignored altogether, or it may become inaccurate. If it becomes inaccurate, it will always be tipped in favor of self, for the reason explained in the last paragraph. So the head injured person is always ready to ask a favor, no matter how out of balance the give-to-get may be in his/her favor. And the head injured person is ready to feel imposed on if you ask for anything. Things get so far out of balance that friends often abandon the person enraged at feeling used.

I'm not sure what to do with this problem. Something needs to be done--it tends to wreck marriages and destroy friendships and respect. But the only solutions I've come up with are hard to put into practice or unnatural. One way to handle the problem is for the survivor to simply assume being deep in debt to the caregiver and anyone else who is still around to be a friend. But most survivors are reluctant to do that, for obvious reasons. The second solution is to literally keep a tab of favors and considerate acts in writing. That is a very artificial kind of action, one that most people are not drawn to perform. And even if it gets tried, the tab is likely to include every favor done by the survivor while skipping over a bunch of favors done for him/her. At a minimum, the survivor can keep better track of this balance by stopping and focusing on each favor he/she receives, even saying aloud, "This is another favor from . . ."

We need to develop better answers to this problem.

CHAPTER FIFTY-FOUR: The Love Relationship and Sex

This chapter is addressed to husbands and wives. For a number of reasons we've discussed, you may have no interest in sex at this point. Your loved one may show no interest also. So--let sleeping dogs lie, so to speak? I don't recommend it. If the injury has stolen your sex life, recovery means trying to get it back. But how, if there is no desire? The plain truth is that the survivor simply doesn't act like a person that many spouses want to have sex with, for reasons we have discussed and you spouses know better than I do. Is it even possible for you to see a bit of your old love in the person, or have things gone too far downhill? If you can still see even a splinter of the old him/her, there is still a chance. But doing this requires some preparation. You and your spouse need to have a really good day together. And for that to happen, it's absolutely necessary for you to explain exactly how you want him/her to act. And even then it may take practice. But you might have a truly nice evening and be treated well for the first time in years, if you do the proper preparation. If it helps any, the love that used to be there is still inside of him/her, even if he/she rarely shows it. In fact, none of it got lost. It just got locked away inside.

Sex after injury is never the same, so why not start back on square one? Sex started out for most of us in our teens as a way to anchor a relationship, to give and get excitement and pleasure, and not as intercourse. As adults, we forget how it started out. That is the hot spot from which to rebuild a sexual relationship--by deciding to experiment with giving one another sexual pleasure, and not planning to have intercourse. If you and your loved one can talk about sex openly, which is not always the case, then you have a chance with this approach. If you can both agree to spend a secluded hour in sexual play, with the only goal of pleasing one another, that can be an opportunity to be partners again and not caregiver and patient. It can be great fun just giving another person pleasure, especially if you know you're going to receive later on. Start with a massage, or a foot massage, if that sounds good. Or start in the shower, with the other person doing the soaping.

If you can get into the spirit of it, just try it out. Don't expect too much, just see where it goes. If you can't, don't feel obligated to do it until and unless it feels right to you.

If you try it, and it goes well, you will probably find within a few sessions that you are sparking a healthy desire for intercourse. For husbands whose wives had multiple injuries, you may be reluctant to engage in missionary intercourse because your weight may cause pain to her injured joints. If that is the case, you might want to study up on the variety of positions (in a good book like *The Joy of Sex*) searching for the ones that are least likely to produce pain. For spouses of both sexes, it will be extremely important to talk to your loved one during intercourse, to let him/her know what you want. Most people have trouble doing this, but try to push past your discomfort. Your loved one has poor empathy, no idea about how the injury has changed his/her sexual techniques, and no capacity to learn by trial and error without verbal feedback. It is only by giving some instructions that you can rebuild sex into something you can truly look forward to, and that may be worth the extra effort.

Some patients who have spinal cord injuries, or focal brainstem or parietal injuries, may have more serious sexual difficulties affecting performance. If the equipment is not working properly, it is a good idea to consult with a physician specializing in sexual disorders to get a comprehensive work-up.

CHAPTER FIFTY-FIVE: Sex for People Not in Relationships

This chapter is written for parents, children and friends. Unmarried survivors often face a lifetime of undesired sexual abstinence. With all the survivor has lost, it seems like adding insult to injury for this to be lost as well. But most caregivers have a relationship with the survivor in which the open discussion of sexual needs is not a totally comfortable subject. So the first issue for you is to deal with your own discomfort.

When I was an intern at America's first outpatient brain injury program, one of the founding staff members told me a story about two staffers taking an extremely impaired patient to a brothel to have his first sexual experience in ten years since getting injured. He had profound physical disabilities from brainstem injury, and could not walk or drive, so he would never have been able to find a partner on his own. The injury also produced spasticity in his facial muscles, which made him look quite abnormal, so he would not be expected to appeal to the opposite sex. I had mixed feelings about the notion of taking a patient to a bordello. Apparently it was a good experience for him, and one with no bad after-effects. There are many risks in such a venture--moral regret, arrest, sexually transmitted disease, and mistreatment by the prostitute, to name a few--so this is far from an ideal solution. But I bring it up to illustrate the extent to which the problem can reach for some survivors.

Here is another way the problem can affect people. A divorced female patient in her twenties had an extremely severe diffuse injury which made her virtually unable to walk and extremely dependent for just about everything. She also had a dependent and emotionally unstable personality. A male nurse from her inpatient rehab unit, also divorced and kind of dumpy looking, befriended her and, when she had a falling-out with her caregiver, offered to take her in. This led to a sexual relationship. Months later, the relationship was going badly, with lots of quarreling. Finally, he asked her to move out. She left after considerable protest, but then began stalking him and making phone call after phone call to beg to be taken back. When he firmly denied her request and told her not to call again, she reported him to the police for rape, and contacted the hospital administrator, claiming sexual abuse. Within a few weeks, she was calling again, begging to be taken back. He ended up getting a new apartment, an unlisted phone number, and a new job.

Here is a third example. At Robert Wood Johnson most of our patients had massive injuries, with coma durations of weeks to months, though we also had patients with less serious injuries. Soon after admitting a hard-partying teenaged boy from a working class family (with an injury that involved several days of coma), we caught him in a broom closet with a mid-twenties female patient with a vastly more severe injury. They were trying to have unprotected intercourse standing up in between their therapy sessions. We discouraged them from having any further afternoon delight.

People with head injuries face a set of serious obstacles in seeking a sexual partner, and a set of serious risks if they find one. Those with the most severe injuries require constant

supervision, and have no opportunity to find a partner or tryst unless the caregiver makes the arrangements.

A fundamental problem is that a head injury makes the survivor less desirable as a partner. But because of poor insight, the survivor continues to pursue potential partners at the old level of desirability. As long as this misguided strategy continues, the survivor is likely to get turned down again and again. To find a partner, the survivor has to lower his/her standards, a change that is usually resisted intensely.

Equally important, severe head injury robs a person of the cognitive skills necessary to engage in the “mating ritual” of showing gradually increasing attraction as the other person gives signals of equal increasing attraction. Survivors tend to be impulsive, which means causes them to jump right into “hitting on” the other person, or making openly suggestive comments without any encouragement, in a way that is offensive to almost every potential partner. In order to become able to pick someone up again, the survivor has to be trained--to resist the pressure of sexual excitement, to watch carefully for the specific signals of encouragement, and to respond in a graded fashion to the signals that are sent out. A related problem is responding to the temptation of increasing sexual excitement with a potential partner by engaging in intercourse too soon, in a way that leads the partner to regard it as a one-night stand when the survivor is hoping for more. This problem is greatest for people who have the lowest level of pre-injury experience in the pick-up arena--that is, teenagers, socially awkward young adults, and people recently divorced from early marriages. If a survivor is to re-learn these fine-grained skills, considerable role playing will be needed.

The second issue is the risk of exploitation. Because of poor person perception and judgment, survivors are ripe to be exploited by sexual muggers and gold-diggers. For the same reasons, some survivors wind up involved with partners with mental illnesses or personality disorders. Many females are also readily suckered into allowing men to use them sexually in exchange for a cheap come-on.

The third issue is the use of protection. As teenagers, we need to learn when to apply it, being careful not to let things go so far that the need for protection gets forgotten in the rush of passion. After a head injury, these old precautions are not good enough, because the rush of passion is stronger and less easily resisted. The potential consequences of going unprotected are also more easily overlooked. This doesn't reflect a change in values--a person who is adamant about using protection before the injury will be just as adamant afterward. But for people who are not completely committed to use protection, it will be far, far easier to slip up after the injury. This is something that needs to be discussed--just buying a box of condoms for your loved one isn't enough help anymore.

The next issue is sexual performance. Since good sex is a kind of dance that involves pacing, sensitivity, and graceful movement, head injury is going to interfere, and learning to adjust the natural style to become a skilled partner requires exactly the same learning process as for any other skill. Since sex is an intensely personal matter to people in our culture, this is something

that is almost never discussed with therapists, doctors or parents, and rarely with friends. So I'm not expecting people to role play this skill set in their living room and write the results in their therapy notebooks. But if the person is very fortunate, his/her sex partner will be willing to give some constructive feedback on performance (see the last chapter) or a friend will be willing to talk about any performance problems that crop up.

