HELPING YOUR FAMILY MEMBER TO RECOVER FROM A HEAD INJURY

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INTRODUCTION

This guidebook is the companion to <u>Self-Therapy for Head Injury: Teaching Yourself to Prevent Head-Injured Moments</u>. It instructs family members, friends, and other supporters in how to assist the survivor of a severe head injury in doing self-therapy. Each issue is introduced in a chapter in the self-therapy guide. The recovery strategies are also presented there. The chapters in this book match the chapters in the Self-Therapy manual. I will summarize the issues and strategies in this book, but to get a complete understanding, you should read the self-therapy chapter first and then the accompanying chapter in this book.

The audience for this guidebook is extremely diverse in every respect. Depending on when the injury took place, your family may be preparing to bring your loved one home from the hospital or may have been living with the injury for decades. Consequently, some readers will be looking ahead with uncertainty and confusion while others will already be very familiar with how a head injury disables the survivor and impacts the family. Some will be dealing with a minor injury, that has only subtle effects on the most complex behaviors, while others will be dealing with an injury so severe that their loved one will never again be a part of mainstream life. Some will have hope for the future, while others will feel utterly defeated. Some will feel that the person who came home from the hospital isn't the person they loved before the injury, while others will be horrified that a family could feel this way. This diversity is always present in the World of Head Injury. I will try to provide information and comments that are useful to everyone, but please bear in mind that sometimes I will be talking to others with different views and needs..

In the same way that I offered a fair warning to your loved one in the self-therapy manual, I now offer the same warning to you. My purpose is to talk about the facts of injury and recovery and what you can do about them. To do justice to this purpose, I need to be honest and direct, which also happens to by my style as a clinician. Life after a head injury involves some hard truths, and I am going to present them openly. If you feel disinterested in or unready for bad news, put this book down immediately. Do not read it unless and until you want to hear about what makes life so difficult after head injury.

Let me begin by introducing myself. I am a neuropsychologist and head injury rehabilitation program director who had the good fortune to train under some of the most accomplished professionals in the history of the field. I have spent 27 years learning my trade, and researching and trying to improve its recovery techniques. I have worked with hundreds of therapists and thousands of patients and families. One of my main interests over the past 15 years has been to find ways to simplify and streamline the long and complicated therapy procedures that aid recovery. Like others working toward this end, I have found that my patients and family members can do a great deal of the work on their own, once they receive a basic education and some guidance. In fact, the therapy has to pass into the hands of the patient and family in order for a good outcome to take place. So over the years, I have found ways to get my part of the job done quicker and to turn the therapy over to the long-term stakeholders sooner.

What makes this therapy so important? If you have not reached the first anniversary of the injury, you may still be under the impression that time has been healing the injury, and hoping that time will heal it completely. The sad fact is that nothing could be farther from the truth. Time has been healing the parts of the brain that were disrupted or hampered by the *temporary* effects of the injury. Most of the brain is badly disrupted at first, and most of it comes back to functioning properly over the course of many months, which is why your loved one has made such huge, gradual gains. However, a head injury kills brain cells, and one serious enough to put someone in the hospital kills thousands and usually millions of them. Time does not heal them. Dead cells don't grow back. In spite of things they say on educational TV, the brain does not rewire itself to do the job of the killed cells. And all of the cells in the brain are there because they perform important functions—the useless ones got pruned away long ago. So the injury permanently stops the brain from doing its jobs. It will never again work the way it used to work.

On the other hand, the brain doesn't have to be perfect to accomplish most of its tasks. There are more ways than one to do anything, and survivors can learn to use a damaged brain in a different way that remains effective--by using a *recovery strategy*. If a survivor self-reprograms effectively, it is possible to function very well, even at the complicated and difficult tasks that are necessary for a full adult life. Some survivors of relatively extreme injuries have been able to function superbly at the highest levels of school, work, and social life, because they made maximum use of those strategies.

Unfortunately, recovery strategies are not intuitively obvious to common sense. The great majority of survivors do not learn to use them, even 20 years after an injury. The great majority of family members do not figure out what these strategies are or how to put them to work. It has been estimated that 9/10 of survivors of severe injuries (that is, injuries that either put the victim into a coma that lasts at least until the person is examined in the hospital, or that put a measurable hole in the brain) end up socially and vocationally disabled, unable to adapt to these disabilities. Bright, well-educated, hard-working, highly-motivated people are totally stymied by the challenge of recovery. Moreover, most professionals are equally ignorant about recovery-physicians, psychologists, educators, rehabilitation therapists, pastoral counselors, mental health workers, and so on. In fact, medical and mental health professionals, who are not trained in TBI, seem to have less success than the general public, because they try to use their standard techniques. Experience has made clear that standard techniques don't aid recovery from a head injury. Recovery requires head injury techniques and strategies. If you don't know what those are, your chances of figuring them out are not good. Education and training are essential.

Very few survivors get this education and training, and so, very few have a fair chance to recover. Far fewer than one in a hundred get therapy from a well-developed program or a professional trained in these methods. (The "gold standard" is called holistic cognitive rehabilitation, and I have included most of the major publications about it and reviews of it in the references at the end of this manual and the Self-Therapy manual.) And because managed care has squeezed the rehabilitation industry hard, very few of the well-developed programs are still standing. Today, it is virtually impossible to get the expert help. Three top-level programs in the New York metropolitan area and one in the Phoenix area still provide this therapy, but at a cost

of close to one hundred thousand dollars. That therapy is not, and probably will never be, available to most of the people who could benefit from it.

A major part of my research has been the study of former patients who have made exceptional recoveries. Although they all left therapy with damaged brains that had serious impairments of their most important mental skills, they were so strongly committed to using the strategies that compensate for their symptoms that they earned straight A's in high school, straight A's in college, in some cases went on to earn graduate degrees, pass America's most difficult bar exam and start practicing law, pass a licensing exam in social work and resume practicing psychotherapy, direct large departments for America's leading technology companies, run a factory, build a new career as a schoolteacher or a paralegal, and so on. These people fixed very severe injuries very well. They show what is possible, if a person is willing to do the work. With perhaps one exception, they were not geniuses before the injury, although most had gone to college. But many had good work habits, and they all were able to learn what we taught them and willing to work hard on recovery.

So what we have learned from thirty-three years of doing holistic cognitive rehabilitation is that many people can be trained to recover reasonably full lives, and a few people can become outstanding, in spite of their severe brain injuries. Clearly this does not happen without guidance. People with severe injuries who don't get this high-tech rehab almost never have good recoveries. The methods of recovery are not obvious to common sense. People need to be taught how to recover. And then it is up to them. Those who work hard can take back a full life, and those who bust their humps can still rise to the top.

Five years ago, I decided that I was ready to write an explanation of the recovery strategies for people who never had a chance to get any of this rehab. No one has ever tried to do this. The pioneering rehab programs are very complicated, and it took me and my colleagues more than a year of apprenticeship to learn this approach. However, in my last hospital program, I found that much of the complicated therapy could be taken out without harming the recoveries. In fact, the new, streamlined version of the program eliminated 4/5 of the therapy and, by concentrating on the most important aspects, got slightly better results. This showed that a reasonably simple program can get the job done, and that is what made it possible to write these guides.

Why should survivors and their families have to build the recovery on their own? The simple answer is that nobody else is going to do it for you. If you want more recovery, this is the only way I know to get it. Whether you have the urge, the enthusiasm, the patience, the hope, and the aptitude to teach yourself recovery strategies, if you don't learn them and begin to use them, recovery will not go forward. It may sound harsh, but it's the simple truth.

Working on recovery is not easy for most people. But then, these guides are not about the easy way to live. Disability is easy. It's recovery that's hard. You probably don't have the time and energy to put everything in this book into practice right away. That isn't expected. Anything you can try out gives you a start, and you have the rest of your life to work out the details. If you

are short on time and energy, get whatever help you can from family, friends, your religious or community organizations. If you have the funds, you might consider hiring a "starving" college student or graduate student to learn these methods and help out, although you will need to be careful about getting enough recommendations to be sure it is someone you can trust. If you have none of these things, you will have to decide how much of yourself to invest in recovery. I will try to help you to know which steps are the highest priority.

I wish people had a source of knowledgeable help in the community. We have started our own organization, called GiveBack, Inc. GiveBack is run by survivors who have completed the training and had good recoveries. They know more about recovery than I do, and they are willing to share what they know with others who are not as far along. GiveBack offers some instruction and inspiration, but our people still have to go home, get out the therapy books, and put in the time working on their treatment plans and their self-therapies. But there is a deep comfort in knowing that others are struggling with the same recovery process, and that we are willing to help and support one another. If you live in another area, you might want to consider organizing a GiveBack for your community. We will be glad to advise you on how to do it.

If you find yourself cursing the government or the medical profession for failing to help you to deal with these problems, may I suggest that you get that out of your system quickly. Blaming others can be an energy trap that keeps you from working on recovery.

If your loved one rejects the idea of reading or using the self-therapy guide, you may find some useful suggestions to encourage him or her to do so at a later date in the chapters of this book. You can move forward in trying to aid recovery on your own if you have to. However, you need to understand that nobody can "fix" your loved one except him/herself. Encouraged with gentle persistence, most survivors can at least take some steps toward recovery, but there are some people who simply will not do it. The best thing you can do is to provide *effective* support—which means whatever kind of support your loved one will accept. That can often be quite difficult, but I will make an effort to explain how it is done. The main reason this book was written was to help family members to provide effective support.

If the brain disorder affecting your loved one is not a closed head injury, you may find some of the material in these books pertinent and useful, but it will not be a perfect fit. You are welcome to try out these suggestions, and to stick with what works for you and your loved one.

Hard as it may be for many heavily burdened caregivers to see any light at the end of the tunnel, let me assure you that some people have found the light. Here is a quick story of one such family:

Eric was the son of a rich man who made the most of his good fortune. He hated school, so he dropped out, and Dad got him a job with a decent salary as a gofer in the mail room of a company with whom Dad did business. Eric was now making enough money that he could marry his pregnant girlfriend, and still have enough left over for heroin for the both of them. Flash forward two years. Eric's daughter

is gaunt and shrill from being left alone for most of the day while her parents nod off in the bedroom. Foolishly, Eric scores from a dealer he's never used before and winds up with uncut heroin. When he shoots up his usual dose, the overdose kills him. The paramedics shock him back to life and take him to the trauma center. He survives, but with severe brain damage from the lack of oxygen to his brain. Social services get one look at the condition of the baby and take her away, placing her in a foster home. Eric's wife deserts him to move back in with her parents. Then he is told that his blood work came up HIV positive, which Eric understands is a fatal disease. When he gets to rehab, he seems disinterested in everything. As he did in school, he just goes through the motions of testing. Then he receives a wake-up call from the treatment team. Making no attempt to spare his feelings, they tell him that he has damaged his brain badly enough to make him permanently and totally disabled, and that people with his history of drug use don't use rehabilitation to get better. He is given two weeks to show what he can do. To everyone's surprise, he starts working hard, and makes good progress in his therapy. At the end of the two weeks, his treatment is extended with no strings attached. By the end of the month, he tells his therapists, and then his father, that he is willing to go into drug rehab once he finishes brain rehab. His good progress in rehab continues. He takes pride in his new-found self-discipline. After graduating from rehab with no restrictions, he completes drug rehab as well. He returns to his old job, and lives in an apartment by himself. More than a year after graduating, he is still clean and attempting to reunite with his wife and regain custody of his child. No one expected Eric to do this well, but at the last minute, he found inside of himself a strength he had never had before.

The recovery strategies in these guides are not complicated medical cures invented by teams of scientists in lab coats. They are special ways to access God-given strengths and capabilities. If God has given human beings the strength to recover, and given us the wisdom to discover how it is done and the power to put it into practice, surely we can do the work.

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CHAPTER ONE: Step One: Learning About the Injury

You are reading this family guide because your husband, wife, son, daughter or friend who sustained the head injury (whom I will refer to as "the survivor") is a candidate for self-therapy. Self-therapy begins when he or she reads the self-therapy manual. That guide is divided up into relatively brief chapters, and the subject matter of each chapter matches the chapters in this book. The first chapter summarizes the basic facts about injury and recovery which were discussed in the introduction section of this volume. (If you have not already done so, please start reading there. This introduction section contains important basic facts.) It spells out how incomplete medical recovery is, which is why survivors need to learn how to "fix the brain." It ends by explaining that a self-therapy book helps only those who are willing to learn.

The most important fact from that chapter is that survivors stop recovering while in a state of partial disability, and almost always remain just as disabled twenty years later. Although we don't yet have any research that extends beyond 20 years, the fact that no change is seen after the first few years indicates to us that the disability is probably permanent. Some of these survivors are disabled by surprisingly mild symptoms that would be pretty easy to fix, but they don't fix them. Specialists in head injury rehabilitation have discovered that most head injury disability can be fixed, but, again, most survivors don't do that.

Survivors don't adapt to the disabling effects of their injuries because of three obstacles to learning. First, most survivors have trouble remembering new information of all kinds. Some have trouble reading the information, more have trouble with their mind wandering when they try, and most tend to forget a lot of the information they read.

