

# *Making Life Work*

## After Brain Injury

---

A Family Guide for Life at Home



BRAIN INJURY  
ASSOCIATION  
OF FLORIDA

1-800-992-3442



# MAKING LIFE WORK AFTER BRAIN INJURY

## A Family Manual for Life at Home

This publication was originally developed by Brain Injury Association of Florida, formerly the National Head Injury Foundation, Florida Association, Inc., under Contract No. V1 031 - G3661, sponsored by the Division of Vocational Rehabilitation, and the State of Florida, Department of Labor and Employment Security, 1991.

The Department of Labor and Employment Security, Division of Vocational Rehabilitation, reserves a royalty-free, non-exclusive and irrevocable license to reproduce, publish, or otherwise use, and to authorize others to use all copyrighted material under this contract.

This manual supports the concepts introduced in the three part video series for families entitled Making Life Work, developed by Brain injury Association of Florida, formerly the National Head Injury Foundation, Florida Association, Inc., under Contract No. V1 031 - G3661, sponsored by the Division of Vocational Rehabilitation, and the State of Florida, Department of Labor and Employment Security, 1991.

Reprinted 1995, 1997.

## Special Thanks

Thank you Deboskey and Associates for allowing the use of its publications in the development of this manual.

## NOTES

Connecting Family Traumatic Brain Injury with a life of hope and opportunity.

For more information on Traumatic Brain Injury call 800-992-3442 or visit the website; <http://www.biaf.org>



## Table of Contents

INTRODUCTION: MAKING LIFE WORK.....	8
I: EQUIPPING YOURSELF WITH KNOWLEDGE .....	9
What Happens to the Brain When It Is Injured?.....	9
Initial Events.....	9
Further Changes .....	9
What Are the Functions of the Brain?.....	10
Brain Stem.....	10
Cerebellum .....	10
Cerebral Cortex.....	11
Occipital Lobes .....	11
Temporal Lobes .....	11
Parietal Lobes .....	11
Frontal Lobes.....	11
Sensory Motor Strip.....	11
Limbic System.....	11
II: PREPARING FOR A LIFETIME COMMITMENT .....	13
Before the Return Home .....	13
If you are eligible for the Florida Brain and Spinal Cord Injury Program (BSCIP), which is administered by the Florida Department of Health, you will want to work closely with your case manager to obtain information on services that may help your family member return to the community. To find out if you are eligible, you should call the BSCIP office closest to your home.....	13
The Rehabilitation Process .....	13
A Preview Home Visit .....	13
Discovering Information Resources .....	14
Modifying the Home.....	14
Physical and Occupational Therapists .....	14
Psychologist and/or Neuropsychologist .....	15
Recreational Therapist and Medical Staff .....	15
Case Manager/Social Worker .....	16
III: HOMECOMING .....	17

Learning to Accept Changes .....	17
Creating an Environment Conducive to Recovery .....	17
Structure .....	17
Consistency .....	17
Repetition .....	18
Setting Family Rehabilitation Goals .....	18
IV: TAKING CARE OF YOURSELF .....	19
Understanding the Grieving Process .....	19
Learning to Deal With Your Own Reactions .....	20
Anxiety (Excessive worry).....	20
Suggestions .....	20
Unrealistic Expectations .....	20
Suggestions .....	21
Frustration .....	21
Suggestions .....	21
Stress .....	22
Suggestions .....	22
Depression .....	22
Suggestions .....	22
Guilt.....	22
Suggestions .....	23
Social Isolation .....	23
Suggestions .....	23
Learning to Love Again .....	23
Suggestions .....	24
V: CHANGING FAMILY DYNAMICS .....	25
A New Family Is Born .....	25
Extended Family Needs.....	25
Dealing with Family Advice.....	25
Growing Together .....	25
Knowing Yourself .....	25

VI. MANAGING COGNITIVE ISSUES .....	26
Cognitive Areas.....	26
Attention/Concentration .....	26
Suggestions .....	26
Orientation.....	26
Suggestions .....	27
Memory .....	27
Suggestions .....	27
Receptive and Expressive Language.....	28
Suggestions .....	28
Expressive Language Problems .....	28
Suggestions .....	29
Problem Solving/ Abstract Reasoning .....	29
Suggestions .....	30
Organization and Planning Skills .....	30
Suggestions .....	30
Lack of Motivation/Initiative.....	30
Suggestions .....	31
VII: MANAGING EMOTIONS AND REACTIONS .....	32
Behavioral Issues .....	32
Agitation/Irritability.....	32
Suggestions .....	32
Outbursts .....	32
Suggestions .....	33
Egocentric Behavior (Me, me, me).....	33
Suggestions .....	33
Dependency .....	34
Suggestions .....	34
Denial .....	34
Suggestions .....	34
Paranoia/ Suspiciousness .....	35

Suggestions .....	35
Impulsivity .....	35
Suggestions .....	36
Depression .....	36
Suggestions .....	37
Sexuality .....	37
Suggestions .....	38
Social Immaturity {Can we go out in public?} .....	38
Suggestions .....	38
General Suggestions.....	39
VIII: BASIC CONCEPTS OF BEHAVIOR MANAGEMENT .....	40
Team Approach.....	40
Structure, Consistency, Repetition .....	40
Practicality .....	40
Is There Enough Reward?.....	41
Is the Reward Meaningful Enough?.....	41
Clear and Immediate Feedback .....	41
Don't Editorialize.....	41
Redirect When Possible .....	42
Model Calm Behavior.....	42
Know When to Say When.....	42
Abrupt Changes in Behavior .....	43
IX: LIFELONG ISSUES.....	43
Regaining Social Contacts.....	43
Guide for Alcohol and Drugs .....	44
Functional Independence.....	45
Transportation .....	45
Driving .....	46
Educational Goals .....	46
Vocational Goals .....	47
Getting Assistance.....	48

Social Security Administration .....	49
Other State/Federal Agencies.....	49
Advocacy .....	49
Financial and Legal Issues .....	50
Life Care Plan.....	50
Guardianship .....	50
After You're Gone.....	51
X: CONCLUSION.....	52

## INTRODUCTION: MAKING LIFE WORK

The long-awaited day comes for you to take your family member home. You may be anxious, apprehensive, and excited about what may be facing you in the days, months, and years to come. Be assured that all of these feelings are normal. For many weeks, you had the security of a rehabilitation team to assist in the care and rehabilitation of your family member. Now the responsibility becomes yours, yours and the team surrounding you. How can you best equip yourself for the challenge of taking your family member home?

This manual is designed to help you make the transition from the rehabilitation facility to your home, and to assist you in managing the cognitive and behavioral changes in your family member as a result of brain injury. It also addresses the lifelong care, vocational, educational, financial, and legal issues associated with a brain injury. The manual is meant to be used in parts or in its entirety, whichever meets your needs.

Brain Injury Association of Florida also publishes the Access Guide to Community Services, which directs you to various resources in the community as well as informing you further about some of the issues covered in this Making Life Work Manual.

Although not all individuals with brain injuries are male, the pronoun "he" has been used to represent the individual with a brain injury, as well as for other general references to various people. We hope this will not offend any of our readers.

## I: EQUIPPING YOURSELF WITH KNOWLEDGE

One of the first things to do is to become knowledgeable about brain injury. In particular you may want to learn about neuroanatomy (the anatomy of the brain) and how brain injury affects cognitive (thinking) and behavioral (acting) skills.

The following is a general explanation of these issues. It is meant to be used as a guide. For more detailed information, contact Brain Injury Association of Florida, its support groups, or rehabilitation facilities.

### What Happens to the Brain When It Is Injured?

#### Initial Events

Three initial events can occur following a traumatic brain injury. The first is immediate damage, which results from the brain's impact against the bony structures of the skull, especially in the area of the forehead (frontal area) and upper cheek and ear (temporal area). This impact can cause tearing, bleeding, and bruising of brain tissue.

Secondly, as the brain turns and twists while affixed to the spinal cord, tearing and stretching of the nerve fibers often occur within the entire brain and brain stem.

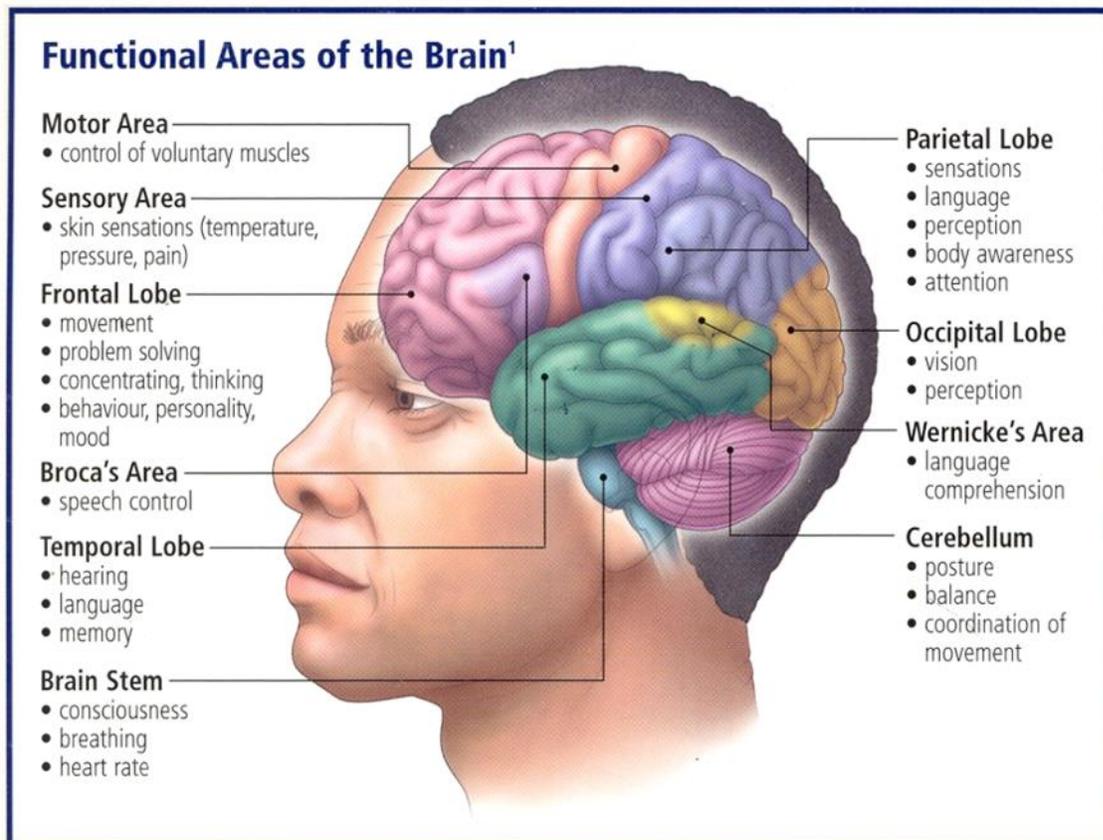
Thirdly, additional complications can arise. The brain can suffer diffuse swelling and in 75 percent of the cases will demonstrate an increase in intracranial pressure. The general swelling and increased pressure reduce the blood flow necessary for the undamaged brain tissue. Unconsciousness or coma may result, depending on the severity of these injuries.