Finally, there is the issue of the emotional significance of the sexuality. When a relationship shifts from a platonic to a sexual one, the emotional meaning of the shift has to be determined through communication. Of course, the meaning of the shift is a very individual matter--it may mean a deepening emotional commitment or it may be nothing more than a good time. A survivor is more likely to jump to conclusions about this meaning than to investigate and discuss it, which increases the chances of getting disappointed or hurt. A survivor who is well prepared for this transition knows that some open discussion, both before and after the shift, is the best way to make sure that the shift is a good idea, and that it is going to improve rather than destroy the budding relationship. And the discussion of these matters, which if it is done clumsily can easily hurt feelings, is something that is best accomplished after role-played practice.

Sex is such an emotionally charged subject for most of us. Many survivors simply won't discuss these issues openly, and even more often, caregivers simply won't listen without getting agitated and uncomfortable. These matters probably won't be easy to talk about, and may never turn into a completely open book, but if you make the effort, you may be able to prevent some painful errors and heartache for your survivor.

CHAPTER FIFTY-SIX: Coolness and Maturity

As an adolescent, few things are more important than coolness. If you have it, you treasure it. If you don't, you long for it, or feel inadequate for the lack of it. Coolness is saying just the right thing at just the right time. Head injury wrecks coolness. Head injury makes people talk too loud, talk too much, say odd things, say and do embarrassing things. Adolescent coolness is related to fads--particularly the use of trendy language, dress, hairstyles, and styles of patter. When the style shifts, the survivor is left behind the curve, using last year's terms and wearing last year's duds. It is the very rare survivor who can stay cool after an injury.

What can be done about that? Is it possible to give lessons in coolness? I'm quite sure it is, though as a middle-aged, ivory-tower intellectual, I'm the last person who could give them to a teenager. How would those lessons work? Just like any other kind of social-skills training: set goals, tape role plays or real interactions, view the tapes to find the coolness errors and Analysis Form them, practice better ways to say and act, then strive to put those better riffs into ongoing social behavior. How well would these lessons work? Well, that would depend on how cool and committed the teacher was, and how much work the survivor put in, but under the right circumstances I would expect them to produce a nice improvement.

There are other kinds of coolness that apply to other ages. There is a kind of coolness that young adults use to hit on members of the opposite sex. There is a kind of coolness that older adults use to make small talk at parties, or to make a good impression in a job interview--we call that kind of coolness social poise. Survivors tend to blow it in those situations by bringing up the wrong topics--talking about things that are too personal, or too self-focused. When survivors practice job interviews on videotape with quality input from a helper or therapist, the level of coolness can be increased dramatically after ten to twenty practice sessions.

Many adolescent and young adult patients give up on trying to be cool at some point during recovery and shift to acting more mature. Instead of trying to give a trendy, clever, strutting reply, they decide to talk about serious subjects in the sincere manner of an older adult. Mature styling is much easier. It also gets a favorable response from many listeners.

When I work on social role plays with patients, I like to ask them what kind of impression they are trying to make. How are you trying to come off? What kind of impression do you want to make on the other person? Are you making that impression? How do you think a person would respond to the behavior we're watching on the videotape? Are you satisfied with making that impression, or is there another way you wish you'd done it?

CHAPTER FIFTY-SEVEN: Making New Friends

Chances are your loved one has lost most or all of his personal friends, yet he/she shows no special interest in getting any new ones. If the injury is new--within the last year--the friends may still be making friendly noises and just not being as involved in his/her life as they were before. If the injury is old, his/her social life has probably taken a beating, except for people who are also a part of your family's own social world.

Making new friends brings a number of familiar cognitive and social problems to bear. It requires insight to realize that new friends are needed, and more to realize that they won't be as high-desirability people as the old friends were. It takes initiation to start up conversations and to guide them toward showing friendly interest. It requires being able to make chit chat. Good control over impulsivity is important to making a good first impression.

Perhaps the hardest thing to do is to find a common interest or activity that can be pursued as the basis of the first connection. Friends made in school tend to gravitate together because of common interests and activities, but when that happens the friends are chosen from among hundreds of casual contacts. An adult who is not working rarely has casual contact with anyone, let alone a number of people from whom to make a choice. The easiest solution to this problem is to meet potential friends in some community activity that represents an interest area--a church group, a volunteer job, or a community organization. However, patients with head injuries generally make poor joiners, so finding an appropriate activity and getting started in it is a first hurdle. Then selecting a person who might be willing to make friends is a second hurdle. Finally, there is a key transition point in making friends in which an invitation is made for involvement beyond the setting in which the people met--come over to my house, let's go get some lunch, want to go to a game, and so on. Many of my patients make positive contacts in their community activities without taking the next step, or finding someone who will give a favorable response to such an invitation. It is easy to feel rejected and get discouraged if the first couple of attempts are unsuccessful, and family can be helpful by encouraging a positive attitude toward making the attempt.

Some well-meaning family members play John Alden for their loved ones, making the arrangements for get-togethers. For example, two sets of parents arranged for their head injured kids to spend the afternoon together at a barbecue at one's house. It was a total disaster. The chances of anything good coming out of such matchmaking are questionable at best. Helping means encouraging your loved one to take the initiative, not doing it for him/her.

An especially promising way to structure a budding friendship is to arrange to do a project together. It could be taking a class, going on a diet, doing an exercise program, or some other kind of self-improvement. Various projects and rehab centers have also made some progress in training social skills through group role plays. However, so far there is no evidence that this treatment has any effect on the ability to make new friends.

PSYCHOLOGICAL TREATMENT GOALS

CHAPTER FIFTY-EIGHT: Should I Tell People I Have a Head Injury?

You will be a front-row spectator to many instances of wrestling with this issue. Is the head injury something that needs to be discussed with others? At first, almost every patient underestimates how much he/she has been affected, and most see no reason to bring it up. However, if it is not mentioned, others expect normal performance, behavior, responsibility, self-control and follow-through. When the patient goes on to show a typical pattern of head-injured behavior, others are disappointed, disgusted, and offended, as they take the poor behavior and symptoms as evidence of dislike, disrespect, poor breeding and manners, or bad motivation and character. Some people realize eventually that they can't meet normal expectations, and decide that giving pre-warnings about the head injury is a damage-control strategy.

On the other hand, telling someone that you have a head injury is not a formula for getting understood. The general public is so ignorant about head injury that the mention of the disorder invites all kinds of inaccurate stereotypes, including stupidity, retardation, and mental illness. It only makes sense to mention head injury if it can be followed up with an explanation, and that only works if the person you mention it to is open-minded and interested enough to learn. Most survivors who try to educate their families and friends find that it takes quite a lot of time and talking before anyone "gets it." So explaining it to someone who is going to have little contact with or time for the survivor is probably more a formula for misunderstanding than for understanding.

There is no general rule here. The best practice depends on the context and the players.

CHAPTER FIFTY-NINE: Anger Management

Anger is a special problem in the World of Head Injury for several reasons. Those who have temporal lobe injuries can become enraged instead of irritated or angry, and they can be easily provoked by unpleasant noises as easily as by running into obstacles or having troublesome social interactions. Those with temporal or parietal injuries are prone to misunderstand what people say to them, and may read something insulting or challenging into an interaction. Those with frontal lobe injuries tend to act impulsively on their anger, saying or doing things without considering their appropriateness or their consequences. Hence anger is prone to produce over-reactions which are not always well controlled. Angry behavior is also not well tolerated by the Normal World. It is easy for people to become concerned about the notion of a survivor gone berserk. Thus people who don't make their best efforts to restrain their anger are flirting with jail time or commitment to a psychiatric hospital. Although some people won't learn to use their best self-control until they wind up in jail or a looney bin, most can learn to prevent a crisis if the issue is addressed through Self-Therapy.

Anger is likely to be your problem, not your loved one's, simply because it bothers you and not him/her. Hence your job is to do whatever you can to transfer the problem back to the person who committed the angry acts. You may attempt to do that by giving feedback. Always keep in mind that your loved one may be unaware of acting angry, or may underestimate how angry he/she is acting. You should begin by describing the person's behavior and explaining how it makes you feel. This is sufficient for the most responsible survivors to produce some concern and enough motivation to get some behavior change. However, it is not sufficient for everyone. It may be necessary for you to audiotape or videotape the angry behavior. Then the survivor will have vivid evidence of the problem. This can produce a stunning revelation to many survivors, as they have no idea how far their behavior goes. However, some survivors, even knowing that their actions are beyond the bounds of reasonableness, don't care. For them, anger control will come only when they face consequences--being beaten up due to getting angry at the wrong person, being taken to the psychiatrist for medication, being thrown out of the home, being required to pay for any property damage, or being jailed.

Once the problem is recognized, the strategy is simple. When angry feelings start, disengage and get away. Don't wait, don't hesitate, don't try to make a point or get something accomplished, because that will end in lost control. Get out while the getting is good, like a passenger on the Titanic.

Some family members tend to lock horns when there are arguments, and the caregiver may be unwilling to allow the survivor to escape. This is a tragic error. By blocking escape, you prevent your loved one from restoring self-control. Under no circumstances should you allow yourself to do this. Resume the argument only when your loved one comes back calmed down.