This problem is fairly easy to handle. Although I will discuss the solutions in detail later, it is important to know how to get past this obstacle right now. Most survivors can learn small amounts of material, so the self-therapy manual is organized into very short chapters. It is best to read it one chapter at a time and then think about it and discuss it. Those who have the most serious reading problems may need help in reading and simplifying the material. Memory problems can also be countered by writing down the main points of a chapter, for easy reference if the survivor should forget some of it later on. If the survivor cannot understand the material even with this kind of help, he or she is not ready for this kind of self-therapy. Since people with severe head injuries show a great deal of improvement over the first year to two years, and sometimes longer, this improvement may make it possible to go forward with self therapy later.

The second, and most important, obstacle is the inability to directly perceive the effects of the injury. In traumatic brain injury (TBI), the brain does not feel injured. It rarely hurts or feels strange, and relatively few symptoms are obvious to survivors. Most survivors overlook the errors they make because of the lasting effects of their injuries. When an error gets noticed, most survivors don't realize that it was caused by their own, defective thinking and self-control. Even when a survivor recognizes the mistake, the injured brain usually serves up excuses that prevent learning about the injury. Serious physical disability is unusual after TBI, but if there are physical symptoms they almost always get recognized. In many cases, survivors also learn that

they are forgetful. But most survivors feel sure that their thinking, behavior, personality, and abilities to get things done are unchanged, or changed very little, by the injury. Common head injury symptoms like unreliable judgment, undependable follow-through on assignments and tasks, inappropriate behavior toward others, reduced frustration tolerance and self-control, and increased emotionality are usually denied no matter how serious they might be. By failing to recognize that these are permanent problems, survivors learn nothing from the mistakes they make on this basis, repeating the same errors again and again. In our TBI recovery society, GiveBack, we refer to these mistakes as "head-injured moments," a term I will explain more fully in the next chapter.

One of the things that makes head injury so confusing, not just for the survivor but for everyone, is that most of the problems it creates do not take the form of lost abilities. Most survivors still know how to do everything they could do before. Information learned in school, job skills, driving skills, computer skills, the "how to do" all of these activities is not lost. We think of these skills as the basis for intelligence, and the fact that these skills return shows that TBI does not rob the person of intelligence. In turn, if the person is no less smart, we tend to think that they are mentally okay. If a person who has reasonable intelligence does sloppy work, makes "careless" errors, and repeats mistakes, we don't usually look to a brain disorder to explain this kind of bad behavior. Instead, we tend to blame it on attitude, motivation, effort, desire to help out, personal standards, and character. We see smart, capable people who keep screwing up as either bad people or people with bad attitudes, not good people with bad brains. In the case of TBI, this is a huge misunderstanding.

You can see the misunderstanding if you look closely. People who have bad character screw up things that are important to others, while skillfully doing things that serve their own needs. But if you carefully watch a survivor, or even better, keep records of the mistakes, it turns out that many of them take place on tasks that are extremely important to the survivor. In other words, this is a person whose bad behavior hurts him/herself. In fact, the survivor shows a tendency to NOT be careful when being careful is most important to self-interest--when someone important is watching, when high stakes are on the line, when an error can cause danger, when learning new skills or how to deal with new situations, and when behaving well is expected (as in important relationships with friends, family, employers, and customers). Survivors forget to do things they want to do, forget their own possessions, fail to take advantage of opportunities in which they are interested, and make bad decisions that hurt them. But they also forget to do things for other people, fail to treat others with the expected courtesy, fail to meet their obligations or meet them with actions that are too casual, careless or poorly planned, and these actions tend to ruin the trust and confidence and even good will of friends, family, and employers.

A person who has been severely injured for two years or longer has had hundreds and probably thousands of head-injured moments without realizing that his or her behavior has become unreliable. The intelligence is still there, but it no longer controls what the survivor does well enough. Too often, actions are taken "on automatic pilot," speaking or acting first and only thinking about it later on, if at all. This kind of behavior drives away friends, stresses family

close to the breaking point, loses jobs, and makes life chaotic, yet the survivor still feels normal.

Another equally strange fact about TBI is that most survivors will indicate that they are pretty satisfied with their lives if you ask them. They may be poor, housebound, bored, lonely, or even depressed, but they somehow manage to not see anything wrong with their life. The injury has broken one system, but unfortunately it happens to be the system we use to evaluate how to deal with important challenges, how to solve problems, how to evaluate the results of action, how to evaluate the self, and how to evaluate life. Because of the way it got broken, it puts out a constant signal indicating that everything is okay: "I did okay," "I am okay," "life is okay." And this signal is turned on full blast, which happens only when you have reason to be totally certain about how things are going. It is unimaginable to them that something could be seriously wrong with them, or with their life. Because of this brain malfunction, they refuse to accept the blame for things they do wrong, which appears stubborn and willful. Because of this symptom, they tend to be uninterested in therapy, and in brain injury education. It is this breakdown that makes them totally unable to adapt to the symptoms of the injury. It traps them in functioning not quite well enough to lead a normal adult life, and by doing nothing about it, most of them remain trapped forever.

It may sound like I'm making a big deal of this problem. I am. It *is* a big deal. This symptom keeps ordinary schooling, traditional rehabilitation, counseling, advice, and parenting from getting through to them. And for most survivors, perhaps as many as nine out of ten, it is a very sold barrier, like a brick wall. No explanation or argument or evidence gets around it. Naturally, if a person feels dead solid certain that there is nothing wrong with them, they are not going to want to read a book about how to do self-therapy. The last part of this chapter discusses your options in handling this obstacle.

The third obstacle is that even if by some miracle or special therapy, someone can get through to the person, convince him/her that something is seriously wrong, and explain the strategies that can be used to fix it, the person has to actually use the strategies in real life activities. In the world of rehab, it is called the generalization problem. It is another whopper of a problem. Fortunately, there are strategies to get around it, too. We'll get back to generalization in later chapters. For right now, we need to worry about obstacle number two.

The first step toward recovery is the decision to find out more about the injury, which leads to starting to read the self-therapy manual. It does not necessarily involve believing that the symptoms of the injury are serious. Very few survivors--perhaps one out of every twenty--worry about being head injured and feel a need to learn more about how they have been affected. These unusual individuals welcome the self-therapy manual and read it hungrily. Even facts about their injury that go beyond their awareness are accepted for further thought and study.

It is not normal for survivors to believe that the things they read about TBI apply to their own injury. All that is needed to make progress at the first step is a willingness to be exposed to new information, not to believe it. In fact, many of my patients were still skeptical when they FINISHED therapy. In spite of half a year of work, and thousands of pieces of evidence about

their injuries, they still tended to believe what their brain told them. But they at least recognized the possibility that their brain might be wrong, and so they learned what the other guy had to say. And that was enough. When they tried out their strategies in the real world, they found that things worked much better, and they often came back to me years later to tell me that they now realized that I had been right all along. All that is need is a mind that is open a crack.

Those survivors who eventually learn about their injuries begin learning out of curiosity, not out of a sense of needing to learn. That is also true of most family members. Right now, you probably are not convinced that the explanations in these books are scientifically accurate. You need to see for yourself. Maybe you need to read comments on these subjects written by other experts. That's only reasonable--many so-called experts are not expert. However, there is one critical difference between your experience and your survivor's experience. As you read about TBI, the facts will ring true to you. They will ring false to people with TBI.

So the challenge at this point is to encourage curiosity about the topic of head injury so that the survivor will read the Self-Therapy Manual as well as other information about TBI, and learn and think about these ideas that seem wrong at first take. If there is curiosity, and some learning, then the survivor may start to notice that a few of these new facts actually fit real life. That will produce a little more curiosity, which will produce more reading and more learning, and that sets a chain reaction into place. The survivor becomes more open, asks more questions, and starts to create a whole file of ideas about TBI that run contrary to his or her feelings. That is how the second step toward recovery gets taken. As the person discovers that his or her feelings about self and life are wrong, he/she begins to realize that a whole lot of new learning is needed.

Some survivors, especially those who are in the habit of learning from reading, are more likely to be naturally curious and to do the reading on their own. Others become curious when they run into something that captures their attention. For example, patients in hospital rehab programs have opportunities to see many other people with head injuries. They very quickly notice that the others act just like the book says they should. The more they read, and the more they watch the others, the more evidence they are gathering that head injury really does have these effects. At some point, they begin to ask themselves, "Am I like that, too?" And once they have asked themselves that question, the cat is out of the bag. Because once they know what the symptoms of head injury are, they begin looking for them.

What can you do if your survivor is not curious about the self-therapy manual? If *you* are curious to learn more about TBI, share that curiosity with your survivor. If you realize that you don't know much about TBI, admit your ignorance on the subject. Point out that there might be good reason to learn more about it. But above all, be honest--don't hype the material any more than you truly feel.

What should you do if the survivor says, "That's yesterday's news. That head injury isn't affecting me anymore. I'm normal. Don't you think I'm normal?"

Do you feel your survivor is normal? That question actually breaks down into two very

separate questions. First, is your survivor unchanged by the injury? Is he or she the same person, with the same capabilities and tendencies as before? Almost all family members who have been living with the injury for more than a year say "no."

The second question is, does the injury make the survivor an abnormal person, someone who should be labeled as defective and in need of special help? There is more difference of opinion among family members, and among therapists, on this question. However, as time passes since the injury, more family members say "not normal" in this way, also.

How should a caring spouse or parent treat a survivor? In our society, we have a standard that says that you treat a person who is ill or injured with support and encouragement, and you avoid calling attention to his or her symptoms. But if the symptoms are permanent, and the survivor is unaware of them, honest feedback may help the person to make progress, while supportive feedback that conceals unpleasant truths may help to hide the problems with which the person needs to deal. We think of TBI as a special case, in which the survivor's need for honest feedback must come first. So if (and only if) a survivor asks me a question like that, I usually say, "I think you are normal for a person with a head injury." Then I stop. If (and only if) they ask me what that means, I say, "You're not crazy or stupid or incompetent, but you are different from the way you were before the injury. A head injury always changes the person." Then I stop. If (and only if) they say, "How do you think I'm different?" I say, "You have headinjured moments. I'm glad you asked me, because that means you're probably ready to learn about them. I'll teach you if you want to learn." The principle that guides my answers is, never answer more than you're asked, because the questions tell you what the person is ready to hear.

Just as some family members hold back on giving negative feedback about head-injured moments out of a sense of loyalty to the survivor, so other family members push hard to get their survivor to realize what is wrong. Criticism, whether it is constructive or otherwise, seldom "gets through" to a survivor, because the self-evaluation process functions so poorly now. Some family members try again and again to convince their survivor to be more careful, more thoughtful, more active, more considerate, and so on. When these suggestions are not accepted, the family climate can often turn hostile, with the survivor resenting the family's input. Many families are stuck in this kind of an unpleasant rut, with harsh words going both ways and no recovery resulting. The family member who is most involved with the survivor, usually a mother or a spouse, may end up having lost all credibility if the conflict goes on long enough. Later, we will discuss ways to repair relationships that have become difficult in this way.

Consequently, if the survivor's first reaction to the self-therapy manual is argumentative or rejecting, it is not recommended that family members try to "prove" that the survivor is malfunctioning and needs help. A direct approach like that is almost never helpful--it usually just makes the survivor sorry that the matter of head injury was brought up in the first place.

Most survivors benefit from having a "therapy partner" to discuss each chapter and to work together to set up self-therapy activities. That person should be the family member who is most available, credible, and honest. In a large family, it may not be the main caregiver.

Sometimes a survivor does better with a close sibling or a dear friend as therapy partner. However, most families in today's world are small, and most people who live in our part of the country (Florida) don't have a big network of supporters nearby. The partner usually ends up to be the spouse or parent by default, even if the relationship is difficult.

When discussing the survivor's reactions to the book, listen for skepticism and distrust, and don't feel it necessary to discourage that reaction. Instead, offer to read up on TBI with the survivor, using the books and other materials listed at the end of these books, as well as other information from the authors that becomes available on the Web.

The most important fact for you and for the survivor to understand and accept is the critical relationship of the length of coma to the extent of symptoms and disabilities. The references from top rehabilitation scientists (Dr.'s Gronwall, Levin, Lezak, Povlishock, Adams, Gennarelli, Boll, Jennett and Teasdale) discuss this at length. (More specific details from the research on recovery are reviewed extensively in a chapter on How Recovery Works, posted on the GiveBack web site, excerpted from a book I wrote with my son, Michael.) All of this research says that the seriousness of the post-injury problems are actually determined at the moment of the injury. This is a fact with which rehabilitation patients cannot argue. All they can say is, "Maybe I'm the exception to the rule." But those articles indicate that the rule doesn't really allow exceptions. This fact about coma length serves as one of the main eye-openers. Occasionally, a patient will argue with this, by pointing out that how long you have a fever doesn't determine the lifelong effects of an illness. My response is, "You can compare a brain injury to a spinal cord injury or an eye injury, because they all damage the nervous system. If you get hit in the eye so hard that it ruins your retina, you will always be blind. If your spine gets twisted hard enough, you will always be crippled. It's no different with your brain. The harder it gets hit, the longer the coma, and the more damage you have to deal with from then on."

It may also be helpful to get testimony to back up this point. Don't expect to get any help from your physician, because medical school includes no training about the long-term effects of head injury. The best testimony comes from other injury survivors who have had successful recoveries. In GiveBack, former patients are the teachers. They advise new participants, "I didn't think my injury was that bad, either. It took me a long time to realize that my brain had been totally changed." We include seven autobiographies from these successfully recovered expatients on the GiveBack Web site (on the Red Discussion Board, under Recovery Stories). If you happen to meet a successful survivor, you may be able to get this kind of support in person.