#### Further Changes

Although the types of injuries described thus far occur within hours or days of the accident, further changes will develop over time. As the brain swelling resolves and blood flow to the tissue stabilizes, two things happen: The nerve tissue that was not severely damaged but merely impaired by complications such as swelling will return to functioning. However, nerve tissue that was severely injured will continue to degenerate and die.

## What Are the Functions of the Brain?

The best way to understand the results of injury to the brain is to understand the function of each area of the brain and related systems and structures.



### Brain Stem

The brain stem, located at the base of the skull, is responsible for life-sustaining functions such as regulation of blood pressure, heart rate, breathing, and body temperature. The system that is responsible for the level of arousal and alertness is also in the brain stem and is known as the Reticular Activating System (RAS). The RAS functions like a dimmer in a light switch, increasing and decreasing the responsiveness to the environment. If the RAS is damaged, like a light that has been dimmed, an altered state of consciousness such as coma or a vegetative condition may result.

### Cerebellum

The cerebellum, located behind the brain stem, is responsible for muscle coordination and balance.

## Cerebral Cortex

The cerebral cortex, located in the upper portion, is what is most commonly thought of as the brain. It is divided into left and right hemispheres, with each hemisphere's lobes responsible for specific functions.

## Occipital Lobes

The occipital lobes are unique in that they control visual perception within both the right and left hemispheres. They receive the pattern for a picture, but do not interpret that picture. Damage to these areas may result in cortical blindness.

## Temporal Lobes

One's abilities to hum a tune (music), identify an airplane overhead (environmental sound), and recall a beautiful sunset (visual memory) are all functions of the right temporal lobe. The left temporal lobe allows one to understand a teacher during a lecture (language comprehension), to name Cousin Joe's wife at a family reunion (naming ability), and remember the pledge of allegiance to the flag (verbal memory). The channel by which one processes and attaches meaning to what one hears also begins in the temporal lobes.

## Parietal Lobes

In general, physical sensations and perceptions are regulated in the parietal lobes. The ability to find one's way around in one's house, in the dark, is due to one's proprioceptive feedback, or the ability to sense oneself in relation to one's surroundings. Visual perception and analysis of space, as demonstrated by the ability to read a map or follow a maze, are also processed in these lobes.

## Frontal Lobes

The frontal lobes control the complex processes that separate man from lower animals. To illustrate their function, consider frontal lobe involvement in the common daily activity of driving a car. Have you ever experienced the phenomenon of arriving at work and not remembering driving there? The planning, organization, and self-correction skills controlled by the frontal lobes are responsible for your safe arrival at work. If there had been a detour on the way to work, the frontal lobes' mental flexibility would have allowed you to alter your route and successfully complete your trip.

Carrying out daily functions requires one to remain in control and generate alternatives when problems arise.

## Sensory Motor Strip

This function of the brain is located in the frontal parietal area and is primarily responsible for reception and organization of higher level motor behavior, such as the coordination of movement in walking.

## Limbic System

In addition to these easily identifiable lobes, there are systems within the brain that connect these lobes. The system most sensitive to the results of brain injury is the limbic system, which

mediates mood, emotions, motivation, attention, and memory. Injury to this system may be manifested in behaviors ranging from flat affect (no expression) to aggressiveness; from mild distractibility to the inability to pay attention for one minute; from a host of imperceptible memory problems to the inability to recall just finishing a meal.

An understanding of what happens to the brain during a brain injury can help you predict some of the cognitive (thinking) and behavioral (acting) issues that may develop as a result of the injury. The next section provides an overview of some of the more apparent cognitive/behavior issues and offers some suggestions for dealing with them.

As the family member of a person with a brain injury, you are already becoming familiar with resultant behaviors; thus some of those described in the next section may not be new to you. However, many of these issues may require resolution with your family member.

## II: PREPARING FOR A LIFETIME COMMITMENT

Although the long-term implications of brain injury can be overwhelming, there are many ways you can prepare to assist your family member with the difficulties of adjustment. The following sections address how you can physically, mentally, and emotionally ready yourself for the lifetime commitment you have made to caring for your family member. Areas will range from making the transfer from the rehabilitation facility to modifying the home environment; from emotional reactions in your family member to techniques for taking care of yourself.

### Before the Return Home

While this manual is intended to guide you through your family member's stay at home, you should set the stage for the homecoming while he is still in the rehabilitation center. Use that time for gathering as much information as possible about brain injury. This is also the time to network with other families and to become actively involved in a support group, such as those available through Brain Injury Association of Florida.

If you are eligible for the Florida Brain and Spinal Cord Injury Program (BSCIP), which is administered by the Florida Department of Health, you will want to work closely with your case manager to obtain information on services that may help your family member return to the community. To find out if you are eligible, you should call the BSCIP office closest to your home.

### The Rehabilitation Process

Your role on the treatment team begins when your family member enters the rehabilitation setting. This is your time to gain useful information about his rehabilitation process. Make a request to the rehabilitation treatment team, to be allowed to observe the therapies. Try to take as much responsibility for the therapy as the treatment team feels is appropriate. Learn about positioning, feeding, activities of daily living, cognitive rehabilitation, and psychological and medical issues. A good place to gain information and ask questions is at the staff meetings. If you have other questions, personally contact the case manager or individual therapist.

Make a point to become acquainted with the social worker or case manager. He will be responsible for the discharge planning. No matter what the funding issues may be, he can provide information about what is available in your community.

### A Preview Home Visit

During the course of your family member's stay at a rehabilitation center, a home visit should be recommended. During this home visit make certain to set some specific goals. Work with your family member in a variety of activities. Position him, transfer him, and work with him in his activities of daily living in your home.

See what modifications can be made so that he can be as independent as possible in the home. Observe how he interacts with other family members. Is he distracted by either auditory or visual stimuli? Take notes so that you can confidently prepare for his coming home. If you have

questions after the home visit, bring a list with you to the rehabilitation center. Make certain that the therapists there give you answers and assist you in planning the rest of his home rehabilitation program.

If the rehabilitation facility does not recommend a home visit, request one. Some rehabilitation settings are limited by insurance guidelines and cannot allow patients to leave the facility, particularly overnight. If that is the case, ask the individual therapists to work with you in the rehab setting in circumstances that are similar to your home. Ask them to demonstrate how you should handle your family member at home.

### Discovering Information Resources

If your family member has not had the benefit of an organized rehabilitation program, you may have to gather some of this information on your own. Use your contacts with the physical and occupational therapists who worked with him in the acute care setting. Ask a case manager or social worker in that setting to assist you. It is often beneficial to maintain contact with professionals at the acute care and rehabilitation settings. They may be willing to answer your questions and offer general recommendations for care at home.

### Modifying the Home

Before your family member leaves the rehabilitation center, representatives from the facility should assist you in determining what alterations are needed in your home to accommodate your family member. You may need to install wheelchair ramps, modify bathrooms, or purchase special equipment. If your family member spent time in a shop or garage working with tools, that environment may also need to be modified.

You should visit with the professionals in each therapy area so that you are aware of your family member's skill levels in relation to living at home. Also make sure you have proper instructions for use of any aids and devices which will be used. For example, if he will be using an augmentation communication device, you should work with the speech/language pathologist to ensure that you are completely familiar with the equipment, batteries, information needed to operate it, and its maintenance schedule. Make sure to find a company to do repairs and provide servicing.

### Physical and Occupational Therapists

Visit with the physical therapist (P.T.) to obtain information about a home exercise program or therapy at an outpatient rehabilitation center. The P.T. can also give you information about the wheelchair or any other supportive device your family member may need in order to be more physically independent. The home modifications recommended by your P.T. and occupational therapist (O.T.) should be made before your family member arrives home.

The O.T. can give you more information about the assistive devices your family member may need for reaching, eating, or other daily living activities. He can advise you on how independent

your family member can be in everyday activities and suggest how to work safely with him in those areas.

## Psychologist and/or Neuropsychologist

The psychologist can give you information about behavioral and cognitive issues that you may not have witnessed to this point in the home or rehab setting. A neuropsychological evaluation should have been completed. Arrange to meet with the neuropsychologist to discuss results of this evaluation and your family member's abilities.

While a neuropsychological evaluation may seem complicated and use unfamiliar terminology, the neuropsychologist will explain the cognitive/behavioral problems your family member may have. These may include difficulties with attention/ concentration, memory, problem solving, organization/planning, outbursts, impulsivity, and paranoia.

Ask the neuropsychologist how these problems can affect your family member's ability to function at home. Ask questions such as:

- Will he be able to resume a daily schedule? How much assistance will I need to give him?
- Will someone need to stay with him or be within phones reach at all times?
- Is it dangerous for him to cook?
- Do I need to handle the finances?
- Should we have friends come and visit?
- What will keep him occupied all day?
- How do I help him remember things?
- How much change or improvement can be expected in his cognitive/behavioral skills?
- How independent will he be now and in the future?
- When will he need a new neuropsychological evaluation?
- What do I do if he:
  - cries at the drop of a hat
  - sits and watches TV all day
  - becomes angry and has verbal/physical outbursts
  - wants to drive
  - refuses to see his friends
  - is getting frustrated at therapy and refuses to go

When you talk with the neuropsychologist, have your list of questions prepared and make certain you understand the implications of his responses. If you have further questions, take the opportunity to ask for clarification.

## Recreational Therapist and Medical Staff

The recreational therapist can provide information on community resources for your family member. He may also offer suggestions about activities for his leisure lifestyle. Contact with the physician will provide you with important information about medications, precautions, side

effects, and limitations. A visit with the nursing staff will yield information about the daily care needs of your family member. You probably will have discussed much of this prior to your first home visit. However, before taking your family member home, it is wise to review these issues again with the nursing staff.

### Case Manager/Social Worker

The case manager or social worker is the key person in the discharge planning process. He will schedule outpatient therapies and follow-up appointments, as well as in-home therapies if needed. The case manager can also give you information about local support groups.

## III: HOMECOMING

### Learning to Accept Changes

The first step for you is to accept what has happened to your family member, and to work with him as he is upon discharge from the rehabilitation center. Without that acceptance of his difficulties, it will be extremely hard for you to set goals for his home rehabilitation program. You also need to accept that you are in for a lifelong commitment. Brain injury is not like a broken leg, which heals over a specific time frame. Every brain injury is different and the healing process is unique to the individual. Formidable as it seems, you need to accept his condition and be willing to work with the changes.

Although it would be ideal for you to accept your family member's injury as soon as he comes home, problems often linger. But they can gradually improve in a supportive environment where each family member works to accept what cannot be changed.

### Creating an Environment Conducive to Recovery

In addition to the home modifications mentioned earlier, it is important to make sure that your home is physically well organized. You will want to keep it free of physical distractions, keep unnecessary clutter out of the way, and organize it in a way that is helpful for both you and your family member. Three elements are needed to achieve this aim: structure, consistency, and repetition. Let's examine them one at a time.