Remember, anger is the preferred response of a person who is trapped and threatened, put in a no-win situation. Without intending to do so, you can easily create such a situation. Make extra sure that you are not doing that. Your loved one needs to have the opportunity to make his/her

case when there is a dispute. Many long-term caregivers, weary of the repetitive nagging and impractical ideas, tend to ignore the survivor's opinions completely. To quote a patient, "Just because I'm head injured doesn't mean I'm *always* wrong."

On the other hand, anger is often the result of frustration precisely because of rejection of a harebrained, impractical idea, and an unwillingness to take "no" for an answer. Angry ranting, in an attempt to get his/her way, should not be tolerated. If the ranting continues after you have issued a calm warning, it is time for somebody to leave, whether that means the survivor heading off to the bedroom or the caregiver taking a stroll.

A good guideline for you is to avoid extremes in responding to episodes of anger. Don't get mad yourself and yell at the survivor, because that will just take away more of his/her self-control and presence of mind. At the same time, don't tolerate extended, inappropriate displays of anger, because if they are tolerated they will never come under good control.

Many head injury treatment programs have achieved good control of angry outbursts. A well-implemented psychiatric program assigned each patient a personal therapy aide during the whole waking day, usually a college student, who could help defuse anger by suggesting self-control procedures. Many "behavioral" treatment programs teach patients self control through token economies. Patients who have outbursts have to pay a price for them, in terms of privileges for freedoms, recreational activities, desirable living quarters and other benefits. These consequences often teach patients the necessity of using self-control quickly and consistently. You may be able to try a similar approach, but if you do, be aware that these procedures work well only if they are used calmly and reasonably. The rewards and penalties are doled out by very specific rules that are put in place at a calm time, not during an outburst. If they are administered angrily, they will generate new hostility and their whole purpose will be defeated. If you are interested in using these procedures, you should do some extra reading about behavior modification techniques, and probably seek the assistance of a behavioral psychologist.

CHAPTER SIXTY: Depression, Discontent and Despair

What exactly is depression? When used professionally, the term is not at the same as the term people use in common language. The common meaning of depression is feeling bad. The diagnostic meaning of depression is feeling much worse than a normal person would under the same circumstances. In other words, a person can be sad, blue, upset, and crying all the time, and not be depressed, if the circumstances justify the reaction. A person who has lost a love relationship, a best friend, a nice home, a cherished career, or a set of future dreams, all of which can be lost during recovery, has every reason to be upset and blue. A depressed person is not just upset and blue, but a hopeless, self-loathing hermit, unable to enjoy anything and uninterested in doing anything. If there is a single thing under the sun that the person enjoys (a back rub, a favorite song, a 3 Stooges short), it ain't serious depression.

If it really is depression, then you're probably wondering what to do about it. There are a number of ways to talk about what depression is, and each of them contains a solution that can get rid of the problem. Some people talk about depression as a problem of brain chemicals. Of course, everything mental and everything emotional is brain chemicals, so depression doesn't mean that some kind of unique chemical disaster has happened. The brain naturally produces several kinds of joy juice, and in depression the joy juice is in short supply, particularly a happy fluid called serotonin. You can reverse depression by taking a drug that increases the level of active serotonin. The good news is that it usually fixes the depression. The bad news is that it takes up to four weeks to do it, may make the person wired and over-reactive, sleepless, and possibly unable to perform sexually, and that it only works as long as you stay on the drug.

Depression is also a condition in which life has become empty, with not much to feel good about, not much to look forward to, and a feeling of helplessness to do anything about it. Fixing it can be as simple as scheduling in a certain number of pleasant events. Increase the predictable, expectable number of pleasant events and mood improves. Simple as that. It works with terminal cancer patients and prison inmates, even Martha Stewart.

Depression is also a condition in which life fails to meet positive expectations. A depressed person is often filled with expectations of doom and gloom, and of course, they are self-fulfilling prophecies. But underneath those bad expectations, often you find a person who has high ideals and expectations to match. If your expectations are too high, all you can do is to fail. This is very often the root cause of the problem in survivors. They are measuring themselves against their old expectations, and failing to measure up. Some kinds of therapy help a depressed person to find realistic expectations, which opens the door to success experiences.

If you want your loved one to take the second approach, you can discuss it, but you can't do it for them. Pleasant events set up by a person's wife or mother have no curative effect. The depressed person has to do the setting up or it doesn't work. Likewise with approach number three--you can recommend it, but you can't make it happen for your loved one. The third approach is usually best left in the hands of a professional therapist.

CHAPTER SIXTY-ONE: How to Think Positive After a Head Injury

What is the difference between positive thinking and wishful thinking? Well, we encourage thinking positive, and we discourage wishful thinking. Positive thinking is associated with success, wishful thinking with being an unproductive dreamer. Positive thinking is realistic, while wishful thinking is not.

After a head injury, many survivors attempt to think positively. Many are encouraged by their family to do so. They think, "I'll be back to my old self in no time." But that turns out to be wishful thinking. They think, "I'm ready to go back to my old job." But they're not, and it doesn't work out. Waiting for another chance at a job equally good, they may end up spending the rest of their lives in wishful thinking and not in working. They think, "My friends won't abandon me." But that, too, turns out to be wishful thinking.

Here is the problem. Positive thinking is perfectly suited for normal life. But it is terribly suited for dealing with a tragic loss of abilities and potentials. Imagine a person who just became addicted to cocaine or heroin thinking positive: "I can handle this. It won't make a problem for me." No, when reality takes a negative turn, you have to cope with it. And coping means you can't afford to ignore the negative. You have to focus on the negative to master it. Then, once you have the negative under control, you can return to a positive outlook.

Another way to put it would be that a person who is a "good copper" thinks positive after a crisis, but the positivity is focused and managed to keep it realistic. A good copper doesn't assume "I can beat this head injury" and more than an alcoholic should assume "I can beat this drinking problem." Both ways of thinking underestimate the problem, the struggle it takes, the two-steps-forward-one-step-back way that recovery works. To be realistic, a person can still be positive: "I'm going to do my best to beat this problem. I'm not going to give up. Whatever it takes to come out on top, I'm going to work my tail off to find out and do." That kind of positive thinking is associated with good recovery.

People who are accustomed to positive thinking and who have limited insight into their disabilities need to "talk themselves down" to a realistic set of expectations. Since this is likely to go against both their grain and their beliefs, it is probably going to be especially hard to do, and to require as much encouragement and support as the family can muster. And it may also be difficult for you to give this help, since you may also be a person who prefers to emphasize the positive. Well, nobody said this job would be easy.

CHAPTER SIXTY-TWO: Attitudes Toward Self

Self-respect comes from accomplishing what you expect from yourself. If what you expect is over the top, too extremely positive, your actions will never be good enough to earn self-respect. This is another reason to lower expectations to a realistic level: only if expectations are realistic can victories be won.

The research on attitudes of long-term survivors finds a massive contradiction. People report being satisfied with themselves--as satisfied as a group of uninjured persons. At the same time, measures of mood find widespread depression and demoralization. Life is hard, with little to look forward to and little to be happy about. It is as if life has gone down the drain, yet the survivor doesn't question him/herself as the cause of the deterioration. So these attitudes are a total contradiction. But even though satisfaction with self is preserved, life is empty of victories. That's where the depression comes from.

It has been an almost universal experience that lowering the standards and expectations of survivors, from those appropriate for the old self to those that suit the new self, produces more joy, a stronger sense of accomplishment, and more hard work. Ask for less, get more done. It seems backward, but it sure works. How to understand it? It's always a good idea to be realistic, not to kid yourself.

The hardest shift for survivors to make is to see themselves as members of a new reference group. What you define as a success often depends on whom you compare yourself to. For example, a student may be getting average grades and feeling down about self because of it, but to realize that he/she is the first person in the family to earn a college degree suddenly puts the school experience in a totally different, and entirely realistic, context. Here is another example of this shift in perspective. Many people run races for fun--a hobby called road racing. There might be a thousand people running in a race, and a runner might finish behind 100 others. Is that a good finish? Well, not in comparison with the fastest runners. But suppose the guy who finishes number 100 is 42 years old. Almost every finisher in the top 100 is younger. In comparison with other people of his age, the guy might be one of the top three finishers. That's quite an accomplishment. If you make the proper comparison, what looks like an okay performance suddenly can be seen as a big deal. Here's one more. My father was once a missile service technician. When they shot off a new missile at Vandenberg Air Force Base, if it blew up on the launch pad, he was the guy who figured out how it happened and how to fix it. He didn't think much of himself for being that guy--there were plenty of guys ahead of him in the company, who got paid better and had bigger titles. But every one of them had a degree in engineering. He was the only guy in the United States at his level who had only a high school education. He had earned the right to be extremely proud of himself, but he refused to accept the respect he had earned.