If your loved one is hostile to the idea, and refuses, don't force the issue. Do your own reading, and take notes in a therapy notebook you make for yourself. Let your survivor know that he or she is welcome to read what is in the notebook at any time. And then leave it at that.

You will notice that most of the chapters end with a paragraph discussing how to read more about the subject of the chapter. Most of these readings are written for professionals, and the language in them is difficult for others to understand. I believe that I should be accountable to my readers by directing them to the highest quality and most respected professional information,

so that they can double check my ideas if they want to. If your survivor wants to try, it is a good idea for the two of you to do that together, armed with a medical dictionary. Reading articles of that kind is a lot of work, but you can usually make sense of them.

I want to end this chapter with a couple of important cautions. First, don't look at self-therapy as making professional therapy unnecessary. If you can get professional therapy, by all means get as much of it as you can. When it is over, there is a good chance that there will still be problems, and the self-therapy will still be available to work on those. If you would like to mention that you have been reading up on self-therapy to the professional therapist, he or she might get interested enough to check out the GiveBack web site (www.givebackorlando.com), which has information for professionals as well as the general public. However, don't be surprised if your therapist takes no interest. Professionals are not trained in school to understand what the limits of their knowledge are in specialty areas like head injury. Nevertheless, they can provide something that self-therapy can't, which is skilled, hands-on training.

Second, if your survivor is physically violent with you, do not follow these instructions in this guidebook, as confronting your survivor could be dangerous for you. Head injuries tend to increase pre-existing tendencies toward violence, and physically abusive survivors are truly dangerous to their family members. A violent survivor should be dealt with by the mental health and law enforcement systems. That is not the appropriate job of a parent or spouse.

CHAPTER TWO: <u>Head-Injured Moments</u>

A head-injured moment is a point in time in which the brain fails to think clearly and carefully, and as a result, fails to notice something that needs to be noticed, makes a poor decision, or tries to do something too casually to do it properly. In a head-injured moment, the survivor may have been able to function correctly, but he or she did not do it. Given a second chance, perhaps aided by a hint or an extra incentive, the person might well get it right.

Is that a symptom of brain damage? As strange as it might seem, that is the *main* symptom of TBI. The typical injury does not cause *inabilities*. We assume that medical disorders generally, and brain damage in particular, takes abilities away. In fact, our stereotype of brain damage is that it leaves the person unable to do even simple things. A person with brain damage should talk funny and walk funny, should be unable to stay alone at home or drive a car, let alone go to college. A person with brain damage should be stupid, dumb, dense. The brain is the seat of intelligence, and intelligence is the queen of the mental abilities, so brain damage should show itself through extreme stupidity. Most people are looking for a brain injury survivor to act like a person with severe mental retardation. Nothing could be farther from the truth.

Although there are some survivors who have obvious or even terrible physical disabilities, the great majority of survivors look *completely* normal. Most of them can do everything a normal person does. They can stay at home alone for as long as they need to. They can go into the community on their own to do business of all kinds. They can pay their own bills. Many of them are safe drivers. Most of them can use a computer as well as they did before the injury. If they could rebuild engines before, they still know how to do that. If they could translate important works of philosophy before, they still know how to do that. They have every kind of ability they had before. Their intelligence, in the most basic way we understand what that term means, is virtually unaffected--they have the same vocabulary skills and reasoning capabilities.

The assumption that brain injury is supposed to damage abilities is not only a bit of questionable folk wisdom, but a viewpoint shared with many professionals. Most books and articles about head injury use the term "impairment" to refer to lost abilities. Because the majority of writers on the subject presume that head injuries affect survivors mainly by producing impairments, I am going to mention the names of the highly respected TBI experts who disagree, so that you can look into this matter further if you are interested. Mark Ylvisaker has written several books and many chapters and articles on TBI in children and adolescents, and is generally thought to be the top TBI expert for that age range. In his latest book (1998), Ylvisaker argues that most people misunderstand the effects of head injuries, thinking that they make survivors unable to do particular things all of the time. His point is, most survivors are able to do just about everything most of the time, but they fail to do certain things that are important some of the time. They experience moments in which their abilities fail them. From this point of view, the problem is not what a survivor can or can't do, but rather when they will or won't do something correctly. If you read extensively into the literature on head injury, you will see than many lists of the major symptoms of TBI include the *inconsistency* of performance.. Another idea that is widely discussed is that survivors seem to have very little problem functioning in

circumstances that are highly familiar, while they have their greatest problems doing unfamiliar things or dealing with unfamiliar situations. Given these facts and ideas, the present guides do not use the term impairment when discussing the common symptoms of TBI.

Most of the time, a survivor does not look impaired or "brain damaged," because the main symptoms of the head injury almost never look that abnormal What, then, is "acting brain damaged?" If you read Chapter Two in the Self-Therapy manual, you will see that survivors are mainly impaired by using the casual, low-effort, low-quality mode of thinking and acting in situations that call for higher quality. So what they do does not look abnormal because the behavior itself is NOT abnormal. The problem is that it is the wrong KIND of behavior for that situation. And the mistake of using the casual, automatic mode instead of the careful, thoughtful mode, is a mistake we all make. It is in fact a NORMAL mistake. And when it happens often, it is usually a sign of being unmotivated, having a bad attitude, being a slacker, or just having a bad day. It never looks "mentally challenged" even though it is. The problem is that the survivor does not even recognize that there is any need to use the careful and thoughtful mode, and that failure to see what would be obvious to any adult is truly abnormal. It is abnormal, but it is a private experience, not something you can see. And the failure to notice something is not an experience that your survivor can see, either. Head-injured moments are hidden from everyone's awareness. You can learn to spot them, but it takes considerable adjusting of your point of view.

If you are to become capable of recognizing head injured moments whenever they happen, both you and your survivor need to become much more aware of the two modes--the automatic pilot, casual way of doing things, and the careful and thoughtful way of doing things. You can see the difference, but only by paying special attention to watching for them. As you and your survivor begin to learn how to do this, it would be a good idea to start noticing these two modes in your own behavior, in the behavior of people around you, and even in the behavior of characters you see on TV. Whenever you see someone acting out of habit, going through the motions in the casual mode, point it out aloud to your survivor. When you see them shift into careful/thoughtful mode, point THAT out. Whenever you see someone remain in automatic/casual mode when they should have upshifted into careful/thoughtful mode, and they ended up making a mistake, point that out as a "head injured moment" even if the person who did it isn't head injured. That will help your survivor to start noticing the difference between the two modes in his or her own behavior. I especially recommend that you do this when watching comedies and sitcoms, because they often have their characters make mistakes by failing to upshift. In the past, shows like All in the Family made fun of Archie Bunker because he almost never upshifted, and Sanford and Son was based on the same comic idea for Fred Sanford. On Friends and on Seinfeld, all of the characters fouled up badly some of the time by being too casual about important things. Today, you can watch William Shatner make an ass out of himself in every episode of Boston Legal by failing to upshift when he should. The main characters on Scrubs all make assses out of themselves in every episode by doing the same thing.

If the survivor is living a low-key lifestyle with few or no responsibilities, little adventure and little independence, mainly staying home or going only to familiar places with familiar people, there will be few head-injured moments, and the injury won't present much of a problem.

It is only a problem in doing hard things, unfamiliar things, important responsibilities. A head injury does not make it difficult to be a couch potato or a homebody, at least under most circumstances. But don't get lulled into a false sense of security. Just because your survivor can handle a low-key life well does not mean that he or she could handle a real job, real outside-of-family relationships, or any changes in environment. The injury has taken away *one* ability--the ability to adapt. When life requires the survivor to adapt, adaptation will not happen.

How can you know whether your survivor has to deal with impairments or just with head-injured moments? It all depends on how the brain got damaged. That subject will be discussed in many later chapters, but I will provide an introduction here. Brain cells are organized into networks. Networks connect several work stations in far-reaching parts of the brain via intercommunication pathways called white matter tracts. The most advanced network in the brain, the one network that makes the human brain most different from the brains of other mammals, is called the "central executive network." For a number of reasons, this network can be regarded as the source of the brain's most powerful thought processes. When the white matter gets damaged, the resulting signal loss is enough to shut down the whole system. In turn, the shutting down of that system leaves behavior totally under the control of the "automatic pilot" with no guidance from the central executive network. Thus the harder the brain was hit, the more the white matter got damaged, the more likely that head-injured moments occur whenever critical thinking is needed. In essence, any severe head injury thus causes this problem.

All head injuries also have a unique aspect. Head trauma sometimes damages particular parts of the brain in a concentrated or "focal" way. The point of impact, the area on the opposite side of the skull, and any areas subjected to bleeding or to pressure from blood clots, may get badly broken on a permanent basis if the zone of damage is large enough. Scans done soon after the injury show these zones of damage. There are also three very small places (the right and left hippocampus and the vermis of the cerebellum) where even the g-force of an accident produces small tears that permanently cause serious impairments of learning ability or balance. So to understand an injury, it is necessary to know both about susceptibility to head-injured moments (which is a nearly universal consequence of severe TBI) and any specific impairments from focal damage (which is an individual matter). We will discuss focal injuries at length in a later chapter.

If you have finished reading this book (or other educational materials on head injury) and accepted the information, you know that your loved one faces two huge tasks: gaining an understanding of what the injury has done, and working on adapting to the deficits and trying to regain effectiveness in the major tasks of life. The more *you* understand and accept, the bigger the task and the more urgent the need will seem. In fact, in most families it is the caregiver who learns the facts about the injury first. So you will probably need to do most of the learning at the beginning. As you get more motivated to make these improvements happen, you will also become aware that you care a lot more than your survivor does. So as you get stronger and stronger in your desire for self-therapy, your point of view will get farther and farther away from the viewpoint of your survivor. This effect is the natural result of the first steps of education. From that point on, our task becomes to help the survivor to see the need as well.

CHAPTER THREE: Learning How to Recognize Head-Injured Moments

Chapter Three in the self-therapy manual begins by introducing the ideas I just discussed at the end of your Chapter Two. Certain situations tend to cause behavior to malfunction. A survivor who wants to recover needs to learn how to spot both the situations and the malfunctions. Once the survivor understands what head-injured moments are, and what they mean, the next step in recovery is to begin to discover his or her own head-injured moments.

The progress your survivor makes in this step depends entirely on where and how he/she looks for them. If he/she looks into memory of the events since the injury, there will be nothing to find. And that is always the first thing a survivor does. "I don't have that problem. I haven't had any head-injured moments." So Chapter Three explains that TBI makes it impossible to see head-injured moments through the natural process of noticing as you do things. To notice them, the survivor has to *watch* for them. In fact, to see them all, it is necessary to watch *carefully*.

Here is a simple example. If you don't live near the beach, then a holiday to the beach is a special event. As you play along the shore, with the ocean breeze keeping you cool, you don't notice any ill effects from the sun until you have sustained a bad sunburn. After you get a few bad burns, you become able to notice those subtle feelings that occur when a sunburn is just beginning. You do that by learning to watch out for them. Along the same lines, if you grew up in a city or in a part of the country that was not infested with stinging ants, you are not likely to notice an ant crawling gently into your socks and up your leg. Once you have been bitten a few times, you notice. Life has to teach you to notice. Learning to notice head-injured moments works the same way, only it is even harder to do, because your brain has become bad at noticing these things.

Fortunately, survivors can learn to notice their head-injured moments. While it doesn't happen naturally, it does happen once a person starts to make the special effort. In doing rehab therapy, we teach awareness in several ways. If I make a patient self-conscious by walking back and forth, looking over his/her shoulder, the self-consciousness is usually enough to get notice taken of some mistakes that would otherwise be missed. If I offer five dollars to the first patient who notices a mistake, every patient in the group will start noticing them right away. Any step that increases motivation or effort to notice mistakes or to get things done correctly is enough. If I offer five dollars to a patient for getting a therapy task correct, and I pick something that is difficult, the patient usually notices errors on that task without my even mentioning the word "mistake." Any step that increases motivation or effort toward quality control is enough to get mistakes noticed. If I keep doing things like that in a therapy group, within a few weeks the patients will develop a habit of watching for mistakes. If I arrange things so that they get attention for finding their mistakes, they quickly learn not only to watch but to watch carefully enough to find all of the mistakes. In this way, it is pretty easy for a therapist to teach patients to notice mistakes during the session. However, this is where the generalization problem mentioned in Chapter One rears its ugly head. Getting them to notice mistakes in my therapy group has no effect on noticing mistakes in any other setting. I have to teach the habit of watching for mistakes in other therapy sessions, and at home, and in the community. If I do that, there is a good chance

that they will become sensitive to mistakes everywhere.

In doing therapies to teach awareness, my therapy tasks are carefully chosen so that the correct response is clear, and therefore, any mistake is also clear. For example, I sometimes use the tabletop game Labyrinth as a therapy task. That game requires you to draw a ball through a maze by tilting the board, while avoiding 60 holes along your pathway. Dropping your ball into a hole is an error. There is no argument with that. All therapies should be scored objectively. When the results are a matter of subjective interpretation, the patient argues all day long that he/she didn't make a mistake. So we agree ahead of time on exactly what will qualify as a mistake. Then when a mistake occurs, there is no room for argument. One form of this tactic is to pick a task where the results can be measured in units of time, and get the patient to predict ahead of time how quickly he or she will get it done. After this prediction is made, I ask the patient to define how much slower than the predicted speed we should call a failure. This cutoff is then used to define an incorrect performance. Again, it leaves no room for argument afterward.