#### Structure

It is very important to structure your family member's environment as well as his day-to-day activities. Keep his room organized, use calendars and wall charts for him to plot his activities, use a watch with an alarm to remind him when it is time to move on.

Provide a plan for his activities and review each day's schedule with him on a daily basis. He will need everything to be in its place and a set place for everything. Always set up the bathroom in the same way, and have his work area arranged in the same manner every day. Be careful not to overstimulate your family member, but use as many visual aids as possible.

#### Consistency

Your family member will find a certain amount of safety in the consistency of what you do. Consistency goes hand in hand with structure, but applies more to how you handle situations rather than the structure you set up in which to handle them. For example: in the behavioral area, it is best if you can always handle situations in the same way. For an outburst, your response should always be the same, giving feedback as to inappropriateness and leaving the room. If you ask your family member to set the table, make certain that you ask him every day. If you work on cognitive rehabilitation activities at home, make certain you always use the same approach and maybe even the same materials.

## Repetition

One of the most difficult things to accomplish is to repeat the same activities over and over in the same way. However, your family member will feel "safe" in the repetition. Repetition is also important because this is often the only way your family member will be able to claim a new behavior as his own. It will have to be repeated over and over again. The nature of brain injury necessitates that you need to repeat things in order for your family member to recall them.

Another issue to remember is that through repetition your family member may perform something he learned long ago. You may be pleasantly surprised when you watch him correctly perform an activity or respond in a way that you have been attempting to teach for months.

By providing your family member with the consistency, structure, and repetition he needs, you will eliminate or avoid many problem situations. Setting up an environment that provides these three elements also helps to structure your relationship with your family member. In this way you will not have to rethink your response each time; it will also become automatic for you.

## Setting Family Rehabilitation Goals

Just as the rehabilitation professionals had a plan for your family member, you need to have a plan also. You will be armed with enough information from the rehabilitation treatment team to know what you can expect. However, when setting goals for your family member it is important to keep a few basic guidelines in mind:

- Be patient and tolerant, especially with yourself. It takes time to achieve the result you want, so don't hurry it.
- Don't go it alone. Use the support systems around you of family, friends, church, or a local support group.
- Remember that the goals you set must be meaningful for your family member. If not, he will not be interested in making them work.
- Be creative and flexible; don't be afraid to change a goal if it is unrealistic.
- Keep a record charting the goals your family member has achieved. In that way, you both will be immediately reinforced for the progress he has made, and you will be able to keep track of his short- and long-term progress.
- Work on just one or two small, attainable goals at a time. Do not be overenthusiastic or expect too much. It will be much easier for all concerned to meet their goals if the family is relaxed, without unrealistic pressure.

## IV: TAKING CARE OF YOURSELF

Most of the pages in this manual are devoted to what happens to the person with the brain injury, but you are just as much a victim of the brain injury as your family member. Your life has not been the same since the moment of the injury, nor will it ever be the same again. Acceptance of this fact and the ability to move on are extremely important for the lifelong care of your family member and your own wellbeing.

Let's take a look at some of the interactions and changes in your life. Not all of these reactions will necessarily apply to you, but an awareness of these issues is helpful in addressing future changes.

### Understanding the Grieving Process

It is important to remember that different people react differently to the grief they suffer over the loss of the family member they once knew, the one who was energetic and vital, who may have been the prime provider and support system for the family. Some individuals respond by involving themselves completely in the rehabilitation process of their family member. They deal with the insurance companies, doctors, rehabilitation providers, and government agencies. In a way this helps them gain some control over their situation. Others may not be able to come around for a while. They may bury themselves in other projects, and with other responsibilities. These individuals will need time to reach a more comfortable level of accepting what has happened to them and their family member.

There is frequently a grieving process that one goes through when his or her family member suffers a brain injury. The process is often experienced in definable stages:

- denial,
- anger and frustration
- depression and withdrawal
- acceptance

Where you are in the recovery process will influence how you respond to situations in regard to your family member. For example, if you are still in a state of denial, you are not going to very easily accept the therapist who says your family member may never work again. Through your denial, you may inadvertently feed into your family member's denial and stand in the way of progress in therapy.

If you are angry and frustrated, it may be a lot more difficult for you to deal with your family member's continual behavioral problems. You may have lost your patience.

It is very difficult to get to level four (4), which is acceptance. Remember that you can only do that in your own time. Acceptance comes when you are ready and open for it. It can be encouraged by professionals; it can be encouraged by other family members; however, it cannot be forced, and you will have to come to your own peace with what has happened to your family

member. When you are able to do this both you and your family member will be on a better road to recovery.

## Learning to Deal With Your Own Reactions

There is no question that bringing your family member home changes your life and impacts upon your mental health status. The purpose of this section is to prepare you for these responses, and to assure you that it is not wrong, unusual, or immature of you to think or respond in some of the ways discussed in this section.

Every family has problems it faces each day. But the trauma of a sudden brain injury is a situation that no one can prepare for in advance. It can only be fully understood by families who have experienced it or by people who have worked with those who are going through it. It is often helpful to find a support group in your community and share some of your problems. If there are none and you have the time and energy, you might consider starting one. You can contact a local hospital or church for a meeting space. You can obtain assistance and ideas from Brain Injury Association of Florida, for additional ways of contacting others in your area.

## Anxiety (Excessive worry)

You have probably experienced this emotion since your family member sustained his injury. When he returns home the nature and content of his behavior may change and you may find yourself worrying about everything that has to do with his life: his rehabilitation process, his daily life needs, and his future. You may ask yourself: Why won't he come out of his room? Why don't his friends come to visit? Why does he get so mad at me? Are the medications causing his lethargy? Will he be safe?

## Suggestions

- Schedule a set time during the day when you will allow yourself to worry; then forbid yourself to obsess or concentrate on your many concerns for the rest of the day.
- If your family member engages in constant verbalization about a concern of his, do not allow yourself to get trapped into worrying with him. One person is enough.
- Work out both physically and mentally in order to clear your head so you are better able to deal constructively with everyday situations.
- If you find yourself going over the edge, get professional help.
- Remember that your worries should not control your life. You should control your worries.
- Participate in a support group for brain injury. Many of the people in that group will have already resolved some of the worries that are new to you. There is nothing like the voice of experience.

## Unrealistic Expectations

It is often difficult to be realistic about what you can expect from your family member. These expectations also change as he makes changes. It would be wonderful to be optimistic about his

progress and to will him to return to his old self, but realistically we know this seldom happens. Often, this type of optimism keeps us going. However, being overly optimistic (not realistic) can be counterproductive, especially if it leads to setting goals you or your family member can't meet. It can give both of you a sense of failure, which is counterproductive to the rehabilitation process.

If at all possible it is best for you to take the recovery period one day at a time without planning too far ahead. In essence, the right mixture is optimism tempered with a touch of realism.

### Suggestions

- Make "one day at a time" your motto.
- Do not make your family member feel that he has failed if he has not met your expectations.
- Be aware of all the positive recovery that has already occurred.

### Frustration

Frustration is an emotional reaction you may experience from the time of the injury throughout your family member's lifetime. The focus and intensity may change, but the presence of frustrating experiences is a given. While in the rehabilitation facility you may have been frustrated by what you saw as a lack of communication, agency red-tape, or problems with funding sources. Now that your family member is at home you will find challenges as you try to reintegrate him into the community. The reality of dealing with society's inability to accommodate the rehab needs of the person with a brain injury may become a source of frustration for you. You may become frustrated if the physician says that your family member has reached MMI (Maximum Medical Improvement) and no longer is a candidate for therapies, or if the case manager says the insurance company will not pay for therapies.

### Suggestions

- Remember that frustrations are a reality. But how you handle them can make a difference.
- Do not allow yourself to be worked into a frenzy; you cannot solve problems in that state of mind.
- Remember that the individual with the brain injury will pick up on your frustrations and may use them in a negative manner.
- Speak with others in a support group and ask how they managed their disappointments.
- Find alternative solutions for meeting goals when one avenue has been blocked.
- Find a self-help course or book on "How Practically Never to Get Unproductively Upset about Anything."
- If you need professional support at this time, get it.
- Be informed about insurance and other issues related to your family member's rehabilitation, so there are no surprises to handle.

## Stress

It would be ridiculous to tell you to avoid stress. What family with a member who has a brain injury is without stress? However, there are effective methods of handling your stress and these methods can be put to good use. You may find your stress level increases when your family member arrives home. Not only will your time be more in demand, but your emotional energy will be expended at an increased rate. You may find yourself turning into a complete grouch, overreacting, finding it harder and harder to remember things, and having a difficult time sleeping at night.

It is very important for you to take care of yourself. You may want to take some steps to do so. Remember that you are important too. You are the key person in your family member's rehabilitation process.

## Suggestions

- Give yourself some time away so that you can be refreshed and ready to deal effectively with the issues when you return home.
- Read stress management books and listen to relaxation training tapes. They are available in most bookstores and libraries, and are helpful tools in managing stress.
- Delegate and divide up the responsibilities. Ask everyone in the family to pitch in and help. Encourage your family member to assume his fair share of the responsibilities.

## Depression

Inevitably, there will be periods of time when you will be depressed. Your first major step is to recognize the symptoms of depression and to move on from there. Some of the symptoms to look for are: feeling tired all the time and having trouble getting out of bed, drinking more than before, having a difficult time getting motivated. Another indication is that you are no longer over-optimistic; you have gone in the opposite direction now and hopeless thoughts occupy your mind.

## Suggestions

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

## Guilt

If you have been a guilt accumulator in the past, you will be easily trapped into taking on even greater volumes of guilt now that your family member is returning home and you are coming face to face with reality. Even if you previously stayed free of guilt you may have difficulty

avoiding it now. The circumstances surrounding living with a person with a brain injury provide a multitude of possibilities for thinking or feeling that you have not done the best thing in a given situation. Guilt will arise from at least four main sources: 1) you, 2) the family member, 3) other family members, and 4) concerned others. Once you have your own guilt under control, you will have to learn to defuse the guilt laden arrows shot at you by others.

### Suggestions

- Accept guilt as a normal human feeling over which you have minimal control.
- To get your mind off the guilt, substitute engrossing activity such as gardening, exercising, biking.
- Schedule your guilt time - feel guilty on Mondays only.
- Go to a professional who can help you to quit focusing on what you "should" have done.

### Social Isolation

When a person with a brain injury is at home, the family often reduces its contact with the outside world to allow the family member to have a quiet environment and to provide emotional support. The danger is that this may become a pattern and will be hard to break later. Studies have shown that the support of family and friends is more important than the assistance of hospital personnel, doctors, or the clergy. Thus; it is a mistake to isolate yourself from familiar contacts.

Even though you may make every effort to foster old friendships, you may find that many will gradually dissolve for a variety of reasons. Some people may not be able to understand your family member's obsession with his physical conditions. They may not be able to accept the individual as he presents himself in the group. They may become uncomfortable because they no longer share common interests and goals with your family.

If you find this occurring with a large portion of your former friends, make every effort to form new acquaintances.