Some of the people you will read about in the third volume of this series are unique in the world. No head injured person has ever done what they did. They are heroes in the battle against disability, truly remarkable human beings. Often they forget that fact. It is only when

they compare themselves to other survivors of head injury that they realize how special they are. As soon as they succumb to the temptation to compare themselves to all the people in the Normal World, their accomplishment shrinks away. It's a huge mistake to do that. Look at Danny Orr. Danny is the only hemiparetic (half-body semi-paralyzed) long-distance runners in the world. Danny can run nearly 20 miles with a right leg that goes forward only because he snaps it forward by swinging his hip. Most hemiparetic people have trouble walking from the house to the mailbox. Danny does it because of an iron will. He forces himself to go and to keep going. It is far easier to race in a wheelchair than to run the way he does. Danny is one of nature's true miracles. And he keeps forgetting that fact. He keeps thinking that it's no big deal to run for two hours with a dead leg and arm. I won't let him do that. Don't let your loved one forget how special his/her accomplishments are in the World of Head Injury.

A young man came into treatment because of a failed suicide attempt. He shot himself in the eye with a large-caliber handgun. Instead of dying, he destroyed nearly half of his brain. When he woke up, he wasn't despondent anymore. He went through rehab with a good attitude, and did well, although he was left with serious cognitive and physical impairments. He decided to get a job as a "bag boy" at a local supermarket. At last reports, he still held the job after more than a year, and he was proud of himself. Holding a job--any job--for that length of time after a severe head injury is an accomplishment that earns the right to pride. Another young man came into treatment because he pulled the ripcord on his skydiver parachute too late, hitting the ground so hard that it shattered both legs and drove his brain into his skull. He, too, had severe long-term cognitive impairments, and he held the same job at a different market in the same chain. The difference is that he quit his job, determined to get a higher paying job selling insurance. He was not proud of himself for working as a bag boy. He felt it was beneath him. If he wound up out of work, he threw away his best chance for self-pride by stubbornly sticking with his old standards of comparison.

Clearly, changing those standards takes insight. It also takes effort, and mindfulness. It may never become entirely natural. But it can become entirely sensible.

CHAPTER SIXTY-THREE: Grief, Anger and Self-Pity: Turning the Page

In a good recovery, a survivor realizes that he/she is a new person, with fewer assets and more deficits than before. A once-bright future has dimmed. Many sources of pride and self-satisfaction are gone and will never return. Constantly making these painful comparisons is natural, in the same way that it is natural for a widow to constantly compare present-day life with the life she had with her husband. Each time a person bumps into a reminder of the things that have been lost due to the injury, and pauses to feel the impact of the loss, it is natural to become upset, angry, resentful, or distressed, or all of these things. Each time the person looks back over his/her shoulder at whom he/she used to be, the tragedy of the injury becomes painfully obvious again. It is a terrible emotional burden that every survivor who becomes realistic must bear.

We call the process of feeling the pain of these losses grieving. Grieving can be a process of adjustment, through which a person comes to terms with the losses and returns to a normal emotional life. Grieving works this way through a process of saying goodbye to, and letting go of, the lost pieces of the past life. When the loss is of something valued and important, it is natural, and even helpful, to shed some tears over having to say goodbye to it. For example, a patient who had a very fulfilling career as a clinical nurse had to give it up because she could no longer think on her feet accurately enough. Another who was a star baseball prospect had to give up his dreams of playing in the major leagues. A man who managed a huge hotel lost his ability to keep things organized, and had to say goodbye to that career. A retired man who loved serving as the captain of a ferry boat at a theme park lacked to judgment to regain that job. Two students were unable to drive, one because of epilepsy, the other because of a vision problem. A famous sculptress lost her artistic imagination. Each of these losses was deeply painful. Some patients grieved them effectively and moved on to other things, others got caught up in the grief and never moved on.

There are two ways to get caught up in incomplete grief. The first is the refuse to accept the loss, or to think about it. A person who ducks the grief puts life on hold while he/she waits for past glories to come back. Life can get left on hold forever. In a life on hold, nothing that happens each day is that important, that worth taking seriously. Only the opportunities of the past life, which never come up anymore, would be worth pursuing. We see this sad ending for many older athletes, child movie and TV stars, and faded movie stars.

The second way to get caught up in grief is to indulge in self-pity. Self-pity differs from grief because in self-pity one doesn't say goodbye to anything. Instead, the past keeps getting brought up again and again, so that the loss of past glories can be protested as unfair. In self-pity, it is bearing an unfair loss that makes the person special. Sometimes survivors and family members join together to hold "pity parties." Self-pity is a peculiar kind of glory, and people who get caught up in it can spend their whole lives playing that one note.

Encourage true grieving. You feel the grief yourself. Don't hide your tears from your loved one. Feel free to say goodbye openly to things you once shared with him/her. Don't get caught up in helping your loved one to hide from grief, or to bury him/herself in self-pity. The chapter

in the book of his/her life in which he/she was normal is over. Close that chapter and turn the page together. You don't know what the next chapter will be, but it could be something good, or even something glorious. Say farewell to the old chapter, and enter into the new one wholeheartedly. That is what will make it possible for your loved one to stop looking back over his/her shoulder with regret and despair. That is what will make it possible to look ahead again.

CHAPTER SIXTY-FOUR: Handling Frustration

Like head-injured moments, the experience of frustration is an inevitable and common consequence of head injury. The survivor expects life to be as it was, and is surprised, disappointed, and frustrated again and again to find that it is not. He/she expects relationships to go smoothly and is surprised to find that partners are deeply dissatisfied with his/her conduct.

The easiest way to contend with frustration is to expect it. This is a harder, less satisfying, less reasonable life. If frustration is the normal outcome in the World of Head Injury, then it can be taken in stride. If it is taken in stride, then the source of the frustration can be examined and analyzed and coped with. Working to fix the frustrations becomes the name of the game. Said another way, the well-recovered survivor tunes up his/her emotions to aid adaptation--to make adaptation the most likely reaction to every encounter with a head-injured moment.

CHAPTER SIXTY-FIVE: Spiritual and Religious Well-Being

This chapter is for people who have a religious life, or who once had one. If you and your loved one have never had religious beliefs, and don't have any now, you can go on to the next chapter.

Why did God let me get into the accident? Why did He make the accident happen? Why did he damage my brain? Does he hate me for some reason? Am I being punished? Does he just not care what happens to me? I tried to be good, and look what good that did me. How can I trust a God who would let something like this happen to me?

Have these questions crossed your mind? How could they not? Do you have easy answers to them, answers that leave you with your faith intact? Some people do, and some don't. Patients who have positive answers they believe with conviction--God was sending me a message to clean up my act, or God has a purpose for me, and that includes my getting a head injury--are made stronger and can use that strength on recovery. Those who don't may become alienated from God, at the very time when they need Him most.

I ask you, as I asked your loved one in the companions' volume for survivors, to simply acknowledge that feeling alienated from God is a problem. Since it is a problem, it calls for problem solving. If it can be fixed, life would be easier and better. So put it on your list of things to fix.

How do you patch up your relationship with God? Well, you begin by wanting to. I want to feel close to God again. I miss the feeling of Him and me being on the same team. I'm willing to try to do things to get back to that point. If your loved one (or you) can't take this step, the problem runs deeper than my Self-Help book can fix.

How can you accept that God, who could have kept you safe, didn't? This is a question that priests, ministers, and other holy men have been answering for thousands of years. The Book of Job contains an answer. That answer works for some people. Some ministers say, "God works in mysterious ways" that we can never know. That works for some people, but not for the people who are having this problem. Is this a message from God? A challenge? A left turn He wants you to make in the direction of your life? If I were having this problem, I would look around and ask around and find a minister who seemed like a helpful person and I would explain my problem. If that minister didn't give me what I needed, I would move on to another one, and if necessary I would keep going until I found someone who could give me peace of mind.

Spirituality is one of the deepest wells of strength people can tap. It's a crime to let yourself be deprived of the strength you need at the time in your life that you need it the most. Don't.

PRACTICAL GOALS

CHAPTER SIXTY-SIX: Driving

Problems with driving may be a matter of fuzzy vision, or lost depth perception, or limited peripheral vision, but for most survivors it is a matter of slow complex reaction time. Complex reaction time refers to the time it takes to evaluate the situation you are facing, to make a decision about how to respond to it, and to do what you decided to do. If that is a huge pothole right in front of me, do I hit the brakes, swerve to the right and go up the sidewalk, or swerve to the left and head into the lane for cars going the other way? Those with slow complex reactions are a time bomb. Sooner or later, they will kill someone who jumps in front of them, or kill themselves by being unable to get out of trouble's way in time.

Driving impairment is never a matter of having forgotten how to drive. Survivors remember how to drive. That's why driving lessons are unnecessary, in fact, make no sense. Driving safely for a day or a week with someone else in the car proves nothing, because the kind of situation in which someone will die due to slow reactions happens rarely. The only way you can know if someone is going to be unsafe in that situation is to put them in that situation--where there is a split second to decide between a safe and an unsafe move--or by measuring complex reaction time some other way, as with neuropsychological tests.