In this second step of self-therapy, the survivor's task is simply to recognize head-injured moments when they occur during the course of ordinary life, and to write each one down on a tablet or notebook. This step does not involve making any judgments about how big the error is, or how much the head injury had to do with it. All mistakes, of doing something badly, of doing something that should not be done, or of failing to do something that should be done, are to be written down, big and small. No little error is too little. Saying the wrong word, bumping into something, forgetting to turn off a light when leaving the room, all are perfect for the list.

Survivors tend to respond to this task in one of three ways. Some set about the task willingly, and while they overlook 95% of their head-injured moments, they begin to write some of them down. Some set about the task reluctantly, and while saying that they are trying to find some, they argue vigorously that they have not had any, day after day. The third group refuses to even try, either by relying totally on their feeling that they don't make mistakes, or by rejecting the recommendation that studying your mistakes can teach you things you need to learn. No matter which pattern you get from your survivor, there are certain things you can do to help move the self-therapy forward.

The most important thing you can do, regardless of which pattern you get, is to make your own list. Get a notebook, and begin to write down every tiny flaw, error, and imperfection in what your survivor does and says. Try to make the list complete. It turns out to be a lot of work, but every step of self-therapy involves a lot of work. There is no easy way to do it. If there are times you are not around but someone else in the family is there, invite them to join you. This list is for you. You are not to call your survivor over and show them what you have written down. Offer it up whenever he/she asks, but only when he/she asks.

Number the head-injured moments. If your survivor asks, "How many do you have for today?" give the number. Your survivor will be shocked, and probably tempted to argue. "I can't have made 35 mistakes in one day! You must have some of them wrong." Don't ever enter into an argument about whether a head-injured moment belongs on the list. You can say, "This is my

list. I'm making it as carefully as I can. But it's for *my* purposes, not for you to argue with." By making the list, you make a strong statement that you believe in self-therapy, that it is important to you, and that you are capable of following directions from a book. By watching closely and making a list that is probably much longer than your survivor's, you show what watching closely and carefully really means, and that kind of role model can help even an angry survivor learn what self-therapy requires.

If your survivor is in the first group, making a sincere attempt to find the head-injured moments, it is okay to offer to help. You can ask whether or not he/she would like you to mention when you see a head-injured moment that he/she fails to write down. That kind of help actually speeds up the second step, by again helping the person to understand how hard one has to look to see all of the moments. After you and he/she have been working together on this for a few days or a week, you will probably notice that he/she is spotting more moments before you say anything, and you should compliment this therapy progress. As progress is made, family members can even enter into a friendly competition, in which the survivor begins to try to pick off the head-injured moments before you mention them every time. This little game produces jet-powered progress through the second step. I like to compliment my patients as they make these improvements, noting that they have stopped seeing their own behavior like a typical head-injured person and have begun seeing it like a recovering head-injured person. I am happy to share my excitement that the person is beginning to show the potential to recover well.

How many head-injured moments should you have each day? That's up to you. I know that I could pick out 100 things I do wrong every day, but watching and writing would take up an awful lot of my time and would be annoying to me. Anyone who is serious should have at least five good ones, and more is better.

If your survivor is in the second group, making a reluctant and unsuccessful attempt to find any head-injured moments, you can say that your book tells you that you can offer to help out, if he/she wants help. Help means two things. First, it means that for some period of time, anywhere from ten minutes to an hour, you and your survivor arrange that you are going to point out the moments you notice. After you point one out, if he/she can see why it was a mistake, you can go on to waiting for the next one to show up. If he/she can't see why you call it a mistake, you should offer to explain *once*. The way I explain a head-injured moment is like this: "If I did something and I didn't do it quite right, I know I could do it better if I got another chance. The same goes for the things I say. If I could say it better with a second try, I would consider it a head-injured moment." If the survivor tries to argue the point, or says it's a matter of opinion, you should just comment that the book instructs you not to argue. It is your opinion that you are offering. The survivor is having trouble seeing head-injured moments, and you are just showing him/her how to do it.

In many cases, when you point out a head-injured moment, your survivor will argue that it was something trivial, unimportant, too small to count. If you get that reaction, you have just hit a home run. Point out the fact that the rules say even the smallest mistake counts, which probably explains why the survivor is having so much trouble finding head-injured moments. If

he/she is waiting for something important to get fouled up, that will be a long wait. Most of the activities in a post-injury lifestyle are simple ones, and so the mistakes are also simple ones. The answer to the survivor's problem is to think smaller.

At some point during these discussions, it is inevitable that the survivor will say, "That has nothing to do with my head injury. That's a mistake I made thousands of times before I had the injury." To that, you need to point out that the *head injury doesn't produce new kinds of mistakes*. It makes the old kind of mistakes happen more often. So almost all head-injured moments are things the person messed up on before.

Both of these misunderstandings of head-injured moments occur because of the false stereotype of brain damage. Survivor assume that if they did have problems from brain damage, they would be terrible problems of a kind that only severely disabled people get. But TBI is not about setting the house on fire, or putting your pants on backwards, or forgetting your name. It's about ordinary errors that happen for ordinary reasons. The reason we call them head-injured moments is that the factory-fresh brain has the ability to prevent those errors whenever there is a good reason to prevent them. The head-injured brain lets them occur. Recovery is based on teaching the brain to notice that a mistake is being made, and to stop it from occurring. Therefore learning to notice ordinary mistakes with special care is the basis for recovery.

If your survivor was willing to receive your help, you should probably work on this every day until he or she is finding and listing at least a couple of head-injured moments every day. If he/she rejected your offer of help and said he/she wanted to do it him/herself, wait a week and then review how much progress has been made by working alone. If no progress has been made, repeat your offer of help. Make it clear that you will only help out until he/she picks up how to do it, and then you will let it go.

If your survivor is in the third group, it is suggested that you refrain from putting on any pressure or even encouragement to participate in self-therapy. Just do your own notebook. Occasionally, you can comment that keeping the notebook has taught you a lot about head injury. If your survivor says, "It's not going to get me to work on it." I suggest you simply let him/her know that you have decided to do the program with or without the survivor.

If your survivor has rejected self-therapy, the only time it is reasonable to criticize is if the person tries to claim privileges or responsibilities on the grounds that he/she is not injured. You then have a right to say, "You haven't taken the steps that are needed to know how injured you are. Don't claim to be an expert on head injury, because you're not. If you want to be an expert on it, you have some work to do."

CHAPTER FOUR: Learning Where to Look to Find Head-Injured Moments

For those survivors who are making progress in step two, they can begin to become more effective and wiser in watching their own behavior by starting to learn *when* their head-injured moments occur. Head-injured moments are not random at all. They occur at the times when the brain needs to shift into overdrive (that is, when the central executive network needs to do thoughtful problem-solving rather than just react by old habits and automatic pilot) but doesn't do so. The situations in which this occurs have been mapped out very well in general terms.

1. Novelty. The survivor functions like a fish out of water in any foreign or strange or new setting, or in any familiar setting where life has changed a great deal. This includes moving to a new home in a different neighborhood or town. It includes functioning on a vacation to see the sights. It includes living in a family whose membership has changed (for example, with a new baby, with elderly parents having moved in, with a new step-parent, daughter-in-law, or son-in law, or with an important person having died or moved away). It includes trying to live without the driving privilege after becoming accustomed to driving. It includes a new job, or an old job in a new workplace. In any of these situations, the survivor relies on old ways of doing things, forcing them into the new situation. There is very little learning of new rules, new conditions, new expectations, or new ways of doing things. Reactions tend to be more impulsive, less thought-through, and more emotional than in familiar situations. Real problems can spring up due to the ways others are treated. The survivor develops a bad attitude over time, because it seems like nothing he or she can do is appreciated or right. Whenever the survivor has to deal with one of these changed situations, head-injured moments become much more likely.

The second kind of novelty that brings on head-injured moments is learning new behaviors or skills. For example, many survivors who are accustomed to the role of breadwinner have to adjust to the role of home-maker or caregiving parent. Obviously, a whole new set of skills is involved. The difficulty the survivor shows in making this adjustment is often written off as a psychological problem, but it is mainly a brain problem--a problem of frequent head-injured moments. Similarly, head-injured moments happen more often during and after training to perform a new job. If the survivor becomes ill or receives another injury, and has to make adjustments to some physical disability, head-injured moments occur around the disabilities. For example, survivors who must learn to use a wheelchair several years after an accident can have a great deal of trouble working it, aiming it, parking it, carrying things in it, leaving it in public places, and so on.

2. Overload.

When the brain gets too much stimulation, input, pressure, stress, or emotion, it begins to malfunction. This produces more head-injured moments than any other factor. For example, situations with loud, harsh noises (babies crying, dogs barking, children's high-pitched chatter and banging around, construction noises, the din of public waiting areas, and certain kinds of music) easily produce overload. Situations with bright or flickering lights, or lots of visual chaos

and confusion produce overload. Situations that require dealing with too many things at one time produce overload. Pressure produces overload, particularly pressure to hurry but also to decide correctly, even if it comes from inside the person. Any strong emotion can produce overload, even the positive emotions like joy, enthusiasm, and excitement. People who have always had temper problems often have special difficulties with anger and the related emotions like irritation, resentment, annoyance, and rage. Being put on the spot, whether it's being asked to remember something or to explain something, can sometimes overload a survivor. During overload, the problems, and the kind of head-injured moments the person has, depend on how much overload there is. At the lowest level, overload just overtaxes the brain, causing it to think slower and at the same time to react more impulsively. As overload gets worse, it begins to affect memory and awareness, eventually causing the mind to blank out. People forget what they were talking about. They forget everything they normally know. They become confused and bewildered. And at the most extreme level, they panic. Overload can bring on a full-fledged anxiety attack. Nothing can be done properly under overload--it is a sure cause of head-injured moments.

3. Extra Effort.

When adults and adolescents have to do things that are difficult, they naturally make more effort. A task can be difficult because the behaviors themselves are hard to do, like learning to play the violin or to steer a hang glider. Or it can be difficult because it has to be performed very well to be acceptable. In this way, competitive activities (sports, other contests, the performing arts, public debates, dares) are always difficult to learn, and they remain difficult for everyone except for the talented few who can easily dominate everyone else. Building or making things may need to be done perfectly to be acceptable, as in heart surgery, sculpture, or diamond cutting, and to a lesser extent, in more ordinary crafts, repair work, home remodeling, and so on. Other activities are difficult because an error can kill, including driving a car, piloting a plane or boat, using various machinery, firing a weapon, handling dangerous animals, getting around in high places like mountain tops, using potentially deadly drugs like heroin or morphine, and so on. Still other activities are dangerous because a mistake is unacceptable, for example, driving in front of a highway patrol car, doing your job while the boss is watching, handling valuable items borrowed from others, or being asked to show that your skills in front of a crowd. In addition, the situation in which a normal activity is performed may make it difficult--like trying to fly a kite on a very windy day, or surf in storm breakers, or even walk across a rocking boat or a moving bus. Finally, some people feel it necessary to do everything well and cannot tolerate any kind of defective performance out of themselves--the more active they get, the more they risk headinjured moments. When doing things that require extra effort, survivors tend not to raise their level of effort. By effort, I am referring first to mental preparation, focusing the mind, concentrating, thinking through what you are going to do, and working out the fine details. I am also referring to summoning up both mental and physical effort to gain maximum control of your thoughts and movements. Survivors behave according to their well-established habits. If they are in the habit of making a lot of effort, they still do that. But whenever something unique to the moment calls for extra effort, they don't do that. Any activity that involves dealing with unexpected surges of difficulty can be expected to produce head-injured moments.

4. Mixed Feelings.

Everyone has difficulty with performing adequately when their heart is not completely into what they are doing. If you are doing a task for your boss or teacher, and you hate him, it is hard to do your best. If you are trying to do something well but struggling with the desire to quit and go home, it is equally tough to do well. If you know what you should do, but you are tempted to do something you shouldn't (drugs, alcohol, sex, and so on), that temptation can either distract you from what you are trying to do, or you can give in to it, and abandon what you are supposed to do. However, a person with a factory-fresh brain, recognizing the conflict, can summon up enough mental effort to fight off the temptation, quell the mixed feelings, and finish the task well. In head injury, this extra effort is not summoned. Situations of mixed feelings are ripe for head-injured moments.

5. <u>Fatigue</u>:

You probably have a good idea of what fatigue does to your loved one. The fatigue that comes of a lack of sleep makes everything the brain does less effective. In fact, fatigue makes the person act more like he or she did earlier in recovery. Fatigue produces more impulsivity, more safety problems, poorer self-control, disorganization--it is the enemy!

Your loved one may well resist the idea of living a lifestyle that preserves adequate rest-going to bed as early as a school child, avoiding caffeine, and avoiding arousing activities before bed. If so, this of course gets handled through the self-therapy system, by keeping track of all the ability problems that occur on days of too little sleep. It is even a good idea to make up a graph, comparing performance on a day of good sleep with that on a day of short sleep. The person will be shocked at how strong the fatigue effect is. But if your efforts to work the program don't produce instant agreement and habit change, stick to the program and keep collecting the evidence that fatigue needs to be managed better.