### Suggestions

- Continue with your former social contacts if at all possible.
- Maintain your job unless it is absolutely necessary that you quit.
- When friends call, talk about things other than your family member and how or what he is doing.
- Schedule outings for social activities and then follow through.
- Remember that other people can care for or help you care for your family member.

### Learning to Love Again

Unless your family member has had only a mild bump on the head (and sometimes even then), you will find that he is a somewhat different person from before. Now that he is coming home you may be fantasizing that he will be his "old self." You will be disappointed if you are expecting this, so please do not set yourself up for this letdown.

As time goes by you will probably see changes indicating that your family member may never completely return to his original personality. You may feel that you are living or sleeping with a stranger. You will need time to adjust, so give yourself this opportunity. If it is your spouse who is injured, you may need to seek professional help to assist both of you in redeveloping your relationship.

In trying to reshape your relationship with your family member, another issue you have to deal with is a change in family roles. You may have to adjust to the fact that your spouse is no longer the dominant one in the home or in the relationship. You may have to assume that role. You may also have to adjust to the fact that he may not be as active or aggressive as he was before his injury.

Learning to adjust to these changes and renewing your love for your partner can present a significant challenge.

### Suggestions

- Talk to him the way you used to.
- Let him make as many decisions as possible.
- Ask his opinion, even if it is not necessarily needed.
- Approach the situation as you would a new relationship.

## V: CHANGING FAMILY DYNAMICS

### A New Family Is Born

The overall result of the changes that your family member has experienced and you are experiencing will affect the manner in which your family unit functions on a day-to-day basis. Family roles and responsibilities will change. Siblings or children may have to assume more responsibility for the care of their family. A new family member will be coming home, and as a unit, you will have to be able to form a new family. The siblings and children of the person with a brain injury need a forum to express their feelings. They are often the neglected and forgotten victims of the brain injury. They still need your time and attention, but frequently this is difficult because you are so busy with your family member. Be cognizant of their needs, and try to make sure they are considered.

### Extended Family Needs

The extended family also has needs that must be handled with great care and caution. Many times, well-meaning relatives offer a lot of advice about handling your family member. While it is important to have all the support you can, do not be intimidated by those who are not directly dealing with your situation. Remember, you are the expert in making this family unit work. When your well-meaning relatives give you unsolicited advice, tell them that the best thing they can do is to give you the respite you need when you ask them for it.

### Dealing with Family Advice

While you may seek the comfort of talking with your extended family and support groups, remember that you and your family members will have to deal with your situation in your own way. Listen to the suggestions offered, but think them through before you act. Do not be concerned about others' opinions of how you are handling your life.

### Growing Together

Look at this as an opportunity to learn and grow as a family. Face each new challenge with the realization that you indeed can provide the best for your family member. Accept the successes and accept the failures, secure in the knowledge that your family grows and learns from each new situation that is presented. In order to do this you have to establish an atmosphere that is open, flexible, and somewhat structured. Use each other as a support system. Use each other to remain strong. It is often helpful to ask family members to alternate in their duties, so that no one person carries all of the burden.

### Knowing Yourself

When you need rest don't be afraid to ask someone in your support system to relieve you for a period of time. Even if it's just a few hours, take some time off for yourself. In doing so, you will be better able to cope with the needs of your family member on a long-term basis. Learn to view your family member's injury as a new beginning and face each challenge of the day with that mind-set. You may be surprised to discover the new blessings your new family member brings.

## VI. MANAGING COGNITIVE ISSUES

### Cognitive Areas

This section offers a menu of ideas to assist you in managing your family member's needs in the home situation. If in trying some of these suggestions you run up against a brick wall, it may be helpful either to contact a professional from the discharge facility or to find a counselor (who knows brain injury) in your community. This section is intended as a guide, not as a replacement for professional help where it may be needed.

As you read through the following section, please do so with a measure of caution. Although generalizations have been made about cognitive and behavioral issues and suggestions will be given for handling them, your family member is an individual and his cognitive/behavioral issues should be treated on an individual basis. For the sake of simplicity and example very general suggestions are given; please use them as they relate to your situation.

### Attention/Concentration

You may find that your family member has a difficult time sticking with a task for any period of time. During the day, he is not able to hold his concentration. In particular he has difficulty reading, which used to bring him much enjoyment. You feel you have to entertain him all the time. Without the structure of the rehabilitation setting he appears to be lost.

### Suggestions

- Give your family member as much repetition, structure, and consistency as you can. Start as soon as he comes home from the rehabilitation setting.
- Set up a schedule for him at home; make the schedule visible and have him check it off as he goes along.
- Put away the novels for a while; buy magazines with short stories of high interest for your family member. In that way he may begin to enjoy reading again.
- While children are a blessing, it may be beneficial to ask them to be quiet for a while. Your family member needs some time to adapt to his new home conditions with some peace of mind.

### Orientation

The process of orientation for your family member is often misunderstood. People tend to think that as a person recovers he becomes completely oriented, remembering who he is and what he is doing.

Unfortunately this does not always happen. On a daily basis you may need to go through certain orientation information with your family member. You may need to review what day it is, where he is going for the day, what he is going to do, and the specifics of some appointments. You may need to do this even though he follows the same schedule every day. There are a number of things you can do in your home that increase your family member's orientation.

## Suggestions

- Place a calendar in his room so that he always knows what day it is.
- Use "Post-it" notes. They must have been invented for the family with a member who had a brain injury, as they are extremely helpful for reminders.
- Use other external devices such as watches whose alarms sound every half hour, to cue your family member to look either at his calendar or his notebook. Be careful, however, that you do not overstimulate him. The more cues you can add without overstimulation, the better.
- In general, provide consistency, structure, and repetition. This will greatly increase your family member's ability to be oriented. Doing things at the same time every day within the same environment adds to the structure and your family member's orientation.

## Memory

From the time that your family member was first in the hospital you probably heard about the memory problems he was going to have, and you have anticipated them with anxiety. Memory problems take on different forms. The most prominent will probably be the short-term memory difficulties. Your family member will easily forget things, such as where he put things, when he ate a meal, that he just talked with someone on the phone, or who just came to visit. The long-term effects of a memory deficit are that learning a new task or succeeding in a new job situation may be very difficult for him. Terms such as retrieval, long-term memory, short-term memory, recall, and the like are used by the professionals. It is important for you to identify and understand the forms of memory loss experienced by your family member. Then you can begin to structure the environment so that he can compensate for what may be long-standing problems.

Never before have the words consistency, structure, and repetition been more important than in dealing with your family member's memory difficulty. Direct drill or therapy for a memory disorder is rarely effective, and as a result compensatory techniques are necessary. In other words, he will have to learn "little tricks" that will help him remember and make up for his inability to remember on his own. The suggestions made in the sections on orientation are also helpful in compensating for memory difficulties.

## Suggestions

- Strongly encourage your family member to carry a notebook. In this notebook, he can record important events and appointments. Work with him so that he has a procedure for organizing his information, such as appointments on one side of the page, and notes about that appointment on the other side.
- Have him use an alarm watch as a cue to look at his notebook periodically for an appointment. Initially, he may have to be cued every 30 minutes or so; however, through repetition of this activity he should be able to move through his day without a cue every 30 minutes.
- Try to assure him that it is OK to write things down.

- Use visual cues within a room setting for jogging his memory (i.e., calendars, clocks, wall charts).

## Receptive and Expressive Language

The ability to understand (receptive language) and communicate (expressive language) the spoken and written word are two of the most complicated cognitive functions. People make many judgments about others by the way they communicate. It is one of the "finer" skills. You may notice obvious or subtle changes in your family member's communication skills. He may not be able to follow or get the point of a conversation. He may talk when it is his "turn"; however, what he says may not be relevant to the question being presented. He may also no longer understand humor, and thus not appreciate jokes. One of the higher levels of verbal comprehension is humor. That is why so many therapy sessions attempt to address this subtle area. Your family member may feel left out of jokes, and by the same token may not understand the subtleties of situation comedies. He may also have difficulty understanding what he reads.

## Suggestions

- Make certain that your family member understands the information being presented. Check for comprehension by statements such as: What did I say? What does that mean to you?
- Use both auditory and visual presentation. If you present the stimuli in a number of ways, he has a better chance of comprehension.
- An activity that once seemed simple may not be. Thus, that old hobby of putting together a model may not be what your family member needs to be doing at this time.
- Keep your language as concrete as possible so that your family member understands what you are saying.

## Expressive Language Problems

Expressive language problems can take many forms. Your family member may frequently have word-finding difficulties. At times he may use the wrong word, such as a four-letter word. You may never have noticed before how many of these expletives were in your family member's vocabulary. A person's quantity of language will often change following a brain injury. You may find that he has a lot less to say; but more likely than not, he will have a lot more to say. He may have a tendency to ramble on and have a difficult time getting to the point.

One of the areas to pay special attention to is expressive language in the form of written communication. Whereas he may not have had any problem with writing notes and memos previously, this may now take him a great amount of time.

Another aspect of expression that is often overlooked is nonverbal language, or body language. Your family member may have particular difficulty establishing a match between what he is saying and what he is doing. Often his communication will be lost because of this. For example, he may present a positive message while in a negative posture (folded arms and crossed legs).

Another area of nonverbal language is eye contact. If it is difficult for your family member to maintain eye contact, simply keep reminding him to look at you.

### Suggestions

- Expressive language skills increase only through practice. Therefore, give your family member an opportunity to practice his expressive language. If it is not frustrating for him, encourage him to try the following:
- Give and take phone messages.
- Take responsibility for his own arrangements.
- If he is having difficulty with expressive writing, set up a format for him. In this way he can leave you a message by filling in the blanks, and not having to construct the entire message.
- Express himself in writing. This can be beneficial in a number of ways. It allows him to express some thoughts otherwise left unsaid, and it may encourage him to schedule his day and analyze his information. Keeping a journal or notebook is very beneficial in this area.
- Use role playing as a helpful method to practice his verbal and nonverbal language skills.
- Be a good observer of other people's behavior. Have him watch their interactions, body language, and message presented.
- Set up a cuing system to let him know when he is rambling and needs to "get to the point." For example, in social settings you might prearrange with him that you will scratch your head or give him a subtle wink when he needs to get to the point. At home, a subtle verbal reminder given in a supportive way may be helpful to him.
- Practice beforehand for any planned interactions so that he feels organized and prepared for any possible conflict or confrontation.
- Help your family member recognize that from this point on he will probably experience some awkwardness with talking "on the spot." Encourage him to avoid these types of situations without feeling inadequate.

### Problem Solving/ Abstract Reasoning

The ability to solve problems is really a culmination of other cognitive skills. It involves the ability to attend to a situation, understand all components of the problem, recall possible appropriate alternatives, and then make the correct choice between the alternatives. Problem solving can be as simple a task as opening a stuck jar or as complex as dealing with a controversial issue at work. The process, although at differing levels, remains the same.

You may notice that your family member has difficulty determining just how to go about things around the house. If there is any kind of unexpected occurrence during the day, he may not be able to accomplish the day's tasks. The unexpected may cause problems within the work setting as well as in the home. Problem solving and abstract reasoning abilities are also greatly affected

by the amount of stress within a situation. Stress can be brought on through time constraints, family and employer expectations, and the complexity of a task.