A colleague and I did some research on driving safety. We took a large group of patients and divided them up into those who had been allowed to drive by the team and the physician, and those who had been forbidden. We then took the ones who drove, whether given permission to do so or not, and divided them up into the ones who got into accidents and the ones who didn't. What we found was that several of our tests of complex reaction time separated out the safe drivers from the non-drivers and unsafe drivers. And the cutoff for safety was at the third percentile. As long as the person was not one of the three slowest people out of one hundred, driving was okay. If the person was at or below the third percentile, it was not. Since then, we've seen people who drove with scores that were too low get into accidents, and 98% of those whose scores were okay had safe driving records.

Just because someone is quick enough to be a safe driver doesn't guarantee that they will use good judgment. A head-injured driver needs to not be driving at 85 miles per hour, or zooming through traffic cutting people off like Dale Earnhardt. A head-injured driver who is tired needs to pull off the road. A head-injured driver should do the same in a downpour or a blizzard. A head-injured driver needs to know how long he/she can drive before the fatigue makes things unsafe. A head-injured driver needs to stay away from driving a Shelby Cobra, or a cement mixer, or a zamboni, or other exotic cars, without extensive practice.

I once had a group in which five members were regular participants. Four of them had used terrible judgment in driving. One jumped on his Harley while drunk and re-enacted the accident that put him in the hospital. He no longer has that Harley. Another one put on her makeup while driving in traffic. She smashed into the back of a stopped car, and no longer has that car.

Another one went on a road rage rampage after being cut off in traffic, and is fortunate to have his family jewels still in his possession. The fourth one was starting his on-road driving test by making a left turn across oncoming traffic. The instructor told him to stop. He jammed on the accelerator. He failed the test. Later, when he got permission to drive, he had three accidents.

Driving safety is a combination of ingredients: quick enough reaction time, adequate vision, and good judgment framed by proper caution. Some survivors who have at best marginal brain skills are safe drivers because they drive like old grannies, hovering around the speed limit on the interstate no matter how many cars pass them with drivers honking and cursing at them. They understand and respect their limitations.

CHAPTER SIXTY-SEVEN: Getting and Keeping a Job

After a head injury, it is always easier to use an established skill than it is to develop a new one. This is why, if possible, people should seek employment in a former career or special skill area. This is also why extravagant plans to take advantage of down time to start a new career, for example in the computer industry, so often come to nothing. However, many survivors are not able to hold jobs in their former careers, for any of several reasons.

Job security comes from four capabilities: skills, productivity, reliability, and behavior. Serious problems in any area can knock a person out of a job or career. Most people regard job fitness in terms of the first area, since it is development there that first qualifies a person for a position. But that is the least important of the four categories when it comes to the effects of head injury.

Survivors of head injury almost always retain their full storehouse of knowledge. This means that the lessons of basic education, job training, and job experience are all there to be used. It is for this reason that many survivors are able to get hired for jobs. Most survivors look and sound normal within a year or two; those who don't usually have brainstem injuries. Thus the ability to make a good first impression is usually intact.

Performance in a job depending upon decision making, especially "online" or on-the-spot decision making, may be so strongly affected by a severe head injury or by focal damage to the frontal or parietal cortex that it proves unworkable after a short period of time. For example, jobs in life-or-death health care applications like EMT, paramedic, clinical nurse, respiratory therapist, or surgeon quickly reveal deficits in decision making. Jobs of this nature that tolerate a higher rate of error, like investing or management, eventually reveal the deficiencies. A whole host of jobs requires good social decision making, and flawed social behavior is not tolerated for long. For example, attorneys, negotiators, diplomats, or ministers who cannot make a proper appearance lose their jobs. Finally, some jobs require the ability to learn and recall information--crime-scene investigator, financial planner, or court reporter, for example. It is rare, though not impossible, to find survivors of severe injuries able to retain careers in these areas, simply because they don't have the processing skills required to get the job done. However, in the big picture, few jobs are lost on this basis.

Productivity is a huge issue. The slowed thinking and responding of a survivor often don't appear to be a problem in casual social situations or around the house, but put that person behind a cash register in a busy store, and the customers end up waiting in a line that stretches out far too long. The same problem, magnified by the effects of forgetfulness, can plague food servers at busy restaurants, mechanics at busy shops, or hair stylists at busy salons. Manufacturing jobs usually have definite productivity expectations. In fact, most jobs have some productivity expectations. Many patients have found it necessary to work extra hours without extra pay in order to meet the expectations that Normal World workers can meet. But not all jobs allow the worker to make up productivity deficits after hours. Slowed survivors are often driven out of productivity-oriented careers.

Many other jobs expect a high level of consistency. For example, most professional and technical positions have these expectations. An optical technician who spoils too many lenses or a lab technician who makes errors on too many tests is going to get fired. People who work with highly valuable products or in high-profile activities (like umpires, air traffic controllers and dentists) or whose work is dangerous (like high-rise construction workers and deep-sea divers) cannot afford the kind of inconsistency which plagues most survivors.

Finally, most higher-paying, higher-prestige jobs, including white collar jobs, have stringent expectations about social behavior, manners, and appropriateness. This is the area responsible for the largest number of lost jobs. Deficits in social skills and behavioral self control can end up disappointing customers, irritating coworkers, and offending supervisors. People with behavioral deficits tend to be employable only in the lowest paying, lowest-prestige jobs.

Most survivors are employable, but most can hold only those jobs that are least demanding of online decision making, new learning, speed, consistency and social skills. Thus, they tend to be relegated to minimum wage jobs. Many survivors choose not to work, instead.

If you look at the problem from the vantage point of Self-Therapy, the problems that take away most of the jobs are in areas where self-treatment could improve functioning. For example, consistency problems are addressed by the Seven Techniques, and program graduates who have had exceptional recoveries are able to perform with high consistency. The same can be said for social skills and behavior. Patients who master the use of self-control techniques, notice and correct their errors, and make strong use of feedback are often able to bring their social behavior back up to a meet a full standard, especially if they do extensive role-playing of difficult workplace situations. Speed deficits may be too great to overcome even with a big push of Self-Therapies, but it should not be assumed that nothing can be done. It might be appropriate to view survivors who can only hold minimum-wage jobs as having not yet learned how to meet higher-level expectations. In that sense, minimum-wage jobs can be looked at as good training grounds for the development of better job skills. Many survivors need to attempt, lose and learn from a number of entry-level jobs before they can be ready to meet the stronger expectations of a better job. However, those who have poor insight may feel insulted by these jobs, and may not realize or accept that mastering jobs on this level is a necessary step to taking back normal earning capacity.

I have known many patients who refused to deal with the demands of entry-level jobs and wound up chronically unemployed. This is particularly true of young adults who previously held white-collar careers and spoiled teens. They are not accustomed to the demanding style and ready criticism that come from a supervisor in such jobs. They feel entitled to be given time off when they don't feel well, or have errands to do or appointments to keep, and they don't realize that by forcing the issue they will get fired. They don't understand that coming in to work or back from lunch five minutes late is not tolerated at this level. With their lack of insight, they do not view the job as a stepping-stone to the future, but rather look on it with annoyance as beneath them. Unable to function at this level, they are unable to function vocationally at all.

Family members who tolerate or echo these attitudes help dig their loved ones deeper into the hole they are in. It is easy to sympathize with a research scientist or company president whose only option is to work the deep fryer at Burger King. However, if the only other option is vocational disability, perhaps the deep fryer shouldn't be rejected automatically, not without some thought about the future. Now, these decisions are ultimately the survivor's to make, and not those of the family. However, when family members provide cash allowances and credit card access that spends life savings to allow the person to live a more affluent life, that allows the survivor to live in fantasy.

Here are some examples of failed recoveries that result from failure to adapt to the real requirements of vocational life. A friendly, enthusiastic young man lost six consecutive jobs because of behavior problems. Rather than to fix his workplace behavior first, he decided that the answer could be found in getting trained for a more prestigious profession, so he invested his mother's money in a training course to become a massage therapist. An earnest young man who was a business major at college was able to get his degree, but he could not advance beyond entry level sales positions, and a long series of those jobs did not last beyond one year. Although eight jobs had not worked out, he continued to look for the same kind of work. Another young man who had never held a job completed four trade school programs but never found a job.

Getting and holding a job is the biggest and hardest accomplishment of recovery. To do so, even for an entry level job, is a tremendous accomplishment that most survivors cannot match. I am extremely proud of a former patient who lost his career as a realtor, but has persisted in keeping his job as a dishwasher at a pizza restaurant he once managed. His pride takes a beating every time he goes in to work, but by learning the lessons involved in keeping this job, he takes the baby steps that can lead him toward being able to earn a living wage at some future time.

CHAPTER SIXTY-EIGHT: Full Independence in the Home

In the World of Head Injury, full independence refers to the ability to maintain a household without help. Behind holding a job, this is the second biggest accomplishment of recovery. Full independence does not have any extravagant requirements. The only thing it does require is adequate judgment. To manage a household, one has to perform certain critical tasks, like paying the bills and provisioning the home with enough food for survival, on a consistent basis as key priorities. To be safe, one also has to avoid taking judgmental risks: not inviting strangers into the home, not allowing homeless people from the park to spend the night, and not attempting to use tools or make home repairs that risk loss of limbs. Many survivors do not have the judgment to make good decisions on these last matters, but they can compensate for the lack of judgment by taking no risks. Those who take risks may never be able to be fully independent. Finally, it is necessary to living within one's means, which means budgeting expenditures and avoiding extravagant and unwise purchases.