The second kind of fatigue, short-term tiredness from repeated or sustained effort, is more difficult simply because the survivor often does not realize that he or she is tired. How quickly this fatigue can hit is shocking. After a severe injury or a focal frontal or brainstem injury, fatigue can set in after less than a minute of full-bore concentrating. It comes on even faster if the person is working under tension or worry. Even after a milder injury, fatigue effects can appear after a few minutes of full concentration. The survivor needs to learn to recognize the symptoms of effort-related fatigue, and to anticipate them, so that activities can be staged with enough rest breaks. Often in doing training exercises I find that early trainees refuse the rest breaks they need. I let them refuse, but before we resume I mention that they will probably regret not taking a rest, and then come back to that point after the next action if fatigue has degraded it.

6. Other Body State Problems:

In the same way that the mind misfires when tired or overloaded, it also misfires when the body is in bad shape from not being taken care of in other ways. During illnesses, headinjured moments become more likely, especially when there is a high fever. It has also become apparent that allergies tend to distract the person's mind and produce more head-injured moments. Malnutrition is a problem which is easy to fall into because the survivor does not always feel as hungry or notice the feelings of hunger when busy with something else. The same goes for dehydration. Some health food nuts claim that eating a bad diet of junk food, sugar, and soft drinks takes more of a toll after a head injury than it did before. Although there is no body of research on this question, my observations of patients in rehab suggest that these concerns are probably legitimate. Eating a well-balanced, healthy diet, including a good breakfast, and avoiding junk food, probably has some mental benefits.

CHAPTER FIVE: Figuring Out What Went Wrong

To have a good recovery, it will be important for the survivor to learn what the situations of error-risk are, so that he or she can go into them prepared to make the extra effort needed to get things done properly. At this point, you can help by studying your survivor's list of headinjured moments and helping him/her to see the patterns. Each individual has his or her own signature situations of vulnerability--certain emotions that "get through to" the person, certain people who bring out the worst in him/her, and certain activities that are not handled with the appropriate caution and attention. The search for these situations, and the ability to see them as risky ahead of going into them, will become a part of self-therapy that goes on across a lifetime.

Whenever working together on an open-ended problem-solving task like this one, it is always a good ideal to ask the survivor to look for patterns first, and to carefully evaluate every suggestion he/she makes. Only then is it appropriate for you to suggest the patterns you have spotted. It is also a good idea to write down the conclusions you reach, both those on which you agree and those on which you each have different opinions. You might want to create a place to file this information by making a therapy notebook (if the survivor has not already done so) and creating tabs for "head-injured moments list" and "problem situations."

CHAPTER SIX: Memory Issues

Nothing should be simpler to understand than the memory problems most survivors have. Unfortunately, the word memory refers to several very different brain functions, only some of which are affected by TBI. This becomes clearer if you think about the problem being one of learning. Making new memories, ever since the time of the injury, is the biggest problem. It can be done, and it can be done well under certain, limited circumstances, but many learning tasks create real problems. New learning is also needed to remember what you did on a certain day or at a certain time and place (also called episodic memory) and what you plan to do at certain days or times in the future (also called prospective memory). There are two problems with new learning. First, the mind can now learn only smaller chunks of new information. And second, memory is less reliable--things that you tried to learn are more likely to get forgotten.

The simple answer to this problem is, if you need to learn new information and remembering it accurately is likely to be important, write it down, and put it someplace where it will be easy to find when you need it. In a later chapter, we will talk about specific strategies that allow survivors to do this. But for the moment, it is important to realize that doing self-therapy requires some learning, and that everything that needs to be learned for this purpose should certainly be written down and filed in the therapy notebook.

Notice that problems with memory for events from the pre-injury past are not expected from TBI. Occasionally, a patient who suffered a heart attack or breathing problem during the accident shows serious problems with this kind of memory, because the supply of oxygen to the brain got cut off (also called anoxia). But most survivors have very little difficulty with these "old" memories.

When you observe your survivor failing to take proper steps to write down information, you have a choice in how to respond. First, you can remind him/her of the information that is forgotten, either by providing it or by giving clues and cues. If you do that, you not only make him/her dependent on you, but you take away opportunities to recover. That is the last thing you should be doing, although most family members frequently do just that. Second, you can remind him/her to write down the information. That is okay for the first two weeks of a self-therapy program, but after that it is recommended that you stop doing that. Again, you are doing the crucial part of the mental work for your survivor. When family members give these reminders, survivors don't learn to remember on their own. Finally, you can draw the survivor's attention to the consequences of having not written down the information. When the information is needed, you can point out that there was an opportunity to write it down that got missed. And you can refuse to "rescue" your survivor by providing the missing information. Every time he/she misses out on something desirable because of failing to write it down, it provides a better understanding of how serous the problem is, and more incentive to use the necessary strategy the next time. This is one place where "tough love" is not just important, but essential.

CHAPTER SEVEN: Figuring Out How Big the Problem Is

The bigger the injury, the more self-therapy is needed to recover. The bigger the injury, the more effort needs to go into the self-therapy, and the more disability there is if the effort is not made. Survivors with bigger injuries need to become much more careful and thoughtful, or pay a huge price in disabling head-injured moments. Survivors who think that their injury is minor when it is major never make enough effort to correct it. A good recovery depends on knowing the situation. Getting life under control depends on knowing how serious the injury was.

In order to understand the seriousness of the injury, the survivor needs to have the facts. Does he/she know how long the coma lasted? That information should be written down. In fact, there should be a section in the notebook for "facts about the injury." It should have the date of the injury, the length of coma, the size of the memory gap surrounding the accident (also known as post-traumatic amnesia), the length of time spent in the hospital, and the damage shown on CT and MRI scans. Many families have all of this information saved in a folder, but that is not always done. If you don't have copies of the medical record from the hospital stay, and don't have this information in particular, then you should contact the hospitals where care for the injury was provided and arrange to get copies of the records. Some hospitals are very cooperative and helpful. Others seem to go out of their way to make it difficult, and require many phone calls and visits to get the records. However, the hospital has a duty under the law to provide a copy of the medical record to the survivor once the survivor asks for it, so don't back off until you get those records.

Most survivors find the facts about the length of coma to be surprising and shocking. If two hours of coma defines a severe head injury, then one day of coma is twelve times as severe, and ten days is one hundred and twenty times as severe. And the fact that the survivor needs to recognize is that this number is set in stone, and really does measure how much the injury can be expected to change the survivor and how hard life is likely to be (unless there is a good recovery). You may well find it hard to accept, too. By all means, read up on length of coma with the survivor, as I suggested in Chapter One. Discovering that the injury is a Big Deal simply tells you that recovery needs to be an equally Big Deal.

CHAPTER EIGHT: <u>At the Crossroads of Recovery</u>

With the survivor having now read enough material to understand the basic challenge that recovery represents, the self-therapy manual calls for a personal commitment. Unless a commitment is called for, survivors pretend that they are working on self-therapy when they are not. Is the survivor going to make a genuine effort to start doing self-therapy? If the answer is "yes" the program moves on to its third stage. If the answer is "no" the program is on hold, no matter what else the survivor (or you) might do. Again, it is imperative to be realistic.

The commitment toward self-therapy that is asked here is to work hard on the list of head-injured moments. A cheat sheet that reminds the survivor of which behaviors to include in the list is also provided at the end of Chapter Eight. A person who chooses to make a real effort toward self-therapy will (1) commit time to look at the self and work on recovery; (2) commit effort to notice more of these moments and to write them down; and (3) commit to accept the length of the list of head-injured moments as evidence of seriousness about recovery. This is the first of a series of commitments required for a basic program of self-therapy, but without a commitment to search for head-injured moments, the rest of it does no good.

Of the chapters presented so far, this one is the most important chapter for family discussion. *Who* is prepared to make a commitment? This is not just a question for the survivor. This is a question for the whole family. Who is willing to support this effort through their actions? How much of a commitment are you willing to make? Is anyone else willing also? As discussed earlier, in some families the survivor is not going to make any commitment, so the only commitment will come from family.

This is a good time to have a short talk about recovery. Is it important to anyone to improve the quality of day-to-day life? Is it worthwhile to invest effort toward a better future?

The survivor may be reluctant to commit because commitment doesn't seem necessary. A brief review of the basic facts is in order: (1) How serious is this injury? (2) The disabling effects of the injury are permanent, unless there is self-therapeutic recovery. (3) 90% of the survivors of severe injuries end up unemployed, socially isolated, and needing some amount of supervision. (4) Most people who commit to recovery through rehab programs end up employed, socially involved with friends, and needing no supervision.

A hidden obstacle to recovery that has not been discussed up to this point is disability benefits. It is virtually impossible for people to recover when they are paid for being disabled. The research suggests that people recover vocationally only if they can make half again as much money working as they could on disability, which is rarely the case in TBI. Now is the time to consult with a disability attorney to find out what is likely to happen to those payments. Most survivors of TBI end up losing their benefits, but talk to an expert on the disability system to find out what you can expect. Once you know the truth, that knowledge alone may be enough motivation for self-therapy. But it is also possible that you may need to put your self-therapy materials in a file cabinet and get them out again only after the payments have stopped.

In other families, especially those who have been dealing with disability for many years, the obstacle may be a lack of hope. People become used to disability after years, which may undermine their confidence that they can recover. There may be help for that obstacle in the inspiring recovery stories that are posted on the GiveBack Web site. Beyond that, it is important to emphasize the fact that recovery depends on two things: effort and structure. Both of those things are not "abilities" or "gifts" but decisions. Anyone can decide to recover.

The most basic strategy for taking control of life is to make only those promises one intends to keep. Each time you make a promise, to yourself or to others, and you keep it, you feel more self-pride and self-control. You come closer to being able to think of yourself as a person who does what you say you are going to do. It makes you stronger. Each time you make a promise to yourself and then don't come through, you lose self-pride and become less able to control yourself. You become more willing to let yourself off the hook, to do what you feel like doing, to choose not to honor your commitments. You think of yourself as a person who is all talk. It makes you weaker.

This program is intended to provide a fresh start, for your survivor and for you. Neither of you should make any promises that you do not intend to keep. It is the very act of keeping the first commitment that makes a self-therapist able to keep the next one, and the next one, until the final commitment (which is never to allow a preventable head-injured moment to happen) becomes the self-healing force of recovery. By keeping your commitments you provide the survivor with a role model for doing what you say you will do. So think hard about how much of a commitment you are willing to make, and when you know, tell the survivor what he/she can count on from you. But you should also know that your survivor is unlikely to make a major commitment if you are only willing to make a minor one, or a commitment to help "when I have the time." A good recovery requires considerable self-sacrifice, on the part of *both* the survivor and the family, and a great one requires everything you have to give.

In many families, recovery will not be the top priority, for the survivor or for other family members. When a limited commitment is made, it is still possible to make limited progress. But it is imperative for you to be aware that the amount of recovery is a function of the amount of effort committed. In a program of limited effort, the survivor can be expected to learn some strategies for coping with head injured moments, and to put them into practice occasionally. The main benefits of self-therapy come from a disciplined approach to thinking and acting, and a casual approach does not produce discipline.

If the reader is a family member who feels a great desire to make recovery happen but has very little time to give to self-therapy because of the time commitments to earn a living and to perform other tasks of family survival, my best advice is to translate your desire for recovery into efforts to find someone who has the time and the willingness to help out. Make an effort to bring a relative into your home to become the primary therapy helper if you can. Ask for help at church. See if a local college will let you advertise for a student helper. It is rarely easy to find a source of reliable hours of help, but you have a lifetime in which to arrange it.

CHAPTER NINE: <u>Taking Control of Myself by Keeping Promises I Make--The Action</u> Window

The action window helps the survivor to keep the promises made to self, overcoming forgetfulness and the tendency for the mind to get distracted or to wander. You cannot change your life, or take control of your life, if you can't remember what it is you need to do first. You need a way of keeping that goal right in front of you, to give the chance to stay focused. That is what the Action Window is all about. If the first goal of self-therapy is to keep the commitment to notice and write down head-injured moments, then that is probably the first goal that should go into the Action Window.

The Action Window only works if it grabs your attention. That is why buying and mounting a dry erase board is suggested. A note that is taped up on a wall or written on a calendar is too easy to overlook and ignore. A brand new dry erase board, put in a location where one has never been, will grab the eyes and seize the attention. And if you use it as a reminder of important things, it will keep doing that even after it has been in your home for months.

The Action Window has to have only one goal on it. If it has two goals, it will not GRAB attention, and by dividing commitments, it will not PUSH for action. There can be only one goal. It must stay up there until it has been met, or until a more important goal is found.

Some people find that this approach to be so helpful that they get a second dry-erase board and put a whole list of goals or activities on it. That's fine. Just make sure the Action Window is kept clear of clutter and used only for the purpose of reminding self about one goal.

Strategically, the Action Window should be mounted in the place where the person spends the largest amount of daytime. For example, many people hang out in the living room during the day. Some families are reluctant to put a dry erase board on a living room wall because it spoils their décor. While this is understandable, a family that makes this sacrifice is making a huge statement 24/7: This family is committed to recovery, and our lifestyle is different now--it's built around recovery! You cannot ignore that kind of evidence of commitment, and your survivor can't either.