### Suggestions

- Encourage your family member to look at all alternatives to a situation before he makes a decision. It often helps to write down those alternatives.
- Help him to become involved in situations that require problem solving, such as family games.
- Most importantly, make certain that he is given enough time to make a decision. Impulsivity can get in the way of a wonderful problem solving plan. So the best way you can help your family member is to make certain that he takes his time with the decision making process.

### Organization and Planning Skills

These skills are important elements of problem solving. Frontal lobe functions, as mentioned earlier, control organization, planning, self-monitoring, and initiation skills. Difficulty with initiation often results because your family member may not be able to organize and plan, rather than his not wanting to do something. Your family member may be able to talk about his plans; however, he may not be able to carry through on any of them. Instead, he may sit and listen to music all day long. He may not be able to start a new activity because he just can't get everything together that he needs for it, so he just sits. Difficulty with organization and planning affects other cognitive areas such as memory and concentration.

### Suggestions

- Keep your family member's environment organized and free of unnecessary distractions. Here is another place where consistency, structure, and repetition play a major role.
- Become your family member's organizational assistant by helping him set up calendars and schedules. Also assist him in keeping his notebook or diary up to date.
- Set up a check-off system for him so he can mark off the completion of one task and know when he should be moving on to the next. He may not initiate a new task because he does not realize that he has finished the last one and it is time to move on.
- Help him learn to estimate how long each task will take. In that way, he can block out an appropriate time and better plan out his day.
- Help your family member break down tasks into smaller steps.
- Never assume that he is able to accomplish a task. Assume that you have to reteach it.
- Remember that your family member may need extra time to complete simple activities. Allow him that time.

### Lack of Motivation/Initiative

There are two main issues to consider regarding an individual who appears unmotivated or lacking in initiative. One of the cognitive deficits related to brain injury is that a person will have

difficulty planning and goal setting (see last section). He may not know where or how to start a project, so he does not begin.

He may understand to some degree that he does not have the abilities he had before, yet he may not want to admit this deficit. Consequently, he will act as if he is not interested or motivated. The reality is that he is interested but incapable of doing what would have been simple for him before the injury.

You may find that your family member has adequate plans and big promises, but has a difficult time following through. He may have lost interest in things that once gave him pleasure, such as his old hobbies. Even in therapy, the therapist may have a difficult time finding a reinforcer that is powerful enough to keep him motivated.

### Suggestions

- Give the family member the needed supervision to start a task.
- Never assume that because he did a task before the injury, he is now being lazy or obstinate if he does not complete it.
- If possible, break the task down into smaller steps.
- Never ask a question in the form of "Do you want to ..." there is too much opportunity to say no and remain passive. Give choices of two or three activities.
- Get your family member involved in a support group. This will help him to participate in one activity at least once or twice a month.

This section included some examples of brain-related cognitive behavior that may result from a brain injury. This list is certainly not all inclusive, nor does it completely address all of the cognitive issues. As mentioned earlier, contact the professionals you have been working with or Brain Injury Association of Florida, for articles and books that further address these cognitive and behavioral issues.

## VII: MANAGING EMOTIONS AND REACTIONS

### Behavioral Issues

The next section of this manual outlines some of the most prevalent emotional and behavioral issues affecting individuals with brain injuries.

#### Agitation/Irritability

One of the most prominent personality changes after brain injury is an increase in irritability. Even those who have only been dazed by a bump on the head will often display a change in mood. For example, the once easygoing husband and father suddenly develops a short fuse. This can be very disconcerting to families who are not accustomed to living with this grouchy individual.

At times you may think that your family member is acting this way because he wants to get back at you for something you did or did not do. It is possible that he is consciously being irritable in order to manipulate you, but it is not probable. Due to the damage to his discriminating abilities, he may be unable to block out excessive environmental stimuli. Because of cognitive or thinking deficits, he cannot always figure out why certain activities are necessary. His memory lapses may cause him to forget that just thirty minutes ago he told you he did not want Aunt Susan to come over.

All of these issues are related to damage to the brain and can lead to a short-tempered, irritable individual

#### Suggestions

- Provide as distraction free an environment as possible.
- It is useless to ask the family member why he is grouchy. He may not even realize that he is.
- Keep surprises to a minimum. If he doesn't appreciate seeing friends at this moment, visit with them on your own.
- Develop methods of compromise with him, and, most importantly, don't take his remarks personally. You are not causing his bad mood.
- Model calm behavior. Remember that structure, repetition, and consistency can help in dealing with his agitation and irritability.

#### Outbursts

Some individuals with a brain injury can display a multitude of physical and/or verbal outbursts. Excessive swearing is a common characteristic, which can be very embarrassing to you in social situations. Often an individual with a brain injury will blurt out something that he is admittedly sorry for later. Yet he may continue to repeat this behavior no matter how badly he always feels each and every time it happens.

At times, the outburst may be physical rather than verbal. Although those situations may seem more explosive, they are not necessarily so. Try to remain calm and safe during those times. If the physical outbursts are intolerable, explore assistance from rehabilitation professionals and

consider admission to a full-time facility that addresses the short- and long-term needs of the behaviorally impaired person with a brain injury.

### Suggestions

- Try to anticipate what events provoke your family member. Many an abusive situation was circumvented by a wise spouse who anticipated and worked her husband through a bad situation before it occurred.
- Let your family member know what your parameters are; don't be afraid to tell him that you will not respond to his needs if he uses that tone with you. Then stick by your guns and don't respond.
- Talk with friends and other people who will be in his company before they come to visit him for the first time. Explain that there may be changes in his behavior and one of those changes may be that he has a short fuse.
- If you are sensitive, you may find that your feelings are easily hurt by your family member. But remember he does not mean his words or actions personally. Develop a thick skin so you are not so easily hurt.
- Don't allow your family member to abuse anyone in your household; know when and to what degree to seek professional help.

It is also important to remember that outbursts may disappear for a while, but then may return again. Recurrence of outbursts can be a result of changes in the environment, function, or stress. You may think that disturbing issues have been resolved, but they may not be resolved for your family member. Be prepared for recurrence, and if it does happen, do not blame yourself.

### Egocentric Behavior (Me, me, me)

Egocentrism after a brain injury is caused by psychological, organic, and situational factors. Egocentrism is maintained by the damage to the brain, specifically the frontal lobes. Situationally, the rehabilitation process, both acute and chronic, may foster some egocentrism. During this lengthy process, the time, efforts, and concerns of many persons are focused on your family member. This indirectly reinforces your family member's egocentrism.

The impact of "me, me, me" on your home life can become very draining. Your family member may not be able to contribute anything in the household setting unless it directly relates to him. He may often say that you don't understand what it is like to have a brain injury. He may put himself in competition with the children for your attention. You may find his need to have his demands met at the drop of a hat very debilitating.

### Suggestions

- You may have to accept the responsibility of getting the point across to your family member that the world does not center around him. To get this point across, you will have to make certain that it doesn't!
- Do not let your family member put you on a guilt trip. If he is allowed to do so, you will not be able to deal objectively with his behavior.

- The "me, me, me" attitude can cause many problems in work and social situations. He must have consistent and repetitive feedback about his behavior to eliminate any future problems.
- He needs feedback on how others view his interactions and responses. Supportive statements clearly demonstrating that a friend or family member was hurt or offended by his "me" attitude can be quite effective.

## Dependency

The person who was once independent and probably somewhat of a risk taker now acts as if he needs permission to eat what he wants for dinner. He no longer wants to make decisions on his own, nor does he want to do things on his own. Consequently, his social circles may begin to shrink, and you may soon become one of the few social contacts in your family member's life. It can be painful to watch a once independent person rely on someone for everything.

## Suggestions

- Given your family member's physical status, make him do as much for himself as possible. Don't always be there for him.
- Don't push, but add one person to his social circle at a time. Ask either an old friend or contacts from the support group to visit or go out with him periodically.
- Again, structure and consistency will assist your family member in feeling comfortable in activities. That way he can begin to feel less dependent.

## Denial

The concept of denial is much misunderstood. It is not necessarily a result of your family member's avoiding what has happened to him. Instead, it reflects a lack of self-awareness. He truly does not see himself as he really is. This can cause many problems in the home situation. He may be very unrealistic about what he is able to do, and thus will try to maintain the lifestyle he had: before the accident. This is never more evident than in the area of driving. People with brain injury very often decide that they are able to drive and will not listen to anyone, giving others the scare of their lives.

Denial or lack of self-awareness may also be evident in the work arena. Many times the individual with a brain injury will decide there is no reason why he can't do his old job. Physically he is back to normal, therefore it is very difficult for him to realize his cognitive deficits. You may hear him say that he has memory difficulties, but that is about all he will be able to admit. The rigidity, problem solving difficulties, impulsivity, or other cognitive and behavioral issues are not evident to him.

## Suggestions

- Continue to be honest. However, it is appropriate to allow your family member to hold on to some of the denial, or else he may lose all motivation.

- If your family member insists that he is able to do something (for example, balance the checkbook}, and you have serious doubts that he can, allow him to try and allow him to fail. However, be there to support and assist him in learning the task if it is appropriate.
- Be able to recognize the smoke screens. At times your family member may complain about a therapy and refuse to do a task. He may be doing so because he is not aware of his need to complete the activity. He may perceive that he is accurate in his activities or interactions with people. Therefore, he may not see the need for continued drill. Do not let him convince you that he no longer needs therapies or these other activities.
- You may find that your family member decides he has outgrown the local support group and will not attend any longer. He is sure he is getting nothing out of it. Don't let his lack of self-awareness stop you from continuing with the activities in the group. Encourage him to accompany you.

### Paranoia/ Suspiciousness

The feeling that someone is out to get you is not uncommon for the individual with a brain injury. In most instances this feeling is not based in fact, yet the paranoia can raise havoc in the home situation. Your family member may have the feeling that people are talking behind his back. Suspiciousness often results from the inability to size up a situation and draw accurate conclusions about what is going on. Cognitive deficits mentioned in the earlier section are affecting his ability to think clearly.

Additionally, your family member now has a number of people who are involved and interested in his life who were not present before his injury. He may be suspicious about what they want. Because of his suspicion, he may assume that if anything is missing it has been stolen. He may assume that people at work are out to get him, or that the therapists are trying to sabotage his progress. The most difficult issue to deal with may be his suspiciousness toward you. Again, remember that it is very important for you to develop a thick skin. You must realize that this is only part of his behavioral pattern and that he does not mean it personally.

### Suggestions

- If your family member is suspicious of you, separate yourself from the accusation, and separate yourself from what is said. Ignore it if at all possible.
- Do not argue with him. That is almost an admission of guilt to your family member.
- If he is suspicious about insurance companies, worker's compensation, or others, point out the inaccuracies in his observations and then move on.
- Do not allow yourself to fall into the trap of responding to these suspicions along with your family member.

### Impulsivity

Your family member's other behavioral issues may be further complicated by his impulsivity-acting before thinking. When we describe frontal lobe function, we include its role not only in

maintaining appropriate behavior, but in stopping us from acting inappropriately. The mechanism lets us know when to stop before we go too far.