Spouses often make no efforts toward independence training, assuming that they will always be there to handle matters of judgment and to provide some distant supervision. Since no one lives forever, this is not something that is safe to assume. Parents often worry about what will happen to their child when they are no longer around to help out. So family members should think about doing full-independence training.

The training technique involves setting goals and defining what acceptable performance involves, and then spending a specific number of days silently observing how the survivor handles running the household, while making no suggestions or even hints. The survivor is allowed to make mistakes, and expected to write them up on Analysis Forms. When no serious mistakes are made, the interval can be lengthened until it extends beyond a full month. At that point, the family may consider taking a vacation without the survivor as a final test of independence.

Of course, full independence requires competence at all of the specific routines involved in managing a home. These include laundry, cooking, provisioning, bill paying, cleaning, and so on. It also includes taking prescription medications for some people. If the survivor is not fully capable with any of these routines, they need to be fixed first. If the injury is severe, the training process may need to employ checklists for each of the routines, and a master checklist on a bulletin board or dry-erase board which keeps track of the completion of all the tasks.

CHAPTER SIXTY-NINE: Parenting

There is no way for a survivor who was a good parent before the injury to be as good afterward. It simply cannot be done. Parenting is too hard, and too diverse--essential parenting functions are impaired by head injuries. A person who cares a great deal about parenting quality can limit the problems by having an exceptional recovery. For some reason, I have not seen this happen. The patients who have had exceptional recoveries are either childless or relatively uninvolved in parenting. A few former patients seem to have done well as parents, while quite a few have ended up estranged from their children or dealt out of the parenting activities altogether.

Does this mean that a survivor cannot be a good parent? No. It means that there are going to be some head-injured moments. It doesn't mean disability is inevitable. But to be good enough as a parent requires exquisite attention to self-control, awareness and consistency. Those who succeed have accomplished a remarkable feat.

Parenting of an infant or preschooler requires being able to maintain undistracted, continuous attention on your child's safety. Most survivors can't do that. All you have to do is to be reminded of Eric Clapton's tragedy in which his baby son Conor crawled out the window of his high-rise when mom wasn't watching. Even occasional lapses of attention are not acceptable. In this age range, parents also need powerful behavioral self-control to avoid abusing a constantly-crying baby. Judgment is needed to deal with a bushel basket of practical problems. And the head injured parent has to make constant efforts to deliberately upgrade his/her image of the child, in order to take proper account of developmental changes.

The older the child gets, the more empathy is needed and the less parental egocentricity is tolerated by the child. The most loving parent in the world does harm if he/she doesn't make time to help the child deal with upsets, or fails to show up for a performance in a school play or sports team. Preserving the emotional bond with the child and providing proper care for the child's physical and emotional welfare require the survivor's best efforts in planning and problem solving at all times.

Though the demands of parenting are hard to meet consistently because of the head-injured moments, the attachment, values, responsibility, commitment, and willingness to sacrifice that are the cornerstones of good parenting are not affected by injury. Perhaps it would be most accurate to say that survivors are capable of being great parents on the basis of their character, and that they can also be good parents most of the time only if they give their best efforts and make full use of Self-Therapy. And nothing is more painful than a great parent who fails to be a good parent. For them, only an exceptional recovery of parenting skills will do.

CHAPTER SEVENTY: Boredom and Loneliness

Survivors get bored because they have monotonous lives with few productive or stimulating activities. They get lonely because their routines bring them into too little contact with peers, and their social networks include too few friends. These are problems that can be fixed, but fixing them requires most people to lower their standards. Few survivors earn the privilege to have a life as exciting and varied as the one they had before the injury. To cure boredom, they need to build a routine composed of a variety of active pursuits--self-improvement tasks (exercise, self-education), productive activities (chores, self-employment tasks, volunteer work, classes, or jobs), hobbies, and only a limited amount of television watching. To cure loneliness, they need to identify and participate in community activities (like volunteer positions, church functions, club and organization memberships) that let them expand their social world. It may be possible to search for recommended options in the home community through chat rooms on the internet. The final set of options may not be exciting. There is no reason to expect them to be exciting. But if they are built into a program of day planning, a set of such activities can cure boredom and loneliness.

Sometimes a parent, most often a mother, tries to make up for the emptiness of her child's life by becoming pal, social director, entertainer, and emcee. This is an effort that is probably doomed to failure if the child is an adolescent or an adult. People don't want their social life to be limited to their mom, not even if she's Connie Chung, Rosie O'Donnell or Oprah. Not only is it doomed, but the child often ends up resenting the lousy job mom is doing, and fails to appreciate that making life worthwhile is one's own job, not one's mom's job. Don't try to fix the problem for your child, mom. Encourage your child to fix the problem for him/herself. Follow the instructions for making up a free-time activities menu in the chapter on day planning.

Many survivors now use the internet to fill the empty spots in daily life. As long as the internet is one part of a whole program of self-improvement, productive and hobby activities, it can be a real asset. If it is the only thing, along with television and video games, it will probably end up feeling unsatisfying to most people.

CHAPTER SEVENTY-ONE: Seizures

Seizures are a part of the World of Head Injury. While most survivors do not develop seizure disorder, enough do to make it necessary to learn something about them. This chapter does not attempt to provide a comprehensive knowledge base. If your loved one has seizures, you should obtain proper educational materials from your neurologist or from the Epilepsy Association.

The incidence of seizures after a head injury varies, depending upon the kind of injury. It can be as low as 1%, in an injury that is totally diffuse, or as high as 5% or even higher in an open head injury, depressed skull fracture or intracerebral hematoma. Head injuries that produce contusions are in between in incidences. In essence, seizure risk comes from scar tissue. As a scar matures it puckers, and the puckering pulls on working brain tissue at the margins and makes it misfire. When brain cells' fire too much, they can set off an electrical storm by a process called kindling. That electrical storm can be right around the area of the scar in a partial seizure, or it can spread to connected areas of the brain in a complex partial seizure. If the fire storm gets big enough, it can seize control of the whole brain, which is what produces tonic-clonic (formerly known as grand mal) seizures.

If your loved one has a tonic-clonic seizure, there will be no question about what is happening. He/she will fall to the ground, lose consciousness, thrash around, and possibly soil him/herself. After a few minutes, the seizure will have passed entirely and he/she will be awake but weak, tired, confused, and unlikely to remember much about what happened. If a seizure like this happens, don't feel like you have to do something heroic. Tonic-clonic seizures don't normally require medical attention, though it is a good idea to call 911 as a protection against the unusual complication. All you need to do is to try to prevent injury by making sure the person doesn't thrash into a stairwell and fall down the stairs, and by moving any nearby hard furniture like wooden chairs or tables away so that there is no risk of breaking an arm while thrashing. Some older people may remember ancient first aid films talking about jamming something in the person's mouth to prevent biting or swallowing the tongue. This is not considered to be proper procedure anymore, and doing it can wind up breaking teeth, so don't worry about the mouth.

There are many other kinds of seizures which are less dramatic. One common type is the absence seizure, in which the person stares off into space for a minute or more unless vigorously roused. Another involves small, repeated, pointless movements of any part of the body. Probably the most difficult to diagnose is complex partial seizure disorder (formerly called temporal lobe epilepsy), which can involve any of a wide variety of sensory and cognitive symptoms. These seizures usually involve no abnormal movements. Instead, they may produce hallucinations in any of the senses, or a sense of unreality, or sudden-onset emotions, or episodes of extreme, obsessional preoccupations with spiritual or philosophical matters. You cannot see most complex partial seizures--you can only notice that your loved one seems strangely preoccupied, and ask about what he/she is experiencing.

A seizure within the first two weeks of the injury is technically not considered to indicate seizure disorder, as there is a good chance that there will never be another seizure. Some

physicians administer anticonvulsant medications (anti-seizure drugs) to patients who have these early seizures--if that happens, get a second opinion from an independent neurologist. Some physicians administer anticonvulsants to survivors who have never had a seizure as a preventive measure. This was once a common practice, but expert doctors don't do it anymore, as the research indicates that it has no long-term benefit. Many anticonvulsants also have some undesirable side-effects, so they should only be used after a seizure has occurred.

Even if your loved one has not had a seizure and it has been many months since the accident, the risk has not been eliminated. The prevailing practice is to regard the window of time for seizures to occur to be two years from the time of onset.

It is important to take seizures seriously, as strong ones can produce some additional damage to the brain. If you observe a seizure, or even suspect that one has taken place, that is enough to justify a visit to the neurologist. You need to know that it may be difficult for the neurologist to come to a firm diagnosis, and that establishing the right dosage of the proper medication is often a slow process which involves gradually increasing dosages and some trial-and-error switching of medications. Also don't be surprised if the medication doesn't completely eliminate all symptoms. It is not unusual for minor symptoms to continue.

Here is how seizures work. Like a nuclear plant, a brain cell has a "critical mass" of excitement called a seizure threshold. When it gets this excited, it goes out of control, firing wildly again and again. Scar tissue that pulls on the edge of the cell lowers that threshold. So do lack of sleep, fever, lack of nutrition, lack of fluids, intense and repeated sensory stimulation, and alcohol and some drugs of abuse. Some research suggests that having a single drink can raise the risk of developing a lasting seizure disorder. The anticonvulsant medication raises the threshold, making it harder for stimuli to set off a seizure.