If your family organizes regular self-therapy meetings (Chapter Twenty-Three), one topic that should probably be on the agenda of each meeting is the Action Window. The family should discuss how the message is working, how it can be made to work better, whether the current message has fulfilled its purpose, and whether or not a new message might be more useful.

CHAPTER TEN: Keeping Appointments and Arrangements Yourself—The Appointment Book

Beginning with this chapter, the next four chapters discuss the four primary purposes of planning and using a daily schedule system. The daily schedule is filled out in advance, followed (or adjusted and then followed) as a guide to what to do on that day, and used afterward as a record of what got done. To put it bluntly, good recoveries require using this system, for the reasons that are explained in these chapters. But your survivor's daily schedule will have considerable effect on your life also. If you work with the daily schedule, you can help him/her to develop and refine the habit of using it to gain control of his/her life. It may annoy you to have to conduct your own activities that involve the survivor through a written schedule, but by supporting the schedule, you can make a major contribution to recovery.

This chapter concerns making and keeping appointments. By appointments, I am referring not only to doctor's and other professional appointments, but also arrangements with friends and family to get together at certain times, and arrangements to attend activities that occur at a certain time.

If yours is like most families, you are probably the appointments secretary for your survivor. You make the appointments, you take home the appointment cards from the doctor or clinic or write down the appointment, you put it on the family calendar, and you tell the survivor when the day comes where and when you need to be there. The survivor is reduced to functioning at the level of an eight-year-old child, a senile adult, or a flaky husband. If there is to be a decent recovery, this needs to change.

The survivor needs to begin keeping appointments him/herself. This means having a place to write them down, whether they are made in person in the community or on the phone. It means remembering to write them down. That will only begin to happen after family members who accompany them make it clear that the family member is no longer going to do anything to keep track of the appointment. It is probably best to establish that, and to set a new strategy for the survivor, in a family meeting held ahead of time. If the survivor accepts the need to write information down consistently, then the family can consider what the survivor is going to write them down on. Most of my patients learn to carry a pocket notebook or pocket pad for making notes while in the community, and also learn the habit of transferring the information from the pocket pad to the daily schedule book (or family calendar or both) as soon as they get home from the trip into the community. If the survivor is to become reliable at keeping track of the appointments, it becomes important to check the day planner or calendar at least once a day to keep track of upcoming appointments, and to plan accordingly. If the survivor is so forgetful that checking the day planner once is not enough of a reminder, it may be necessary to set an alarm clock (or alarm watch), put up a reminder note, or quite possibly both so that the appointment is not forgotten during the day it is supposed to be kept.

What should you do if the survivor does not agree to use all of these strategies, or uses them in a half-hearted and ineffective way? Should you let him/her miss the appointment as a

lesson? My recommendation is to do exactly that unless the appointment is an important one. Then the decision not to use proper strategy can go down on the list of head-injured moments. If it is something that is not crucial like a haircut appointment, you certainly should leave it up to the survivor to keep it or break it, and then encourage him/her to learn from any mistakes. When this responsibility is handled in this way, almost all survivors learn to take care of their own appointments.

CHAPTER ELEVEN: <u>Structure and Productivity—The Activity Routine</u>

This chapter begins by pointing out how much difficulty survivors have in organizing and making productive use of their time. Head injury makes people into time wasters. The simple solution is to organize the use of time. That is done with a day planner. If you take time to plan out what you need to do, and make sure to put each task into your schedule when it comes to your attention, you can expect to get a lot more done.

Some people are naturally organized. They make lists of the things they need to do. They write out schedules when they are in school, and some even write out schedules for their time at home. We call these people "compulsive" and laugh at them. But when they get a head injury, they excel in their ability to be productive because they know how to structure their use of time. I have never seen a student with a severe head injury finish college without failing out without using a day planner.

Most survivors are not compulsive by nature. They are not used to filling out a daily schedule, and they are certainly not used to following it. One of the very few joys of being disabled is your freedom to do whatever you choose to do each day, even if there are no good choices. In order to recover, the survivor must give up this freedom.

The most effective recoveries usually have a strong daily structure. The survivor does not sleep in, or wake up whenever. Instead, there is a specific wake-up time each day, and it is almost always early in the morning, just as a person working at an ordinary job would do. Rather than to lounge around the house for a few hours taking it easy, the survivor gets out of bed and goes through the morning routine, washing, grooming, dressing, having breakfast, and being ready to do useful things by 8 a.m. If the person is not working, home life also tends to have routines built into it. The survivor might clean up the kitchen from breakfast, then do physical exercises, then work on therapy activities, then take a walk. After lunch, the daily routine might call for chores or for personal projects, cleaning, shopping, walking the pets, writing letters, and so on. But as much as possible, life would be based on a routine. Once the survivor became accustomed to that routine, things would work smoothly, and things would get accomplished. In addition, a routine like this provides the framework on which a program of high-intensity self-therapy can easily be organized. A day that is spent doing things in this way does not seem like a day that was wasted. There is a sense of accomplishment.

For people who are spontaneous and unstructured by nature, accepting the importance of developing a structured routine, and adjusting to it, may come slowly. It may be helpful to talk to other survivors about this, on a chat room or through a Web site like GiveBack that has a discussion board.

If you are willing, you may be able to encourage this habit by structuring your own day more. If you are also a spontaneous, unstructured person, you can share your feelings of struggle with the survivor. But if you are willing to do it, he/she may be more able to see the point.

There are three practical problems in following a schedule that you will probably need to cope with. First, because the survivor is not going to be able to remember the whole schedule, the actual schedule form has to be present wherever the survivor goes. It is a good idea to keep the forms in the therapy notebook to keep them organized, which means that the notebook has to go with the survivor into the community, on visits, on vacation trips, and so on. At first, this may be a difficult habit to get into, as it may seem inconvenient to carry a notebook everywhere. There also may be a problem in leaving the notebook behind when returning home. But these minor annoyances can be worked out quickly. The survivor needs to learn to only put the notebook down in plain sight, and to look around for his or her possessions every time he/she leaves a public place, which will always lead to retrieving it for the journey home.

The second practical problem is knowing when an hour has ended, and the time has come to move on to the next activity in the schedule. A person with a factory-fresh brain is equipped with enough of a sense of the passage of time not to have to worry about this, but after a head injury, these signals are easy to ignore, and the survivor can do something for three or four hours after the schedule called for it to end. You cannot organize your day if you keep running that far over your scheduled times. So to the extent that this is a problem, it is helpful to have something that will signal the new hour. Most digital watches have the option of a chime that sounds on the hour. Cuckoo clocks sound the hour. Some digital organizers or PDAs can be programmed to sound on the hour. Any of those pieces of equipment solves the problem. I always recommend the digital watch because they are cheap and fairly easy to use.

The third problem is being willing to stop when the hour is up and move on to the next activity. Again, it is a matter of keeping your day organized. If you write down a schedule and then don't follow it, it doesn't do you any good. In the first few weeks of working with a schedule, it is often clumsy to use because the survivor does not plan enough time to get tasks finished, and has to plan a second session to finish up. However, after working with scheduling for a few weeks, most survivors become much better at estimating how long it takes them to get things done. This knowledge comes in handy in many ways, not just for scheduling.

Any mistakes in schedule-making or schedule-following should be added to the list of head-injured moments.

CHAPTER TWELVE: Memory for Daily Events—The Activity Diary

"What did I do yesterday?" "Did I order that birthday cake?" "Did I pay the bills?" "Did I give the neighbor back his ladder?" How often are you asked questions like these? How often do you *answer* them? If you answer them, you have become your survivor's auxiliary memory, and he/she doesn't have to deal with his/her weakened memory.

The basic principle applies here: If the survivor needs to remember something, it should be written down. If he/she wants to live a life that includes a "yesterday," there needs to be a written record of the things that were done yesterday. Some therapists advise survivors to keep a detailed diary, and that is not a terrible idea. But why do that if you are already making a detailed daily schedule, and the schedule includes a record of all of the things you did. Just be sure to keep your old schedules. Keep them in an organized manner and in a place where they are easy to find. If using the forms I provide in the self-therapy manual, they can be kept in the therapy notebook, and when they are a month old, they can be transferred to a file folder in a file drawer. Do that, and you have a complete past, a well-kept record of what you have been doing and when you have been doing it.

This procedure only works if the survivor follows the schedule. Now, it would be very uncomfortable and impractical to be locked into a schedule once it gets written. So the scheduling procedure I have been using with my patients since 1991 allows them to make changes in the schedule at any time. The only condition is that when a decision is made to do something other than what is already scheduled, the change is written onto the schedule form, and the thing that got cancelled gets moved to an open slot later on. This keeps the record accurate, and makes sure that everything that needs to get done actually gets done.

This schedule not only records what the person does, but has a column on the right side of the paper in which to record the outcome--success (goal met), failure (goal not met), incomplete activity, and any problems that have occurred during the hour.

Most survivors who take up using the schedule try to use it in the way a person with a factory-fresh brain might--by looking it over once, and then checking it only occasionally if memory fails. Some patients who don't take the task seriously only filled it out after the day was through, so that they would have something to show their therapist at the next session. These approaches simply don't get the job done. It is important to learn not to rely on memory, especially if the entries for success/failure and extra problems are going to be filled out accurately. It usually takes about two weeks of careful attention to build the habit of checking the schedule every hour and writing in the outcome of the previous hour. Most patients need family help to get this done during those two weeks. Once the survivor realizes that you are serious about checking and marking on the hour, he/she will probably pick up the habit, and from then on be able to do it on his/her own.

CHAPTER THIRTEEN: <u>Using The Daily Schedule as a Planning Technique</u>

The damage to the central executive network has a particularly strong effect on planning, since most plans for unfamiliar activities or events are made through the network's processes of anticipating and problem-solving. Planning can be made effective by stopping, thinking, concentrating, calling up mental effort, and then working out the details step by step.

A daily schedule can be transformed from an appointment calendar, an activity diary, and a time organizer into a planning tool by simply arranging to routinely fill out the entire schedule at least twelve hours in advance. Most of my patients used the time just before or just after dinner to fill out the schedule for the entire next day. It took some of them an hour to do, while others were able to finish in half an hour.

To be done properly, there should be an entry for each hour block from wake-up time to go-to-bed time. The entry should be as specific as possible. Scheduling begins with fixed responsibilities. A certain amount of time is set aside for the morning routine. Your family may eat certain meals at specific times, which means helping with clean-up and dishes at certain times also. Appointments and classes at school are put in at this time. Then meals that can be eaten at various times now get plugged in. Sessions for self-therapy are scheduled next, along with other chores that can be done at various times, as well as shopping trips. Exercises for conditioning or long-term physical therapy are scheduled here as well. Now the schedule contains everything but free-time activities. If the survivor has an extremely severe injury, almost all of these items may be set at the same time from one week to another, so a basic schedule that includes all of them can be xeroxed.

To put in free-time activities, it may be useful to make a list of activity choices. It is difficult for survivors who have lost the ability to drive and been abandoned by their friends to think up things to do. So this list can be a valuable resource. It should include every activity he or she has chosen to do, and any activities that are available but have not been pursued. It should go beyond the typical recreational activities (TV, music, video games, surfing the net) to include as many activities as possible. For example, there should be a list of different web sites that offer different kinds of activities and information. Although I have not played chess on Yahoo for two years, I would include that in my own activity list. With a little effort, you should be able to come up with a decent list, and you can add to it when new activities are discovered. This list can then be used like a menu to pick out free time activities to fill the open spaces in the daily schedule.

Why schedule free time activities? There are several reasons. First, it improves organizational skills and adds structure to daily life, which improves thinking and awareness. Second, it pushes the person to think about how best to spend free time, instead of just flipping on the TV and vacuum viewing for hours, which is what most survivors do. Third, you can look to the priority list discussed in the last chapter to see if the free time choices are good ones. If the person has put spiritual first but spends no time in praying or talking to God while spending four hours watching the tube, that deserves re-thinking. Is spiritual really that important? If so,

shouldn't it be a part of every day? If physical conditioning is high on the list but there is no time set aside for exercise, something is wrong with the day plan. This process allows the person to at least have an opportunity to make good decisions about his or her activity commitments.

If your survivor does not fill out the day plan, can you do it for them? The answer is no. The day plan is a planning activity--for the survivor, not for you. And a plan filled out by another person is not going to be followed, certainly not willingly. The survivor has to fill out the plan. All you are permitted to do is to encourage them and, if they want it, to assist them in getting it organized. At first, most rehab patients do not like doing this. It is not something they did before, and they don't recognize its value. We ask them to do it anyway. It is only after doing it for awhile that many of them come to realize how much it helps them.

CHAPTER FOURTEEN: Controlling Overstimulation

We have already discussed how overstimulation makes survivors extremely prone to head-injured moments. This chapter discusses what to do to prevent them, and what to do to control them if they start to occur.

The best way to prevent overstimulation is to anticipate it ahead of time. When making up the daily schedule for tomorrow, the survivor can figure out that a certain setting where he/she is going to go is usually overstimulating. For example, if the schedule calls for a visit to the home of a friend with a young baby, overstimulation should be expected and steps should be taken to prevent it. In that example, buying a pair of earplugs for reading (soft foam plugs that cut down noise without blocking it out completely) in a bookstore or drug store can equip a survivor to go into a noisy environment with little or no risk of overstimulation.

