



# **Picking Up the Pieces After TBI:**

## **A Guide for Family Members**

Angelle M. Sander, PhD

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# ***PICKING UP THE PIECES AFTER TBI: A Guide for Family Members***

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**I**n the book *Missing Pieces: A coping Guide for the Families of Head Injury Victims*, Marilyn Colter Maxwell wrote, “Living with head injury is like trying to work a jigsaw puzzle without all the pieces.” You may have felt this way at times since your family member was injured. Even if you have not felt this way, you may still have some questions about the injury and some concerns about the changes it has caused in your life. We hope that the following information will help to answer some of your questions and help you learn some things to make your everyday life a little easier.

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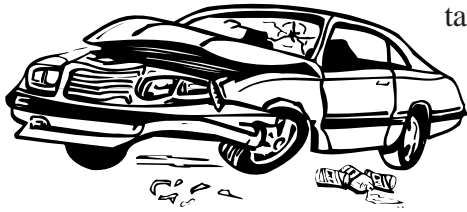
## CHAPTER 1

### What is a Traumatic Brain Injury (TBI)?

A TBI is an injury to the brain caused by something outside the body. It is different from a stroke, which is caused by something inside the body: weak blood vessels, blood clots, etc. There are many things that can cause a TBI. Some of them are: a car accident; a hit to the head with a bat, bottle, or other object; hitting the head during a fall; or a gunshot wound to the head.

#### THERE ARE 2 TYPES OF TBI:

- **Closed head injuries** happen when the brain is damaged without opening of the skull.



Think of the brain as being like jello in a container. If you move the container quickly then suddenly stop it, the jello will bounce off the sides of the container. In the same way, the brain bounces off the skull when the head stops suddenly after being in motion. Damage to the brain is caused by bruising and bleeding within the brain, tearing and stretching of nerve cells, swelling of the brain, and the building up of extra fluid.

- **Penetrating (open) head injuries** happen when a sharp object goes through the skull and enters the brain tissue. Examples of objects that can cause a penetrating brain injury are a bullet, a sword, and a knife. In these cases, the most damage occurs to the part of the brain that the object goes through. But damage to other parts of the brain can occur because of bleeding and swelling.



The brain controls most of our abilities, including memory, speech, vision, movements, making decisions, and our ability to get organized and get things done. Our brains also affect our emotions, such as whether we feel sad or happy, or whether we're easy-going or irritable. The brain is divided into many parts, and each part controls different abilities and behaviors. For example, one part may be important for talking and another part may be important for understanding other people's speech. ***Brain injury can lead to different problems, depending on the parts of the brain that are damaged. Each person's brain is like everyone else's in some important ways, but each brain is also unique.*** Because of this, there are some problems that are the same for all persons with brain injury, and some that are different for each person.

## CHAPTER 2

### What Problems May Your Loved One Have After TBI and What Can You Do To Help?

A TBI interferes with the way the brain normally works. The nerve cells in the brain can no longer send information to each other the way they normally do. This causes changes in the person's behavior and abilities. The injury may cause different problems, depending upon the parts of the brain that were most damaged. There are 3 general types of problems that can happen after TBI: physical problems; problems with thinking abilities; and changes in feelings and behaviors. Most people have some problems in all 3 areas, but the exact types of problems will differ. Not all people have the exact same problems after injury. However, no one's brain works as well after injury and it may take a long time before the person can return to the activities they did before injury. Some people will never be able to return to all the activities they did before injury, but they may return to some. The following problems are common after TBI. Keep in mind that your loved one may or may not have each of these problems-everyone is different. Below each list of problems, we are suggesting some things that may help you and your loved one to get around the problems. Again, not all things will work for everyone. We can help you to choose the ones that are right for you and your loved one.

#### ***3 types of problems after brain injury:***

- ***physical problems***
- ***problems with thinking (for example, memory)***
- ***changes in emotions and behaviors***

### **PROBLEMS WITH PHYSICAL ABILITIES**

#### **MOVEMENT PROBLEMS**

- Moves much more slowly.
- Difficulty picking up small objects and moving them around
- Weakness on one side of the body (or weakness in arms or legs)
- Seems more clumsy, uncoordinated, or unsteady when standing or walking (for example, loses balance easily)
- Bumps into things



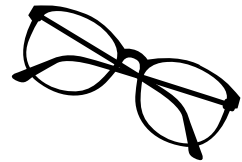
**Hello, I'm Mrs. Smith. My son, Tim, had a brain injury in a car accident 6 months ago. After his injury, Tim moved much more slowly and was off balance a lot. He also seemed to be tired all the time.**

**WHAT TO DO ABOUT MOVEMENT PROBLEMS:**

- Accept that your family member will take longer to walk and to move around. Allow extra time to get to appointments.
- Ask the doctor if your family member can have a referral for a physical therapist, who can help with improving balance and movement.
- Ask your doctor if there is any equipment that can help, such as a walker or cane.
- Place things within easy reach so your family member can get to things easily.
- Help them when they are picking up small objects, such as coins, pencils, etc. Ask your doctor if there is some equipment that can help with this.