A person with a brain injury has lost this function. He will go too far. He will say the wrong thing; he will deck someone; he will drive a car when he has been told a million times not to do so. He will engage in an unsafe work behavior when he has been warned about his limitation. He will increase his physical exercise level, even though he has been told his limitation. His attempts at ambulation and transfers may not be safe, even though he knows the appropriate procedure. These examples give you a glimpse of what you may be dealing with in the home setting. If your family member has been home for a while, you can probably add to the list.

Dealing with impulsivity is tough, especially since it is such a well-ingrained brain-related behavior, and applies to so many situations.

### Suggestions

- Allow your family member to assume responsibility for controlling his impulsivity. He must learn to think before he talks; to know what his limits are; and to assume responsibility for staying within those limits.
- He needs repetition of correct responses in order to control his impulsivity. Let him practice these responses at home before he gets involved in volatile situations outside of the home.
- Attempt to keep your family member out of danger. If you know he wants to take the car, hide the keys. If you know he plans to move unsafely, be there to make sure he doesn't fall. Beyond that, you will only find yourself in a verbal confrontation with him if you attempt to control this behavior. By the time you respond, it is usually too late.

### Depression

Many rehabilitation professionals view depression as a sign of progress. It often means that the individual with brain injury has come to some level of awareness of his difficulties. He is letting go of the denial.

It is important for your family member to accept the fact that he has deficits and that they will impact on the future. If you see that your family member is depressed, your role becomes that of walking the fine line between keeping him motivated and helping him to modify his goals realistically.

Signs of depression to look for are: a change in eating habits, with either increase or decrease in consumption; sleeping more hours at night and more hours during the day; remarks about the futility of what is going on; remembering the past with great frequency, duration, and emotional labeling. Spending much time in non-directed behaviors, such as watching television, may also be a sign of depression.

## Suggestions

- Do not assume responsibility for your family member's depression. You have nothing to do with it. By the same token, do not buy into what he is doing and become depressed yourself.
- Keep your family member busy. Do not let him dwell on himself. Encourage him to leave the house, get involved in projects, and keep and maintain social contacts.
- Do not become too overprotective of your family member while he is in this state. Remember you can be a support. However, he has to deal with the depression through his own coping mechanisms.
- Watch out for and take seriously any expressions of suicidal thoughts and plans. Seek professional assistance and guidance.
- Watch carefully for signs that your family member may be turning to alcohol or drugs as a method of coping with depression. It is important to remember that while depression is transitory and situational, it may disappear and reappear frequently. You and your family member may have to deal with it again and again.

In the course of rehabilitation your family member will have his ups and downs. At different times along the way he may realize that another aspect of his life has changed and depression may again be an issue.

## Sexuality

One's self-perception is often tied to the issue of sexuality. Given all the changes that may have occurred for a person with a brain injury, it is pretty safe to say that he may have a modified self-perception. Fear of losing effectiveness in the sexual area is a cause for grave concern, especially for a young adult.

The second issue that effects sexual openness is the same issue that affects impulsivity. Your family member may always have had the sexual thoughts he is now expressing and attempting to experience. However, he may never have expressed them before his injury. Now his remarks and actions are closer to the surface and expressed more often. Sexual remarks may be more offensive to others simply because of the nature of their content. However, they should be treated in the same way as his other impulsive remarks.

In some cases of brain injury, there is a physical reason for the obsessive need for sexual fulfillment. However, it is usually the socially inappropriate outward behavior that causes problems for the person with a brain injury. If you have had a fairly conservative family upbringing in relation to sex, this change can be very difficult. You are not used to the overt comments, jokes, or overtures that can become daily occurrences in your family member's life. You are not prepared to witness this behavior, much less able to modify the responses.

Social contacts may turn away from your family member because they are uncomfortable in his company. They may be hard pressed to understand why he is making a pass at their girlfriend or

wife. The result will be social isolation. If this occurs, your family member may try to blame others for the isolation. He will have a difficult time understanding how his remarks have been offensive.

### Suggestions

- Each time your family member behaves inappropriately, call him on it, in a non-threatening and non-combative manner. Repeat and repeat that his behavior is unacceptable.
- If you think that your family member will attempt to make physical contact with someone, warn those in his company to stay at arm's length from him. Do not let them put themselves in a vulnerable situation.
- Tell others not to bother with excess verbiage, like "I'm married," or "I'll tell your mom." It won't matter at that point.
- A lecture about the moralistic implications of his behavior will do little to change it.
- Contact a trained professional to provide an outlet for your family member to express his sexual feelings and frustration. A sex therapist who has some understanding of individuals with brain injuries should be contacted if the case warrants.
- Keep cool and don't overreact. Try to be detached from the content of the message.

### Social Immaturity {Can we go out in public?}

The overall result of a brain injury may be that the person appears and acts less mature. His language may be characterized by egocentric responses. He may have difficulty engaging in conversation because he is not able to follow it properly or know when to jump in. He may ask inappropriate questions in both the social and work settings. At times the subtleties of a social situation may be lost on him. In addition to the verbal interactions, his body language and other responses may be less mature. He may laugh excessively at the wrong time, touch people inappropriately, and play childish games.

Because social interactions are a culmination of many cognitive and behavioral issues, the return to near pre-injury level skills in this area is extremely difficult. The most common verbal behavior is that the person with a brain injury cannot stop talking about the injury. Another common behavior is that he will become too familiar with people in a conversation. For example, he will tell the cashier at the grocery his whole life story or even ask the cashier for a date.

### Suggestions

- Retrain your family member, if you can, on how to act appropriately in social situations. He may need to be cued on an ongoing basis. Set up your cuing system to signal inappropriate behavior. As cited in an earlier example, use a clearing of the throat or subtle raising of a finger if he makes inappropriate remarks in social situations. Always review the cuing system before you go out, every time.
- Do not get discouraged with this activity. Remember that even though he lost his social skills overnight, he did not learn them overnight originally and the restoration process may be lengthy.

- Do not avoid social situations for fear that your family member will not act appropriately. The only way he will learn is to be placed in these types of situations. Social skills must be practiced outside the home or outside the immediate family.

## General Suggestions

- In addressing the cognitive and behavioral issues associated with brain injury, it is important to keep a few general observations in mind:
- Although the recovery from brain injury is somewhat predictable in terms of cognitive and behavioral issues, each person is an individual and his recovery should be viewed as such. The concept of time and its role in the rehabilitation process can never be overemphasized. Cognitive/behavior issues are very personal, therefore the person with the brain injury can be encouraged, given therapy, and consoled, but when changes are made, they are his changes made through his motivation for change and on his time schedule. Our task is to be patient and allow for this process to happen.
- Recovery from brain injury is like a roller coaster ride. Even though you think you have resolved many issues, you may find that in a few months or maybe even years an issue you thought was buried will reemerge. For example, if your family member's work conditions change, all his old issues of suspicion and immature social behavior may arise, until he feels comfortable with the change. Another example is self-awareness. When your family member becomes more aware of his difficulties, depression may again become a reality, standing in the way of progress.
- Ongoing cognitive issues will change with the situation. Life never stays the same. Jobs change, family structures change, friends change, financial issues change. We lose people we love, we make new friends, our stress levels change at a constant rate. All of these changes are difficult for the person with a brain injury.
- There is no Band-Aid or quick fix for any of these issues. You and your family member have no choice but to adjust to the fact that you are in this for the long run, and use whatever professional help and support you can muster from those around you. You, as part of the family support team, are the key to your family member's future success. Meeting that need will present a lifetime challenge for you.

## VIII: BASIC CONCEPTS OF BEHAVIOR MANAGEMENT

### Team Approach

The basic concept underlying successful home care is that the family takes a team approach to adapting to the changes in everyday behavior in the home. Every individual should be informed about their family member's behavioral, physical, and emotional needs. Decisions should be made at family meetings about how behavioral issues will be handled, and how to respond consistently to the family member.

Family meetings are a good time for mutual support and reinforcement. Remind each other not to confront your family member when he is angry; not to return anger with anger; not to put yourself in danger; not to reinforce him by repeating yourself. Remind each other to reward him often and for small steps. Find rewards that are motivating for him. Rid his environment of unneeded distractions. Keep family directions clear.

As a team, remember that your family member came home with organically based behavioral problems. However, if he learns to manipulate his family, the organic behavior will be complicated by manipulative behavior, and you will have a more difficult problem on your hands.

### Structure, Consistency, Repetition

These terms have been referenced throughout this manual. It is important always to keep them in back of your mind. They are important concepts for behavior management. When using rewards make certain there is a particular schedule (structure) that your family member can count on. Is there consistency to your reward/punishment system? Do you always reward with the same activity or privilege? Can your family member anticipate what his reward/punishment will be? Does it directly relate to his behavior? Is the system clear enough for your family member to understand?

The concept of repetition is extremely important. As stated elsewhere in this manual, your family member must be presented with information a number of times before the task or behavior becomes his own. On the opposite side of the coin, however, you are negatively reinforcing your family member's behavior when you repeat directions for him once you are certain he understands them. Having you repeat yourself can be a manipulative behavior on the part of your family member. This is a behavior you do not want to reinforce.

### Practicality

It is easier for you as a family member to have a few practical behavioral management techniques up your sleeve than to have read a mountain of literature on the subject and become over persistent in tallying responses, measuring baseline behaviors, and varying types of consequences and reinforcers. Use the easiest system your family member will respond to, but keep it visual and meaningful. Do not make the behavior management program so complicated that you are burdened by the process.

## Is There Enough Reward?

Reinforcement (rewards) should occur in small steps along the way. Early on, your family member may not be able to change any behavior unless he is rewarded for very small steps. For example, in getting ready in the morning, help him to break the task down to brushing teeth and hair [reinforcement/verbal praise], and after he has established that behavior you can move on to showering, or to dressing. But don't attempt the whole process without rewarding for the small steps along the way. Later, the reward of a token or check mark for completing the entire dressing process may not be enough. However, the reward of his favorite food or an outing may be. The reward has to be enough in duration (small steps) and amount (large) to encourage your family member to behave in the appropriate manner.

## Is the Reward Meaningful Enough?

Your family member needs to be included in the behavior management process. He needs to make the choice of rewards, because these rewards need to be meaningful for him. If there is a particular item that he wants very badly, make that his long-term reward. If there is a place he wants to visit, make that his reward. If that does not work, offer small monetary rewards along the way, in order for him to earn either the trip or wanted item.

Saving money rather than tokens may make rewards much more concrete and meaningful. A drawback might be that he has difficulty reaching that goal because he spends his reinforcers along the way. Find the method that works best for him, knowing you eventually want your family member to respond less to concrete reinforcers and more to verbal praise.

It may take a long time to achieve, but that is OK as long as the goal is to change his behavior, not earn tokens or model cars or other items which presently may be his goal. You also have to keep reminding him that his long-term goal is to change a particular behavior.