Some post-traumatic seizure disorders are temporary, while others are permanent. There is no reliable way to predict which is which. If your loved one is prescribed anticonvulsant medication, it should be taken exactly as prescribed religiously--it does absolutely no good if doses are missed. It should never be combined with alcohol, as the combination is dangerous. You should never change the dosage or stop taking it without the permission of the physician. If your loved one has been symptom-free for an extended period of time, the physician may recommend gradually stopping the drug to see if the seizure disorder is gone.

Medical researchers are working on new technologies that control seizures better than pills. At this point, it is not clear what the best methods for seizure control are going to be, but don't be surprised if your neurologist suggests a new approach.

CHAPTER SEVENTY-TWO: Public Transportation

If your survivor is not a safe driver, and it is two years post onset, or if it is earlier but the permanent symptoms of the injury forbid driving, it is essential for him/her to become adept in using public transportation. If you live in a neighborhood or a town without access to public transportation, life will be profoundly limited and dependent. If that is the case, you should think about relocating to a place where public transportation is available and practical.

Learning to use public transportation after a severe injury contains a number of serious obstacles. The survivor needs to be ready to deal with getting lost in an unfamiliar part of town. That step is essential, requires specific equipment (such as a city map and a cell phone), and should be practiced to make sure it can be handled properly. Preparations to dress for the expected weather are important to avoid getting chilled or overheated. He/she must learn to accurately use a bus/train schedule, which is considerably harder for many survivors than it sounds, and so it must be practiced with your supervision. Learning to get on the bus without falling may be quite challenging if balance is quite impaired. And learning when to get off the bus is perhaps the most difficult problem; you or another helper must ride the route with your loved one several times until the necessary landmarks can be spotted consistently. Thus there is a fairly large investment of time up front, which pays off in achieving full independence and requiring no supervision in the long run.

CHAPTER SEVENTY-THREE: Restoring the Meaning of Life

Some rehabilitation experts suggest that when recovery moves forward it goes through stages. There is a stage of being unaware that things have changed. Some survivors reach a stage of realizing that things have changed, and feeling angry and/or upset about it. Some of these reach a stage of accepting the changes, and finding ways to be proud of self again, either because of regaining lost competencies or because of going on to develop new ones. Many survivors don't seem to reach this stage, at least not in the span of 10 to 20 years across which their progress has been followed. Finally, for the warriors of recovery, there is a stage of getting life to make sense again, in other words, of discovering a new purpose for life. These stages apply equally to family members.

Survivors can gain great satisfaction from the accomplishments of Self-Therapy. Self-Therapy gains can be appreciated on several levels. First, Self-Therapy is hard in and of itself. It involves competing against him/herself, and earning a track record of scores. Done with decent effort, the track record is one of improving scores. So there is the accomplishment of the therapy tasks and the pattern of gains in scores. Second, to self-improve gives the survivor a sense of fighting back against disability and regaining some control of an out-of-control life. Third, the gains provide an infusion of new hope about the future: "If I can make myself better, maybe I can make something of myself eventually. If the successes can be shared with family and friends, they can be that much sweeter."

Survivors may also take pride and hope in gaining or regaining competencies for specific real-world tasks. For example, one of our most accomplished patients recently learned how to climb a mountain. She had to overcome not only her lack of technical knowledge but her terror of falling. She takes great pride in this attainment. Another survivor who suffered from multiple sclerosis learned to make some of the decorations and charms made by her Native American ancestors. She made them for many friends and family members, and was delighted to see how well they were received.

Some survivors have reached back into their own past lives to find crafts or skills they once used, reviving them to use in present-day life. Several resumed knitting, quilting, or hooking rugs. Resuming an old skill is far easier than learning a new one.

Many of my patients have discovered that the injury has awakened in them a depth of feeling and compassion that they never had before. They find themselves caring about unfortunate people and willing to reach out and help them. The transformation some people undergo can be quite remarkable, as people who are extremely selfish and self-absorbed can suddenly begin to care deeply for their fellow humans. Those who follow up on these feelings by doing volunteer work or by befriending an unfortunate person can gain a great deal of satisfaction. For example, one patient who had been a high-powered clinical nurse-specialist, disabled by a very severe injury, became a regular volunteer at Give Kids the World, and said that the experience had transformed her life and given her something to look forward to every week. Another highly accomplished patient has taken up the practice of giving inspirational lectures to church

congregations, a highly rewarding activity for her. Several have become volunteers at hospitals, and particularly on rehabilitation units.

In the Normal World, people re-examine and question their lives, asking if they have been successful in making their life meaningful. This process usually takes place in middle age. Survivors who have very good recoveries often ask and try to answer this question at a much younger age.

If you were to try to justify your life, and it included undergoing a head injury and all of its losses, it would take a powerful justification to do the trick. Many patients have found great meaning in learning through the injury to turn away from what they consider to be sins, habits including sexual promiscuity and drug or alcohol addiction. Others have used the injury as a motivational springboard to make themselves rededicate their careers to work that is more meaningful to them. Some have said they don't regret the injury because "it made me a better person."

This desire to write a new, positive chapter that makes sense of the book of life is perhaps the most ambitious of the goals of Self-Therapy. Self-Therapy gives a person the tools to re-examine self and life and to set and implement new personal goals--it makes adaptation and change possible. Those who take advantage of that possibility to re-invent a better self wind up feeling like they have lived a good life, weathered a great crisis, and are a better person for having done so.

CHAPTER SEVENTY-FOUR: Back to School

School is one of the most demanding and difficult environments with which to cope after a head injury. There are expectations for behavior in a number of different contexts, including classroom conduct, teacher relations, heterosexual and dating behavior, and peer interactions. All are potential problem areas. The central job in school is to learn, and that is likely to be an area of focal impairment. Not only is the new information difficult to learn, but the survivor must struggle with learning new skills and executing old skills under close tolerances. Moreover, teachers and special educators are unlikely to have received any training concerning TBI. The school system has for many years been forcing head injured students into the mold of specific learning disabilities, the latter being a developmental brain disorder which is very different in its effects and requirements. The situation is so serious that a federal law was passed in 1990 requiring schools to refrain from testing, pigeonholing, and educating students with TBI as if they were learning disabled. Unfortunately, Congress passed zero funding for this wonderful law, a winking way to let schools ignore the new law and they have done exactly that. The net effect is that the schools say (and, sadly, believe) that they have proper help available for a student with special needs, but in practice they have little genuine help to offer. (Don't blame your local teachers or administrators for this national problem.)

Many years ago, I designed a special modification of the head injury rehab curriculum to prepare high school and college students to return to school. The outcome research says that these methods work as well for a group of our students as the program works for adults returning to work, if not better. However, the home program that is required is extensive and difficult. In general, school is much more difficult. Students who did not put their full program into practice ended up educationally disabled. So if your loved one is your minor child, plan to closely supervise the home program if you value the educational outcome. Expect the schooling to take longer--one to three extra years to finish high school and complete undergraduate college.

If the student is in high school, one important role for a family member is to interface with the school system. The school will convene a formal evaluation process termed a "child study team" if you request it, but they are likely to do nothing if you don't ask. At this meeting, they will attempt to staff your child like a learning disabled child, according to public laws passed more than twenty-five years ago. If you allow them to do that, they will probably order testing by the school psychologist. The purpose of this testing is to investigate the difference between the child's IQ and achievement scores. Learning disabled children fall behind their peers in achievement, and when the difference is large enough, they qualify for special services according to standards which vary from state to state. It is important to understand that neither IQ nor achievement tests are appropriate to or effective in measuring the effects of TBI, and that the typical student with TBI does not qualify according to the learning disability criteria, usually for several years. If you allow the school to follow their normal procedures, your child is at risk for falling behind the other children, and becoming confused and discouraged about school.

The new federal law, called the Individuals with Disabilities Education Act (or I.D.E.A.), requires the school to provide special services based solely on a physician's documentation that

there has been a significant head injury; no qualification testing can be required. Moreover, the law stipulates that the child study team is required to create an individualized educational program which can include any service offered at the school, with requiring the child to be enrolled in any program. It further requires that the school either provide or purchase all services that the child may need in order to be educated in the least restrictive environment. If special help will allow the child to be taught in a mainstream classroom, the school is required to obtain that help whether they have an appropriate helper on their staff or not. Finally, the team is required to arrange to test functioning for every item in the educational plan, and to repeat the testing at least once a year to make sure that the student is progressing appropriately. Some schools have had so little experience with IDEA that they just look confused when it is brought up. Others know about it and attempt to get around it.

Before attending the first meeting, it is strongly recommended that you read a pamphlet outlining the law and your rights under it. You will have to decide how you want to try to deal with your school administration. If you let them do things their way, you risk getting no help. If you come in prepared and determined to get at least some of the special help the law calls for, you may get some concessions. Parents who have arranged for the student's neuropsychologist to accompany them to the key planning meeting usually had more success. If you want to try to take full advantage of the law, you will probably need to bring your attorney with you.