**VISUAL PROBLEMS**

- Double or blurred vision
- Trouble seeing things in some parts of space (for example, can't see things in left side of space).

**WHAT TO DO ABOUT VISUAL PROBLEMS:**

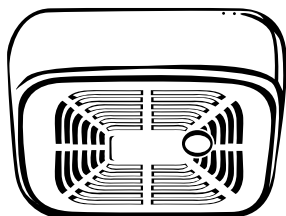
- Tell your doctor about the problem. Ask to see to an ophthalmologist (a doctor that works with the eyes). Often, glasses that worked before the injury won't work after because of changes in vision. Your family member may need a new prescription.
- Don't let your family member drive until a doctor says it is O.K.

**TROUBLE TASTING AND SMELLING**

- Complains that foods don't taste the same; may use a lot of extra salt or other spices.
- Does not smell things burning on the stove, smoke from a fire, or leaking gas.

**WHAT YOU CAN DO TO HELP GET AROUND PROBLEMS WITH TASTE AND SMELL:**

These problems may not go away, but your loved one can live safely in spite of them.



- Add extra spices to their food (try to use spices other than salt because too much salt can cause health problems).
- Have a smoke alarm in the house so your family member does not have to rely on smell to know that there's a fire. A carbon monoxide detector would also be a good idea.

## TIRED A LOT/INCREASED FATIGUE

- Always complains of feeling tired.
- Sleeps longer than usual at night, or sleeps a lot of the day.
- Can only do a little activity at a time. For example, must sleep several hours after a trip to the grocery store.

### **WHAT TO DO ABOUT TIREDNESS:**

- Understand that feeling tired is normal after injury.
- Allow extra time for rest between activities.
- Schedule shorter activities at first, and gradually increase activity little by little as your family member gets stronger.
- If your family member has trouble sleeping at night, talk to your doctor about medications that could help.
- Schedule important appointments and activities for times of day when your family member is most awake and alert.

***Feeling tired is normal after injury. Your family member should start with short activities and increase them little by little when he is stronger.***

## PROBLEMS WITH THINKING ABILITIES

### MEMORY PROBLEMS

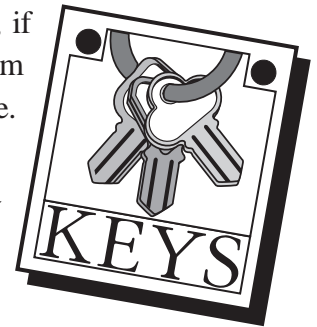
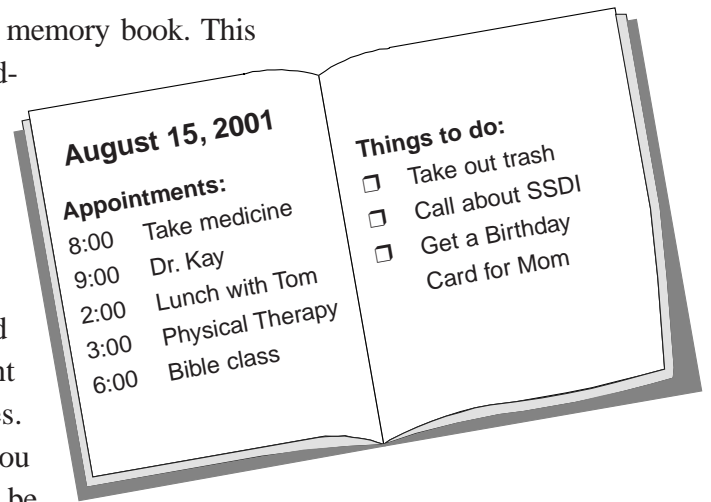
Most people have some type of memory problem after injury. Here are a few of the most common ones:

- forgetting appointments
- forgetting peoples' names
- needing to have things repeated many times
- taking longer to learn new information
- forgetting things very quickly
- frequently losing or misplacing things (like keys, wallet, etc.)
- forgetting to take medications or forgetting they were taken and taking them again
- repeating questions or the same story over and over again

***Most people can remember information that they knew well before injury. But they have trouble learning and remembering new information.***

**WHAT YOU CAN DO TO HELP WITH MEMORY PROBLEMS:**

- Help your family member make a memory book. This can be as simple as a notebook divided into sections or as fancy as an electronic organizer. Help your loved one to decide what sections should be in the memory book. Possible sections include: a calendar; daily lists of things to do; and an address book with important phone numbers and addresses. Everyone's needs are different, so you should add sections that would be important for your family member. Make sure that the notebook is part of your family members' daily routine. In order for the book to help them, they need to carry it with them everywhere and use it often.
- Allow extra time for your family member to learn new things. Keep in mind that they will learn more slowly than they did before the injury.
- Repeat things that you want them to remember more than once. Repeating things over and over makes it more likely that they will remember.
- Write all important information down for them. For example, if you want them to do some chores during the day, write them down on a list. Have them check each chore off as it is done. Write down instructions to new places.
- Keep household items in specific places. For example, have a hook for keys or a special drawer for medical papers. Label drawers with the contents. You may also want to write the locations of different items in the memory book.
- Buy a pill box and label each dose with the time and day that they should be taken. Each dose should go in a different section of the box to avoid confusion.