## Clear and Immediate Feedback

Whether your family member has made a negative or a positive response, your feedback should be clear and immediate. We all remember from our own childhood, that "Wait until Daddy gets home" never worked. Feedback must be immediate and given in non-emotional terms. If your family member begins using abusive language toward you in a social situation, you should respond to him the way you would at home. Tell him you will not listen to that language and walk away. Clear and immediate feedback is particularly important when you are dealing with his negative behavior.

## Don't Editorialize

Once you have given your family member feedback, particularly in relation to unacceptable behavior, drop it. You do not need to continue referring to his behavior as childish or as a personal assault on you. It may be difficult not to be abusive and combative in return. However, since you have given him the parameters for acceptable behavior, repeating your personal feelings about his noncompliance will do nothing to increase appropriate behaviors.

## Redirect When Possible

It is to your advantage to foresee explosive situations and to prevent them before they occur. For instance, if you are entering a restaurant that reeks of smoke and your family member hates smoke, go somewhere else. If you see that the restaurant is noisy and overcrowded, go somewhere else.

If you know that a certain person within the support group always sets off your family member, let your family member know in advance that the person is there, and you will be watching and cuing his behavior. He should look to you for support and cues. If you realize a particular household task is difficult for him, stay with him and give consistent rewards/reinforcers for his efforts to complete small parts of the task.

## Model Calm Behavior

No matter how volatile the situation may become, remain calm. Don't feed into your family member's behavior. Don't escalate the behavior. Apply calming techniques to get through the situation. Feel confident in the fact that you can handle this situation. No one knows your family member as well as you do or can handle his behavior any better. Be confident, be calm, and do what you have to do.

## Know When to Say When

There are times when your family can't go it alone, when it is too dangerous for you and your family member in the home environment. At those times it may be necessary for you to call in professional help. The first place to try is the rehabilitation center where he was an in- or outpatient. Often, the rehab center can provide you with additional services. If funding or other issues preclude you from obtaining services there, contact your local mental health center for assistance. Members of your support group may also have information on facilities that provide services on a sliding scale, where charges are based on your income.

If your family member is returned to a rehabilitation setting, professionals may evaluate the situation and determine that with outpatient therapy his behaviors can be monitored and controlled. They may recommend an alternative temporary placement outside the home for your family member. This may not be an easy solution, and you may regard the situation as some form of failure on your part. Be very careful not to do that to yourself. At times in the lifetime rehabilitation process, there will be a number of ups and downs. The roller coaster has its peaks and valleys. Often we don't know why a person's behavior will suddenly deteriorate to the point of needing a placement outside of the home.

A specialized setting for the brain injured, which will address his behavioral problems on a twenty-four-hour basis, should be strongly considered. Use this time as a much-needed respite for you. Pull some of the loose ends back together in your life, so you are fresh when he comes home.

## Abrupt Changes in Behavior

In a fairly short amount of time, your family member will establish a behavior pattern that is fairly predictable. You will be able to recognize any changes in his behavioral pattern. If you see that he is less attentive, more aggressive, less motivated, or more lethargic, your first call should be to the physician to find out if there is a physical reason for the change. Medication levels often need to be monitored, or follow-up testing may have to be done. Medical changes often occur on a lifelong basis with people who have experienced a brain injury. So be alert to these changes.

Your family member should be scheduled for periodic evaluations, at least annually by both the physician and a rehabilitation treatment team. These evaluations will monitor changes in his physical, psychological, and functional status. Recommendations for further rehabilitation or medical care can be made at that time.

## IX: LIFELONG ISSUES

Throughout this manual we have stressed the long-term nature of brain injury rehabilitation. We emphasized the fact that your family member will never be the same, and that you need to make lifelong adjustments. This section of the manual addresses some of the lifelong issues for which you will need to prepare.

### Regaining Social Contacts

The cognitive and behavioral issues discussed earlier result in long term changes in lifestyle, for both you and your family member. Some psychological issues are quite apparent and others are more subtle. However, one area that is consistently affected in a not so subtle way is the change in your family member's social circle and availability for social activities. After a brain injury, all of the people in your family member's social circle may remain there for a while. However, don't be surprised if they soon disappear. Although you may take their reaction personally, remember that in their eyes, your family member has changed dramatically. He doesn't act the way he did before, and they no longer have anything in common with him.

He also may not seek to continue their friendship. His social circle may change for a while, as he goes through different sets of friends. The result may be that your family member ends up with no stable social circle, and no idea of what to plan for social activities. Building a new circle of friends may be very difficult, but opportunities should be made available for him to be part of a social environment out of the home.

To make social contacts your family member needs to be involved in social situations. Suggestions include: parks departments, singles groups, churches or synagogues, volunteer services, senior centers, brain injury support groups, community colleges, athletic clubs, and hobby groups. These groups and agencies usually publicize a listing of activities they are sponsoring, and costs are usually minimal.

You and your family member need to determine what is most appropriate for him. He may be interested in a hobby club that races model cars. Or in a community college course in career

development. Or he may decide to get back in shape and become involved in the local YMCA or health club. The point to remember is that you will need to assist him in making the process become a reality. As with any other activity your family member wants to attempt, it will not just happen. This may mean setting up the situation, providing the transportation, going with him when he asks, and making certain he follows through on what he started. If possible, your family team can take turns giving your family member the support he needs. One relative may be more interested in the sport-related activities, while another may want to accompany him to the community college activities.

At some point, we all run out of suggestions and ideas. You may want to return to the team at the rehabilitation setting, in particular the recreational therapist, to explore other appropriate outside activities for your family member. An activity that was not of interest for him at one time in the rehabilitation process may be at a later time. For that reason you will always want to keep your options open. It may be fun for you to learn some new leisure life skills too.

This section is not intended to give the impression that you have to hold your family member's hand all the way through his social integration process, nor does it imply that you should. You will want to fade out of the situation, but encourage him along the way. You need to maintain a delicate balance between your support and your family member's feeling of independence in carrying out these activities. In order for him to succeed, he must feel like he is empowered to do so. This balance is difficult to achieve, but one of the most rewarding experiences in the brain injury rehabilitation process.

### Guide for Alcohol and Drugs

An issue that usually arises when discussing social interaction is the use of alcohol and drugs. A person with a brain injury makes less appropriate decisions about this issue than does the rest of the general population. Opinions vary from the viewpoint that people with a brain injury should not drink at all to the viewpoint that they should drink only in moderation. However, if your family member is on any kind of medication, he should not be drinking at all. Obviously, this is to avoid the possibility of a negative reaction between the alcohol and the medication.

It is difficult for the individual with a brain injury to attempt to drink in moderation, because he may have poor judgment in determining what moderation is. He does not stop after a few beers. The best advice to give your family member is not to drink again after his brain injury. Obviously, drugs are dangerous for anyone and there is no question that your family member needs to avoid them.

Convincing your family member that he should change his lifestyle so that it no longer includes alcohol or drugs may be difficult, particularly if his friends regularly engage in drinking, drugs, and partying. But it is absolutely necessary and may even save his life.

## Functional Independence

An issue that goes hand in hand with your family member's ability to become involved in social situations is how independent he can be. For his long-term planning you may need to ask yourself some searching questions about how well he could function in the home and community without your assistance.

Ask yourself the following questions: How independent is he in bathing, dressing, eating, and in his personal hygiene? Does he or will he always need someone to assist him in these areas? And who should that person be? And more importantly, if that person is you now, who will that person be after you are gone? Is his walking functional? Is he too unsteady to be independent in the home? What precautions need to be taken for his ambulation and wheelchair mobility in the community setting? In what environments can he be independent? Which shopping malls, which stores? Can he meet his own needs independently in shopping, going to the post office, paying utilities?

What about adaptive devices and modifications? Are modifications needed for safety's sake in the home, such as alarm systems or phone monitoring? Have arrangements been made for any kind of adaptive devices or environmental controls?

It helps to keep up to date with the latest advances in rehabilitation technology. The best way to do this is to network with other families in the support group, and by keeping in contact with vendors for the current equipment.

If your family member will not be able to function independently in the home or community environment, or someone in the home is not able to provide that supervised care, a full-time structured environment outside the home may be needed for him. If that is the case, you will want to explore your community options. Long-term care facilities, group homes, and supervised apartments can be reasonable options for those who cannot manage independently.

## Transportation

One of the key issues in independence is transportation. How will your family member get to where he wants to go? One of your first contacts should be with the local public transportation system. Are you in a location that has city buses? Can these city buses take your family member where he needs to go in a reasonable time, and is your family member capable of handling the bus schedule on his own, without assistance?

If the public transportation system is not an option, explore the handicapped transportation systems. They may have various names, depending on the area. They should be able to provide transportation to and from therapies and doctors' appointments. Restrictions vary from county to county, and services are usually handled at the county government level. There is a fee for this service, which is usually either covered by the insurance carrier or through private reimbursement.

## Driving

Nearly all persons with a brain injury want to drive again. It is a sign of independence and very important to their self-esteem. In some cases this decision has already been made. Either your family member has been cleared to drive or it has been determined that he should not drive again, and he no longer has a license. If your family member is awaiting a driver's evaluation, driver's training, or medical clearance for driving, the issue is more difficult to handle. He may continually assert that he knows he will be able to drive again, so why don't you let him try now? However, when you make long-term plans, make arrangements based on current conditions; do not assume that your family member, who does not have a license, will be cleared to drive at a later time.

## Educational Goals

Interfacing with the community for your family member often involves exploring the options in either the school or work setting. If your family member is of school age, there may be programs open to him. However, children with a brain injury sometimes do not meet criteria for traditional programs within the school system. A great boost for all children with brain injuries came in October 1990, when a special category under public law 101 .47 6 was established for the child with traumatic brain injury. It calls for local school districts to provide for the educational needs of this group of children as a special education group, not unlike the specific learning disabled, emotionally handicapped, or mentally handicapped groups. Children with brain injuries should benefit greatly from this new emphasis on their educational needs.

Your child may currently be served through a variety of programs within the school system. He may be placed in a regular classroom, a special education classroom (such as learning disabilities, emotionally handicapped, educable handicapped), or a classroom for the physically handicapped. He may also be taught at home through the hospital homebound program. In any case the curriculum will be designed for him through an individual educational plan (IEP), which in essence is a treatment plan used in the school system.

Because children with brain injuries comprise a new population for the school system, you may need to play an active role in educating the educator, assisting the teacher by helping him understand your child's specific needs and how they relate to the classroom. In particular, your family member's classroom teacher will need to know about the cognitive/behavioral issues associated with brain injury, so he is prepared for them in the classroom setting.

One of the issues you may face is that your child's educational goals have changed. While a college career may have been an appropriate consideration prior to the brain injury, now the completion of his high school education and vocational training and placement may be more realistic goals.

It is more difficult to determine what the long-term effect will be with someone who is injured as a child or adolescent, so educational prognosis varies greatly. Be cautiously optimistic about future educational goals for your family member, but temper your optimism with the reality of

his educational potential. The closer his educational goals can be to his actual potential, the greater his chance for success. The more your family member is able to make a long-term commitment to an educational field or vocation, the more likely he will become socially viable and empowered to control his own life.