Suppose the schedule calls for going to a setting where he/she is likely to meet a person who is very annoying. That makes it possible to plan ahead to deal with the problem. What can the survivor think about when that person comes around that will prevent becoming annoyed? (My mother used to suggest picturing the person in their underwear. I like to suggest picturing them with a flowerpot on their head or wearing a football helmet.) The idea is to do something to get rid of the annoyance. That way, when the person shows up, the survivor is taking steps to control the situation rather than to be controlled by it.

If the schedule calls for an activity that makes the survivor nervous because he/she puts so much pressure on self, the answer is to make a deliberate effort to set lower goals and be more relaxed about it. Stress can always be controlled by being more patient with yourself and by allowing yourself the freedom to be less than perfect.

Survivors often feel overloaded when someone asks them a question that puts them on the spot to remember something. There are easy ways to be prepared for that. One way that works in some situations is to refuse to answer those questions, or to prepare a humorous answer. Another way is to refuse to answer quickly--to take a thoughtful pose or to simply say, let me get back to you on that, if it is appropriate to the topic being discussed. A third way is to be ready to excuse yourself to go to the bathroom, get some fresh air, take a smoke break, or some other social excuse, if the conversation suddenly creates that kind of pressure. One of the simplest things you can do to relieve overload is to simply label it. Survivors who are experiencing the symptoms of overload usually don't realize that it is overload. Once they label it, it loses a lot of its threat. If you say to yourself, "This is overload, and all I have to do is chill for a moment, and I will be fine." that sentence can work miracles. Taking a deep, slow breath can also help.

Overload has a snowball effect: The more often it happens to you, the worse it gets. Controlling overload has the opposite, snowball effect: The more you learn to control it, the less it bothers you and the easier it becomes to control. With good self-therapy, overload soon turns from a monstrous, crisis-level problem into a minor annoyance.

As a family member, the first thing you can do is learn to recognize overload. What makes it obvious is that the survivor *suddenly* becomes unable to think straight. Thinking slows down, easy-to-remember information is forgotten, and much more impulsive or clumsy headinjured moments begin to occur. The survivor might even admit to forgetting his/her train of thought in mid-conversation. The second hint is, what happened just before this mental lapse happened? Did something happened that produced stress, pressure, or strong emotion? Soon, you will learn to recognize a subtle look that the person gets when a moment of overload hits. You will probably become able to see it every time it happens.

The second thing you can do is to help the survivor to recognize and label it. A group of patients with whom I worked closely for several years adopted the pet nickname of "fishbrain" for overload. When I saw the look on one of their faces, I gently asked, "Did you go into fishbrain?" Soon they could all identify it as soon as it started.

The third thing you can do is to encourage the use of the corrective strategies. If the problem is emotion, the answer is to calm down and back off of the feeling. If the problem is stress, pressure, anxiety, or tension, the answer is to chill out and ease up. If the problem is too much stimulation in the environment, the easiest answer is often to move the conversation or activity to a lower-key place.

By the way, noises that don't bother you can produce overload in a person who has a focal injury to the temporal lobes. One of the most annoying and disturbing kinds of stimulation to those who have a left temporal injury is being in the room when more than one person is talking at the same time. The best answer is usually to get out of that room.

CHAPTER FIFTEEN: <u>Increasing Mental Effort</u>

The closest thing to a cure-all for head-injured moments is to develop the habit of stepping up the level of mental effort deliberately. Everyone knows how to do this, but we usually rely on our brain to make effort adjustments for us automatically. That simply does not work after a severe head injury. The injured brain does not realize when a task is extra-difficult or extra-critical, does not understand that the mechanism to cope with those moments is broken, and so produces head-injured moments by acting too casually and carelessly when better thinking is clearly needed.

Even when training people to step up their level of mental effort, we find that they don't increase it enough at first without being reminded again and again to do so. So self-therapies that make them aware of the issue, that focus attention on how much mental effort they are making, that require a high level of mental effort to be done properly, help to build awareness of the problem and a readiness to crank the levels of concentration and think-through up to the top of the scale.

You can be extremely helpful in this process. First, you need to start thinking about mental effort, because it is something we all take for granted. Look at the tasks the survivor is doing. How many of them are non-critical? How many involve familiar activities and not particularly high standards of performance? Taking out the garbage doesn't require much thinking, and even if you do it wrong the first time, you can always pick up any unexpected mess and toss it away with no harm done. How much of the survivor's life style even requires high quality thinking right now? Then look closely at any critical tasks the survivor does perform, seeing how much mental preparation and planning go into it. Is he or she totally focused at the start? Does he/she think harder when there is an unexpected turn of events? The head-injured moments that come out of not making enough mental effort are extremely valuable. They are the mistakes that could teach the person the most important lesson in how to run his/her new brain, if only they got noticed and carefully examined. These are the ones you want to make sure he/she notices. These are the ones you want to discuss, so that he/she begins to learn how often making too little effort causes a problem, and how much good it does to crank the effort level up.

In my rehab programs, I often used money bets to prove my point about mental effort. I would challenge a patient, pointing out that they performed a task poorly, and guaranteeing them that they couldn't do any better. When they protested, I would bet twenty-five cents that they couldn't raise their score. A lousy quarter doesn't seem like a big deal, but when you make a bet like that in a group of ten patients, it becomes a matter of saving face to win the quarter. One of my patients put my quarter in a frame; she showed it to me 14 years after she won it. And she had a world-class outcome. When you place a larger money bet on a task, you create enough extra incentive to raise the effort levels very high, enough to overcome almost anything a head injury can do. And once the person wins the bet, it provides an excellent opportunity to discuss what it means to be mentally effective only when money is riding on it. This can be a wonderful opportunity to get across an important lesson about how necessary increased mental effort has become.

CHAPTER SIXTEEN: Better Living Habits to Help My Brain Work Better

In Chapter Four, we discussed how being careless about nutrition, health, and hydration can bring on head-injured moments. Healthy living--getting enough rest, avoiding stress, and getting regular exercise, also appears to benefit brain fitness and thus to reduce the frequency of head-injured moments.

Families often share a particular health lifestyle. If you are a fast food family, this would be a good time to reconsider those ways. If you are not particularly health-conscious in your own life, you might want to set a different example for the survivor.

When you or your survivor are discussing head-injured moments, be sure to check out the relationship between the state of physical health and vitality, and the way the brain is working. There will be an obvious relationship between getting tired and having more head-injured moments. In TBI, there is a kind of exhaustion from performing a mental activity repeatedly for many minutes that can be relieved either by taking a short break or by simply switching to another activity and then switching back after a few minutes. But you also may notice that your loved one has a "low point" every day that is related to what--and when--he/she eats and drinks. That tends to be a very individual matter, so you will have to look closely at it to see how it may be affecting your survivor.

CHAPTER SEVENTEEN: Booze, Dope, Caffeine, Nicotine, and Other Drugs

Our society contains a wide range of attitudes toward alcohol and drug use. Some families strongly forbid both. Some are positive about alcohol, with the members drinking and allowing or even encouraging drinking by other members. Some are positive about certain drugs, some about drugs and alcohol, some about most or all drugs. Some families tolerate drugs, in others everybody gets high. Some families have members who sell drugs as a way to make a living.

People get all kinds of advice from doctors and other professionals. I have known physicians who permit or even encourage daily drinking, as long as it is limited to one or two drinks. I have known professionals who slyly encouraged smoking marijuana. I know at least one medical group who prescribes stimulant pills for every head injury patient. And many doctors hand out sleeping pills when asked for them, even though the research says that regular use of the pills only makes things worse. On the other side of the coin are professionals who discourage using anything.

I don't think there is anyone who doubts that using drugs and alcohol make life at least a little harder in some ways for every user. Alcohol and certain drugs make tiny holes in the brain, and even if you are only punching a few tiny holes in your brain every night, that doesn't sound like a particularly good idea. Both alcohol and drugs temporarily interfere with thinking, which increases safety and self-control problems while high or intoxicated and also increases headinjured moments the next day. The stupefying effect of alcohol clears up pretty quickly, but many drugs (particularly marijuana and ecstasy) stay in your system much longer and continue to pull down brain function. Marijuana remains active in interfering with the left brain for 24 hours, so a daily smoker never has a normal brain. Because it shuts down the left brain, marijuana interferes with motivation to work and achieve, leaving a stoned person content to listen to music, watch TV or movies, stuff cheeks or just veg out.

The second problem with drugs and alcohol is their potential to be habit forming. We all know that some people lose control of using, allowing it to ruin jobs, marriages, friendships, lifestyles, and even health. People try to understand these out-of-control habits in many odd ways, but it comes down to saying "no" to feeling good. Some people choose feeling good in preference to everything else; for them, to choose not to feel good simply does not work. A good way to think about problem use is this: the more important the things a person gives up in exchange for feeling good, the more serious the problem is. We also know from experiences with AA and other treatment programs that these same people can learn to say "no" to feeling good, although many of them pay a terrible price before they come to that.

The risks of alcohol and drug use after brain injury are serious. Among the former patients who have good recoveries, none of them is a user of drugs or alcohol. Perhaps that is the best bottom line on this issue. The price paid for using after an injury is giving up a shot at a good recovery. Some people who drink have been able to hold minimum-wage jobs. Some who smoke have been able to keep friends. But that's the best people have done. There are also

some issues that are more serious. After a head injury, intoxicants hit harder, and thinking gets more screwed up. One of the key problems of people who have drug- or alcohol-related crises and tragedies is that they use at times when it is not safe to do so. The decision about whether it is safe to be high in a particular situation is hard enough to make before a head injury. After one, the survivor is more gullible, and can easily talk him or herself into believing that he or she can handle some booze or drugs while driving, working, or being in a dangerous place. Some of our patients have gotten second head injuries because they drove while intoxicated after the first injury. Some have lost jobs they loved because they got high and got caught. Our patients have also found that it is much easier to lose control of drinking and drug use after the injury. It is easier to get hooked, easier to become addicted, because self-control is reduced now.

What if you follow this advice and encourage your loved one to stop drinking and using drugs, while you go on doing it? Is that going to take away your credibility? Of course it is. Those in the alcohol rehabilitation industry generally believe that a sober program graduate can never stay sober if the husband or wife drinks, nor if the friends drink. To remain substance-free, a person must associate only with people who do not use. This problem runs very deep. We have worked with alcoholic patients whose alcohol-using parents give them permission to continue to drink after the head injury, in spite of medical advice to the contrary. I understand their thinking-recovery has been so hard for my son or daughter--at least let him or her have this tiny pleasure! In one case, it came close to costing the son his life--his one or two beers at home got out of control again, led to another DUI and almost a long jail term, broke up his marriage, and left him out of work and desperately depressed. A young lady whose mother was a serious alcoholic sat around the house for several years after leaving school, smoking high-grade marijuana and feeling no compelling need to make the effort to keep a job.

If you are one of those people who enjoys a drink or glass of wine at dinner, or just one slender joint afterward, should you have to give up this simple pleasure simply to set a good example for your loved one? How important is recovery in the big picture? A good recovery is terribly expensive--the family and survivor have to give up so many things to get one. Giving up drugs and alcohol is one of the up-front costs.

CHAPTER EIGHTEEN: <u>Dealing With Sleep Problems</u>

Survivors usually have sleep problems for several reasons:

- 1. They drink too much caffeine-containing beverages because the stimulation feels good after a head injury.
- 2. They don't get enough exercise.
- 3. They no longer wake up and go to sleep at a regular time, and this has fouled up their sleep-wake rhythm.
- 4. They received sleeping medication from a doctor and now they have become dependent on it, which results in restless and inadequate sleep.
- 5. They are depressed.
- 6. There is injury to the sleep system controls in the brain stem, or the communication lines to and from this part of the brain.

There is something to do about each of these problems, but each one calls for a different solution. Caffeine, which we discussed in the Chapter 17 of the self-therapy manual, is extremely tempting to most survivors because it makes them feel fully alive for a brief part of every day, but it also ends up getting them exhausted early in the day. If they drink too much, or drink it in the afternoon or evening, it can make them unable to get to sleep, and cause their sleep to be light and unsatisfying. So if sleep is a problem, you can start by gradually cutting out the caffeine. Don't stop cold turkey, because discontinuing suddenly produces terrible headaches.

Couch potatoes tend to have fitful sleep. Since there is another reason to recommend a program of physical exercise (See Chapter 16.), that is a good second step. An hour of walking or at least twenty minutes of more vigorous exercise, as allowed by the physician, is a good minimum level of exercise for a healthy lifestyle. This may also be a good time to set up a more healthy routine of waking up and going to bed at a certain time (See Chapter 11.)

If your survivor has been taking sleeping pills, they may be contributing to the problem. You should read up on this medication, and discuss the problem with the physician who prescribed the medication. If depression is a part of the problem, an anti-depressant medication can improve sleep. However, the diagnosis of depression in a person with a head injury is a complicated matter (See Chapter 60.)