The school is in an impossible position, in that they are not funded to implement any part of IDEA. They may be willing to ask a teacher or a homebound instructor to provide some individual tutoring. The most important concession you can get is a special arrangement for regular communication from the classroom teacher. The teacher will be the first one to see the problems appear. They will not be the same as the problems other students have, but the differences won't become obvious to the teacher until too late. If the teacher is willing to discuss the student's progress and behavior once a week, or at minimum once every two weeks, you can get an early warning of the errors the student needs to analyze and fix. If the teacher doesn't agree to this kind of early warning system, the problems will not come up until months later, once the student has fallen well behind and cannot catch up.

What do you need to know about through this early warning system? Key problems include not writing down assignments, or writing them down in incomplete or inaccurate form, not paying attention during lectures and class discussions, failing to tape record lectures, making impulsive and careless errors when taking tests or doing other in-class work, arriving late to class, failing to bring everything that is needed to class (including completed homework), getting frustrated, having conflicts with specific students, disrupting the class through inappropriate behavior, or becoming confused by new concepts. All of these problems can be solved promptly with a well-designed Error Analysis. However, if they are allowed to continue and become chronic, they become more difficult to solve.

Should you help your loved one with his/her homework? The answer to that question is an unequivocal "It depends." Some kinds of help are extremely destructive; other kinds are very useful. You need to be clear about your own strategies and careful about your behavior.

The kind of help that is useful is “cuing the process.” If your loved one comes home and doesn’t open his/her backpack, you can be sure that work is not getting done. There should be a structured and highly routine procedure whenever the student gets home. The class notebook or notebooks should be taken out, and the homework assignment sheets (There should be a sheet for each class.) should be checked. The homework should be planned out on the daily planner, with blocks of time assigned to each specific task (not just a big block of time for “homework” or blocks for each class). You can help to set up that procedure. You should always monitor to see if the procedure is being followed, and you should bring it to your survivor’s attention if it isn’t, including a call for an Error Analysis each time. You need to make it clear that you expect this level of time organization every day, and that nothing less is acceptable. Your concern is how things are being done, and if they are not being done properly, you make sure they get done properly.

The kind of help that is hurtful is doing things *for* the student. A caregiver should not ever assume responsibility for doing homework tasks. Even filling out the day planner is something that should never be done by the caregiver. The responsibility must fall on the survivor. If the family member does the task, the survivor not only learns nothing and remains disabled, but develops an attitude of “Let Mom do it” that encourages disability.

Does this mean that a parent should not discuss the assignments? No. By all means, discuss the assignments if you are concerned that the work is not going to get done properly. You can ask all the questions you want--just don’t give any answers. If you ask, and your loved one gives you a bad answer, mention that a better answer is needed. You can even cue your loved one to look up the information in the text book.

The hardest things a survivor must do to compensate for problems in school work are to transcribe taped notes and to study for exams. You can be helpful in both areas. When a student tries to make notes from a tape, the usual approach is to turn on the tape and then get as much written down as his/her thinking and writing speed will allow. This produces lousy notes. Fortunately, there is a pause button. The pause button needs to become your loved one’s best friend. Some students who have unusually good immediate memory can pause the tape after each sentence, but most need to pause it after each phrase. Done this carefully, it takes approximately three times the running time to transcribe a tape. If the lecture is 20 minutes long, it will take about an hour to make the notes from it. That is what you can do to help--watch how the notes get taken and cue for enough pressing of the pause button.

When studying, the procedure is to turn underlined notes and book chapters into flash cards. A sloppy approach produces a small stack of flash cards, overlooking a lot of important information, and leading to a failed test. The helpful caregiver watches and cues how carefully the flash cards are being written. The flash card questions also need to be written carefully. The most important information always needs to be found in the answer, not the question. Here is a silly example of a fat question which is too easy: what is the name of the Civil War general who won the battle of Vicksburg, was appointed commander of the Army of the Potomac in 1864,

elected to two terms in the White House, and buried in Grant's tomb? This one should be written as a number of specific questions: What was Grant's first great victory? When was he appointed commander of the Army of the Potomac? What did he do after the Civil War ended? Here is another one: Xenon, Argon, Radon and Helium are "noble" gases, true or false. It should be "Name the noble gases." If you want to be extra nice, it is perfectly acceptable for you to quiz your loved one with the flash cards, as long as you don't give any hints as to the answers.

Another "how" issue for which caregiver feedback is often important concerns the conditions under which studying gets done. The typical 21st century student does homework with the television and the stereo running, and cell phone calls coming in at all hours. How can the student get anything done under those conditions? The answer is, probably nothing gets done, but a student without a brain injury can often do well in school without any studying. Your loved one may have to do serious studying for the first time in his/her life. When that time comes, he/she may choose to create as many distractions as possible to make the study time more like playtime and less anxiety-producing. Your job is to comment on that problem, call for an Analysis Form, look for an effective solution, and remove the TV, stereo, and cell phone if absolutely necessary.

Be prepared to monitor for extremely distressed emotional reactions. Students tend to lose their friends and their romantic partners during the first two years post onset, winding up socially isolated. At some point, most students suddenly take stock of the extent to which their lives have lost quality. They become upset abruptly, and some become depressed in reaction.

A well-prepared child who goes back to school will have to choose between trying to graduate on time, with some social life and outside activities, but with reduced grades and future options, or taking some extra time, taking less than a full course load, while at the same time studying all evening and all weekend. The student in the second group may be able to get excellent grades and go on to the next level of education successfully. Like everything else in the World of Head Injury, school is harder and doing well in it requires paying a lot of dues.

CHAPTER SEVENTY-FIVE: Surgical Anesthetic

General anesthetic--gas given to knock you out so that major surgery can be done--is neurotoxic--it kills brain cells. The question of how many it kills, and how serious the effects might be, is controversial at the present time. It produces enough of an effect that there is sometimes a noticeable dulling after surgery, which may improve for several weeks thereafter. Whether there is any long-term effect is not clear, and drug companies are not rushing to have their long-approved anesthetics tested, but some physicians and neuropsychologists advise minimizing the use of anesthetic on survivors of head injury.

There are several things you can do to avoid risking further brain damage when surgery needs to be done. The first is to opt for a local, epidural, or spinal anesthetic, which do not damage the brain, if it is the kind of surgery for which one of those methods can be used. The second is to discuss the risk of additional damage with the anesthesiologist. The anesthesiologist has the option of putting a patient “deep under” with a heavy dose of anesthetic or to administer less anesthetic and have the patient be closer to consciousness. Some surgeons prefer to have all of their patients deep under so that they don’t have to bother with any interruptions if the patient starts to wake up, and many anesthesiologists routinely do this to make the surgeon happy. On the opposite end of the spectrum, some top-notch anesthesiologists at teaching hospitals that are also known for neurology always put their patients with head trauma under with a light dose because they don’t want to put the damaged brain at any further risk. That fact is enough to convince me that I would want to insist on light anesthetic if a loved one needed surgery.

There is another option, one that is incredibly safe, but one you probably won’t be allowed to use. Hypnosis produces very effective surgical anesthesia at no risk to the brain. In fact, the year that the use of chloroform as a chemical anesthetic was begun was the same year that a doctor in India published a report of 3,000 consecutive cases of hypnotic anesthesia without a single bad reaction. Despite the obvious value of this procedure, I have never known a surgeon to allow its use.

CONCLUSIONS

We know that head injury means poor recovery for almost all survivors, but at least one of the reasons is that the pathway to recovery is not accessible to common sense. Both the general public and the professions are stuck with old-fashioned ideas about how mental abilities work, and these ideas lead everyone down the wrong tracks in trying to deal with the after-effects of these injuries. Until now, only a small handful of highly complicated, high intensity rehabilitation programs have been able to direct survivors toward recovery, and they have found a remarkably high rate of success. This success seems to last, as former patients who do well after rehab are found to be doing well many years later.

No one has ever tried just giving survivors the guidance, without hundreds of hours of expert therapy and high-impact feedback from fellow patients. How much use can survivors and their families make of it? We have seen some successes already, but we will not know how much good this does for most people who try it until the end of another generation.

What we can say is that when they get used, these strategies and techniques produce recovery. We can also say that getting people to use them is an immense struggle, one which requires all of our skills, and one which does not get through to everyone. So we have taken pains to advise you that you cannot expect recovery to be quick or easy or a sure thing. We have urged you to get involved, go give it your best shot, hopefully to put your heart and soul into it, because we suspect that the good recoveries are going to require at least that much.

It has always been my belief that those individuals who made the best recoveries were blazing the trail that everyone else needed to follow. In almost every case, they made their spectacular recoveries because they decided to cover themselves just in case their feelings were wrong. They learned methods they felt they didn't need, but they were just worried enough to make sure things worked out. And when things didn't work out, they grabbed up the strategies and used them with all their strength. So if you can do for your loved one what we did for them, and just get a little worry and concern about what it might take to recover well, perhaps the rest will take care of itself. I think we convinced our patients to worry by taking our therapies very seriously, and by taking our patients very seriously, but most of all, by making recovery our top priority. May God smile on your efforts to do the same thing.