## Vocational Goals

Long-term vocational goals are closely related to educational goals. If you need assistance with vocational placement, one of your first calls should be to the State of Florida, Division of Vocational Rehabilitation (D.V.R.). If your family member was admitted to any hospital within the state he should be listed in the Brain Injury Central Registry. You may have already received services from the Florida Brain and Spinal Cord Injury Program, which is administered by the Division of Vocational Rehabilitation. If so, you may have been referred to the regular vocational rehabilitation division by the D.V.R. Brain Injury Case Manager. If not, and if you feel your family member could return to work, contact the regular D.V.R. yourself to determine if the Division can assist you in obtaining appropriate therapies and services for returning to work. The D.V.R. will assist your family member with work evaluation, job placement, and training once he has completed the necessary therapies. The Florida Brain and Spinal Cord Injury Program may be able to help you with other non-work-related services.

The best case scenario is when your family member can return to his old job with an understanding employer who is willing to work with him. However, this is not always the case. Return to work is often a long process, with many ups and downs along the way. If your family member is able to return to competitive employment he may have to be retrained in a new vocation, which may take a period of adjustment on his part.

The cognitive/behavioral issues addressed throughout this manual would certainly affect his performance on the job. While they may not affect his ability to get a job, they may well affect his ability to *keep* a job. Research tells us that keeping a job is much more difficult for the person with a brain injury than getting a job.

If your family member is unable to enter the competitive job market, he may be helped by working with a vocational counselor to structure a job for him that he is able to perform successfully. If this is the case, your family member may be able to work for part of the day or week. A reentry to a vocational setting can do much to enhance your family member's independence and feeling of having control over his life. Again, he may well find a job, but because of cognitive/behavior problems may not be able to retain it.

Another alternative for employment is the sheltered workshop setting. Individuals with a brain injury sometimes object to this type of setting, because they think they are very different from others in the workshop (usually a developmentally disabled group). The wages earned are usually much less than the individual was used to earning, and some people with brain injury do not consider this "real work." However, this may be a very beneficial setting for some people with brain injury, giving them a feeling of independence and control over their lives.

The search for vocational pursuits is an ongoing process. Just because your family member is not ready for a structured job or competitive employment now does not preclude future possibilities. Never close that door for him. You do not know when the right opportunity may be available.

One area where a person with a brain injury can make a great contribution to society is as a volunteer. Volunteers are desperately needed in schools, nursing homes, churches, private and government agencies, and recreational departments. The list is limited only by your imagination. If your family member is not able to work right now, explore some area where he may volunteer. Although he may not be earning a salary, he will be making a worthwhile contribution that is greatly needed. Volunteer positions also often lead to jobs.

## Getting Assistance

If you are committed to the lifetime care of your family member, become familiar with all of the agencies that can serve you. You must become the advocate for your family member, and as such, for all people with a brain injury. In essence, you are a case manager for his lifetime needs.

There are many systems you need to be familiar with in taking care of the long-term needs of your family member. A key person in the rehab process who can help you with this process is the case manager or managers who have worked with you in the past. You may have a case manager who supported you while your family member was in a rehabilitation center, or you may have a case manager who is handling the case for the insurance company, worker's compensation, or vocational rehabilitation.

These people can be a wealth of information throughout the rehabilitation process and often long after the formal process ends. A case manager keeps up to date on new programs and researches possible new funding sources. He is also current on insurance laws and recent legislation. He coordinates the therapy programs and is accountable for maintenance or appropriate programs for people with a brain injury. Case managers also assume responsibility for the coordination of therapy with the funding source.

Most likely, your family member returns to the rehabilitation center for an annual follow-up. During this time, meet with the case manager, and ask to be updated on any new insurance or legislative information. Ask again for the resources available, just in case there is anything new with which you are not familiar.

Listed below are state and federal agencies that can provide assistance on both a short- and long-term basis. Information on other agencies may be obtained from Brain Injury Association of Florida, and through your local support group. Never underestimate the knowledge you can gain from being involved in your local support group.

Please remember that processes may not happen as quickly as you might like within some of the following organizations. Be persistent in your quest for services, but learn to be patient in waiting for them.

## Social Security Administration

Information in regard to social security disability insurance and social security supplemental income can be obtained directly from the Social Security Administration office. In making application to Social Security, a person is often turned down the first time. However, on reapplication he may meet the criteria for a program. Your case manager should be able to give you information on how these services generally work, and within what time-frame your family member may be eligible for services.

## Other State/Federal Agencies

A number of other agencies maintained by the Department of Health, the Department of Children and Families, the Department of Labor and Employment Security, or other government branches may provide assistance depending upon your particular need. A partial list includes:

- Medicaid
- Food stamps
- Aid to families with dependent children
- Developmental Services
- Vocational rehabilitation
- Medicare
- Veteran's Administration
- Worker's Compensation

There is always a lot of red tape when dealing with a government agency. To facilitate the process as much as possible, become a good record keeper. Start keeping a log of all your family member's appointments, and the results of these appointments. Keep a phone contact log, documenting all phone calls with the name of the person called and the results. Maintain a copy of all your family member's medical records, and never give away your original copies.

## Advocacy

You are an advocate for your family member, and you will have to be very resourceful to get everything you think he needs. You have to approach the task in an assertive manner and not be apprehensive about what others may think of you. Don't ever be ashamed of having to ask. Because brain injury rehabilitation is a relatively new field, use as much pressure as you can to get what you need for your family member.

Remember that when you pave the way you make it that much easier for the next family dealing with the same issues as you. Never forget the importance of political advocacy for the population of people with brain injuries in general. In order to make a difference, you need to get to the people who hold the purse strings, the legislators who make the rules, and the cabinet members who make the decisions about policies. If you are so inclined, political advocacy can be of great benefit not only to your family member but to all survivors of brain injury. If you have the energy, please give it a try.

## Financial and Legal Issues

Your role as a personal case manager/advocate is not complete without a close scrutiny of the financial and legal issues that surround your family member's future. It is easy to get caught up in the day-to-day activities with your family member, and not consider the long-term issues. But it is extremely important to do so.

### Life Care Plan

If there was a settlement involved in your case, the attorney may have used a life Care Plan to determine the future cost of medical, rehabilitation, caretaker, transportation, building modifications, vocational training, and other lifetime care issues of your family member. This plan would have outlined the dollar cost for these services. If you have this plan at your disposal you are fortunate. If you are so inclined, you may want to hire a life care planner to do this for you. If you do not have the financial resources to do so, you will just have to become a case manager/advocate/life care planner yourself.

In determining the cost of these services, seek out your family member's current or former therapists and physicians as resources. Ask how much therapy, medical attention, medication, equipment, equipment repair and replacement, and the like will be needed for your family member. Be sure to estimate and include the cost of transportation to maintain that therapy. Include future equipment costs as well as costs for replacement and repair. It is important to project any future medical, rehabilitation, and medication costs. If he needs them today, anticipate that he will need them in the future. Contact with the facilities that provide these services should give you that information.

Keep a positive emotional attitude, but be realistic about your family member's future. When it comes to a plan for life care, you should anticipate anything that could possibly go wrong and include that in your cost projections, such as the possibility of inpatient behavioral admission or potential surgeries.

Another issue to consider is who will take care of your family member when you are gone. What arrangements do you need to make? Sometimes this can be best handled through a life insurance policy, or through the structuring of the settlement. Whatever the situation, you need a realistic idea of what the cost will be. You also need to build in extra allowances to allow for future inflationary factors.

### Guardianship

In addition to financial plans, legal issues also must be addressed on a long-term basis. The most important issue is that of guardianship. Since guardianship laws frequently change, you should contact your family attorney for more complete information about how those laws apply to you. However, a couple of scenarios will be reviewed in this section.

In some situations your family member may obviously not be able to handle his affairs, so there is very little question as to whether or not a guardianship needs to be established. Guardianships

can be established for the purpose of managing money, property, or the person. If your family member was declared incompetent (incapacitated), it has been rendered that he is unable to handle his own needs in any of these areas.

In some cases, guardianship is divided among different individuals; one may be responsible for money and property and another responsible for the care of the person with the brain injury. An example of this is in a settlement in which an outside fiduciary is responsible for handling and management of funds, while a family member is responsible for guardianship of the individual. Those arrangements are made through the court system.

In other cases, the family may be responsible for all levels of guardianship. This places a burden of responsibility on the family caregiver to manage what can be a very large sum of money. A life care plan and financial advice from an expert is often very beneficial.

New guardianship laws in the State of Florida may mean some changes for family caregivers who are presently dealing with this issue. Language has been changed. The term incapacitated is now used instead of incompetent. Different levels of incapacity are determined by the court. Various civil and legal rights may be maintained by the individual declared incapacitated. Under this new law, a limited guardianship can be established for a particular purpose or for a limited span of time. This change makes it easier for the individual who has been deemed incapacitated to regain his former legal status. The law is applicable in providing a guardianship for an individual while he is in a rehabilitation setting. The guardianship can be time limited, and his status restored once he is discharged.

If you have any questions about the new guardianship-laws and you think they may be applicable to your situation, contact your attorney for clarification.

### [After You're Gone](#)

Your family attorney can help you in setting up life insurance policies to ensure financial security for your family member, and assist you in drawing up a will that will name a new guardian for him.

Your choices will differ depending on the available long-term options. Your family member's needs may be best met in a long-term facility such as a nursing home, where professionals can be responsible for his daily medical care. They may be best served in a group home setting. There may be another family member who will assume responsibility for his lifetime care. Choices for your family member will greatly depend upon your financial and family resources. Each family must make a choice that is specific to them. Because of the immense responsibility of lifetime care of your family member, you cannot leave these issues unattended or to chance. Settling this question, no matter how difficult it may be, will give you peace of mind.

## X: CONCLUSION

This manual was intended to present an overview of the issues you face in bringing your family member home and in taking care of his lifelong needs. It was not meant to be comprehensive, nor does it cover all of the issues. For more in-depth information, you are directed to Brain Injury Association of Florida, resource list or other professional sources available on particular topics of interest to you.

When your family member's life changed in the split second it took for him to be injured, your life changed too. You have been handed one of life's greatest challenges. How you deal with it is as individual as the circumstances that surrounded your family member's injury. Your actions now may very well determine the path you follow for the rest of your life.

*You* need to be comfortable with the choices made in regard to treatment, medications, behavior management, long-term care, financial and legal issues, and the like because you have to manage those choices. Assume as much strength and power as you need to make things happen for your family member.

As you ride the roller coaster of brain injury rehabilitation, remember that even as you dip down to the base, the roller coaster will rise again. It may be a slow uphill climb, but there will be improvement and adjustment.

There may be times during your family member's rehabilitation process when you feel you just cannot meet the challenge any longer. When this happens, listen to yourself, and take some respite from your family member. You may only need a part-time respite, or perhaps a longer period of release. Whatever the case, do not look at it as a personal failure. If you need to explore the possibility of placing your family member somewhere else rather than your home for either a short or long-term period.

You have to know when you have reached your limit. If you do not, you will be unable to meet the challenge of managing your family member's rehabilitation program. You are your family member's greatest resource at this time, so protect and take care of yourself.