Finally, some injuries produce permanent obstacles to normal sleep. Damage to the brainstem interferes with the signals that tell the body to go to sleep and to wake up. When this damage is a part of the picture, the person often shows a great deal of difficulty in waking up every day. Another kind of brainstem damage produces a breathing problem called apnea which can wake people up out of a sound sleep again and again. Apnea tends to produce terrible snoring, but to get a true diagnosis, you should have your physician refer your survivor to a sleep lab where they are equipped to diagnose the problem and try out treatment options.

Regardless of the cause, sleep problems are improved by planning an hour of quiet time before going to sleep. That means no action movies, horror or suspense flicks, or comedy shows.

CHAPTER NINETEEN: Full Analysis of Head-Injured Moments

This is the second turning point in the self-therapy process. This chapter trains your survivor to use the most important tool for recovery in this program: the Analysis Form. This form is used to examine the head-injured moment in order to figure out what went wrong, why it went wrong, when it is likely to happen again, and what can be done to prevent it. Analysis Forms make recovery happen. They require time, effort, careful thought, and facing symptoms, but each one is a stairstep toward recovery—the more Analysis Forms a survivor fills out, the more recovery can be expected.

You will want to read Chapter 19 in the self-therapy manual, because it provides the detailed instructions in how to fill out an Analysis Form. If your survivor is willing, you should get involved at first, helping him/her to learn how to fill out the form, encouraging the completion of as many forms as possible, and critically reviewing and signing each form when he/she has completed his/her part of it. Once your survivor is filling out Analysis Forms on his/her own initiative, he/she is a full-fledged self therapist.

Since an Analysis Form is a tool to help the survivor to prevent head-injured moments, any time an analyzed head-injured moment is repeated, it calls attention to the fact that the first analysis was unsuccessful or incomplete, and requires a different, more thoughtful approach the next time. Errors that continue to be repeated despite analysis call for feedback and suggestions from family, and those that continue to be repeated even after family input call for feedback and suggestions from an experienced head-injury professional.

A copy of the Analysis Form is included on the next page for your reference.

ANALYSIS OF A HEAD-INJURED MOMENT 3.0: Analysis # _____

Where it started:	On what day?	At what time?
Who suggested writing up the	his head-injured moment?	
	at apply) excited optimistic enthusi	iastic confident motivated
	ated irritated angry furious jealou	
	d tense pressured afraid hungry t	
	couraged self-doubting pessimistic	•
	rushing disinterested other	•
	rted to make the mistake?	
Task factors: What was the	e task?	
I was trying to do some	thing new. What was new?	
I was trying to do some	thing hard. What was hard?	
	d organizing, careful timing, or mid-	
	eration, agreement, or assistance fro	om someone else.
Process factors : How I wer	_	
	nyself. It happened in a situation who	ž.
•	before, but I didn't use my fix-it pla	•
	before and used my fix-it plan but it	
	thing the way I would have done it I	
	o it at all—it wasn't on my daily plan	•
	happened while I was doing it. Wha	
I didn't take enough tim	ne to plan out what I was going to do	O.
	and being careful enough when I did	l 1t.
what are the main things I r	need to fix?	
Fix-It Plan for the next time	e I am in that situation:	
Put the activity on my daily planner and make a plan for success the night before.		
	d a warning by	
	ead-injured moment by saying	
	d by	
	nink through what I need to do.	
Get focused and summo	on up the mental effort to be ready to	o act.
What I will do:		
Watch how I perform ca	arefully to make sure my plan is wo	rking.
Feedback from my Therap	by Partner: I think the main things	that need fixing are
	Plan probably will work proba	bly won't work.
Signature:	Date:	

CHAPTER TWENTY: Summary of How You Fix Your Brain

Here is the summary provided in the self-therapy manual to explain how self-therapy works.

- 1. Know that you have a new brain, one that can work well once it is reprogrammed. It needs to be reprogrammed because your old programs don't run quite right on your new brain. Help yourself to keep this fact in mind as you go through your day.
- 2. Since your old habits don't quite work well enough, you need to TAKE CONTROL of your brain and get it to think through the things you are going to do. Your BRAIN no longer does its job well enough on automatic pilot. Now, your MIND has to make sure it does its job properly, whenever you do anything in which the results are important. Any time you need your actions or your words to have quality, your mind has to make sure that your brain produces quality at every step. It's as if your mind now has to be the boss. You need to be MINDFUL so that you can be an effective boss.
- 3. Don't depend on your brain's weak systems for organizing and memory to manage your time and your activities. Get your brain to use your full intelligence to plan your day thoughtfully, a day ahead of time, when you can think everything through well. Write that plan down on a schedule form so that you take no chances of forgetting what you need to do. Develop the habit of writing plans and following them, and soon you will be in total control of your time and your productivity.
- 4. Learn how your new brain works by studying your head-injured moments. If you study them carefully, they will teach you a great deal about your new brain. The more you become an expert on your new brain, the better you will be able to make it do what you want it to do.
- 5. By analyzing your head injured moments, you will realize that you make most of your mistakes when you are not mentally prepared. By writing a good daily plan, and by warning yourself whenever you are about to get into a situation in which you tend to make mistakes, you will help yourself to become well prepared for almost everything. As you do this, you will have fewer head-injured moments.
- 6. Your analysis will teach you how often you get overloaded, what overloads you, and how overload affects your thinking and your ability to do things. Once you know what overloads you, you will be in a position to plan to prevent it from happening. This will make a big difference in reducing head-injured moments.
- 7. Every time you discover another head-injured moment, that is another step toward recovery. Celebrate the discovery, just like finding a twenty-dollar bill in the street. Develop a great attitude about recognizing when your brain malfunctions, because that is what makes a great self-therapist.

- 8. On the other hand, if you analyze a head-injured moment, it shouldn't happen again. If it does happen again, you should be ticked off at yourself. What did I miss? How could I let this happen to me? I'm supposed to be in charge of these head-injured moments, and this one snuck right past me! Figure out exactly what went wrong with your plan, and be determined to never let it happen again.
- 9. Be sure to understand that fixing your brain is not like fixing your car. This is an ongoing fixit process. Whenever something important in your life changes, the change creates a flurry of head-injured moments that need to be fixed. Whenever something stresses you out or makes you ill, you have more head-injured moments. As you do self-therapy, you will also discover new, unexpected and quirky head-injured moments, even after years of self-therapy. So self-therapy is not a task. It's a way of living. If you live this way, you control your head injury and keep head-injured moments from interfering with your life, but if you slack off, the head-injured moments will be back. So help yourself to welcome self-therapy as something good you do for yourself, and avoid thinking of it as a chore. That will help you to make it a part of your life.

CHAPTER TWENTY-ONE: <u>Home Therapies for Basic Cognitive Control</u>

These are exercises that are useful in (1) providing opportunities to recognize the problem caused by the injury; (2) learning to watch for and to analyze the errors made when trying to use the new brain; (3) putting the basic corrective strategies into practice, and refining their use, in order to become effective at using them to prevent head-injured moments in real-life activities.

It is important for you and for the survivor to realize that these activities are not like exercises in physical therapy. Just doing them again and again is not of value. They are only useful if they teach the survivor how to run the new brain. What is important in each exercise is how it is performed. When it is being performed properly, and under the proper conditions, the scores will go up a great deal higher. This provides evidence that the survivor has learned ways to make the new brain work well. The same procedures will have to be used deliberately and by choice in real-world situations--nothing will ever become truly automatic about running the new brain.

We have already reviewed the main things the survivor needs to learn. A poor performance on a therapy exercise is a head-injured moment. When it happens, the question is, why did it happen? It is the survivor's job to think about that, to try to figure it out. And your help may be accepted in doing that. The main causes of a head-injured moment have already been reviewed in the previous chapters, and they are also summarized on the Analysis Form. But knowing what they are is one thing, and being able to see how they affect performance on an exercise is another one entirely.

As a therapy helper, the job is to help to set up each exercise, to make sure that the survivor reads and follows the rules, to score the performance, and to see that the scores are written down. More importantly, the survivor's job is to use strategies to improve performance each time an exercise is done, and you can help by making sure that step does not get skipped.

For example, many of the exercises involve finding something hidden within a bunch of things--for example, the newspaper search and the number search. In these activities, the normal, casual, low-effort way to perform is to look at the material in a rushed, helter-skelter fashion, using only the normal level of concentration. When it is done that way, the search process tends to overlook most of the targets. What is needed is a very careful approach, in which the searching is paced--slowed down so that the eyes focus on each item that could be a target and stay locked on it until the brain can decide whether it is or is not the target. It often helps for a person to run a finger beneath the items to help guide where the eyes are looking, and to help to pace the eye movement. It is only when pacing totally controlled, when concentration is raised to and kept at a high level, when everything is checked very carefully, that the exercise is performed well. And when that level is reached, the survivor is encouraged to go a little faster each time, until a totally focused and controlled search can be done quickly. This produces extremely strong control of the damaged brain. In addition to learning to recruit maximum effort, the survivor learns to control the effects of overload and fatigue.

A second factor in these exercises is the requirement to put on the brakes mentally--to stop self from responding to the wrong thing. This is called impulse control, and it is generally recognized as the main key to recovery. Exercises like the jigsaw puzzle and Taboo have rules that require the survivor to refrain from doing things that are tempting to do, while trying to do other things instead.

Survivors of severe injuries show strong improvement if they do therapy exercises like these for four to six hours per day, four to six days per week, for a period that ranges from three to twelve months. In other words, recovery can be furthered by devoting hundreds of hours to doing these exercises at maximum effort.

One important difference between home therapy and therapy in a rehab center is that in the clinic, we have people do the therapy in groups, which pits them against one another competitively. If they don't make enough effort they fall behind other people. On top of that, we require certain scores on some of these therapies before we will recommend a person to resume driving a car. These conditions produce very high levels of motivation and effort. When a person just goes through the motions of doing these therapies at home, it is unusual to get enough effort to produce a truly good recovery. You may find it helpful to enlist someone who is not injured to work alongside your survivor, making his or her best effort, to provide a standard against which the survivor can compete. It is also a good idea to display the survivors scores on a graph so that he/she can see how much progress is being made.

The instructions for each therapy are given in the self-therapy manual and will not be repeated here. You should become familiar with each of the activities so that you can help to set it up and score it.

CHAPTER TWENTY-TWO: Filling Out and Following the Treatment Planner

A program of brain-injury therapy is relatively complicated, even in the form of self-therapy where I have tried to make it as simple as possible. Real progress requires making a specific commitment to do certain therapies a certain number of hours per week, to try to reach certain goals in each therapy, and to evaluate progress toward those goals on a regular basis. A treatment plan is like a contract, in the sense that it represents a formal promise to do certain therapies, and a structure, in that it specifies what they are and how many of them are going to be done. Rehabilitation would be ineffective and chaotic without a treatment plan, and the same thing is certainly true for self-therapy.

The self-therapy manual contains a sample treatment planning form and a set of instructions for how to fill it out. It makes a commitment to fill out complete daily schedules every day. It makes a commitment to fill out a certain number of Analysis Forms. It also allows the survivor to choose the therapies he/she is going to do, but it asks to specify how much time will be committed to each, and it records the average scores achieved in each therapy activity. When this contract is completed, and if it is honored, home therapy is taking place very much like the therapy that is done in the best programs.

As with the other aspects of the program, your role is to know what has been recommended, to observe how well your survivor follows these recommendations, and to provide him/her with feedback about these observations. It is not your job to make your survivor write a treatment plan or fulfill it well. That is the survivor's job, and the results are the survivor's destiny. Your job is to provide the feedback that will allow your survivor a reasonable chance to make the choice of pursuing a good recovery.

CHAPTER TWENTY-THREE: Organizing Self-Therapy

This chapter discusses the issue of making self accountable for the treatment plan and the treatment process by actually forming a treatment team, presumably composed of self and family, and scheduling regular monthly treatment team meetings for the review of progress and for planning the next month's therapy. Accountability is the gasoline that runs the engine of recovery--this came out of some research we did 20 years ago at the internationally known program in which I learned the holistic model. If you make yourself accountable, you motivate yourself to do well, promising that if you don't keep your commitments you will make it public knowledge. By setting up and following through on team meetings, the commitment to self-therapy is made real.

If you are invited to come to these meetings, it is imperative that you show up at every one of them, on time, serious, and interested. If you let other activities or interests cause you to miss meetings or to cancel them, or show a non-serious or mocking attitude, you will be telling your survivor that you don't take self-therapy seriously, or that you don't believe in his/her capacity to recover. Whatever else you might say, your actions will speak louder than your words. How you deal with these meetings will have more of an effect on the self-therapy progress than any other single thing you can do.

Think of the treatment plan as your survivor's game plan for recovery. How can you make it stronger? How can you make it work better? If he/she is not following through, not making enough effort, what can you do to shore up those crucial aspects? And it is equally important to show your respect and admiration for the things he/she is doing well. Doing a self-therapy program is difficult, because it asks for an awful lot of self-discipline. Most people need help, and those who have involved family members to help them are lucky. Those who can achieve self-discipline are impressive, and they are the ones who recover!

CHAPTER TWENTY-FOUR: Mind Control and the Problem of Consistency

This chapter reaffirms the ideas already expressed in early chapters by reframing recovery as the pursuit of consistency. We discussed this in Chapter One. Head-injured moments interrupt consistency. So in recovery, the self-therapist becomes effective at watching for head-injured moments in order to prevent them. By preventing them, he/she regains consistency, and that opens up a whole world of options for ordinary life.