## ATTENTION PROBLEMS

Sometimes what seems to be a memory problem can really be a problem with attention. Your family member may not be able to make new memories because they have a hard time paying attention to things. Here are some common attention problems:

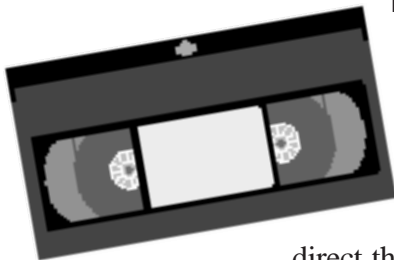
- Trouble keeping their mind on one thing and ignoring things around them
- Easily distracted by noises that wouldn't have bothered them before (e.g., trouble listening to a conversation in a crowded restaurant because they are distracted by other people talking and moving around)
- Trouble concentrating on reading
- Difficulty doing more than one thing at a time (e.g., watching T.V. and cooking a meal; answering the phone and watching the children)
- Difficulty “switching gears” or changing focus from one thing to another (e.g., may continue to do things the wrong way even after you explain why things should be done a different way)
- Often disagrees with you about what you or someone else said



**My name is Mrs. Jones. My son, Richard, had a head injury from a sports accident. At first I thought he was ignoring me, but then I realized he was having trouble paying attention. Now I turn off the T.V. or radio when I talk to him, and I ask him to repeat what I told him.**

### WHAT YOU CAN DO TO IMPROVE ATTENTION:

- Make sure your home is free of clutter. Keep things organized. Try to keep things in the same place without changing things around much.
- Make sure that everything is put away except the things they are working with. For example, if your family member is going to cook a meal, have in sight only the things they need for that meal.
- When telling your family member something you want them to pay attention to, turn off the T.V., radio, etc. Make sure there are not a lot of other people around to distract them. Don't leave the T.V. or radio on all the time, but only when someone wants to hear it.
- Make sure your family member works on only one thing at a time.



- Encourage them to take notes when reading something that they need to remember. If they liked to read for pleasure before but have difficulty doing so now, consider buying some books on tape. That way they can listen and replay parts that they forget or don't understand.

- If your family member gets stuck on one idea or task, gently direct their attention to a new task or idea. For example, say “We are no longer talking about that; we are now talking about...”

## LANGUAGE PROBLEMS

- Difficulty finding the right words to tell others what they want to say
- Talking around a topic, never really getting to the point; getting off topic when telling a story or answering a question
- Trouble understanding what others say to them
- Difficulty keeping up with a conversation especially if talking to more than one person
- Difficulty starting a conversation.

### ***WHAT YOU CAN DO TO GET AROUND LANGUAGE PROBLEMS:***

- Allow more time for your family member to answer you or explain what he or she wants. Encourage them to speak slowly and not to be nervous about finding the right word.
- Encourage them to use gestures or signals (for example, hand motions and facial expressions) to help express themselves.
- Develop a signal that will let your family member know when they have gotten off topic. For example, you could hold up your index finger to let them know they are off topic. If signals don't work, try saying, "We were talking about..." Remember to use kind words and a gentle tone of voice. This will make it easier for your family member to accept what you say.
- When talking to your family member, ask every so often if they understand what you're saying. Ask them to repeat the information to you.
- Encourage them to ask for information to be repeated. Let them know they shouldn't be embarrassed about asking others to repeat things; we all have to do this sometimes.
- Try to have only one person at a time speaking to them.
- Praise them when they start conversations on their own.



## VISUOSPATIAL PROBLEMS

- Difficulty seeing things on one side, usually the left side
- Bumping into things, usually on the left side
- Difficulty recognizing shapes and telling the difference between shapes
- Difficulty finding their way around, especially in new places.

**HOW TO HELP WITH VISUO-SPATIAL PROBLEMS:**

- Arrange things in the house to make it easier on them. For example, if they are cooking a meal, put all the things they need on their good side. If they have trouble looking toward the left side when reading, draw a red line down the left side of one page to draw their attention to the beginning of the line.
- If you're worried about safety, make sure that another adult is there when your family member is cooking or using tools or appliances that could be dangerous.
- Carefully check their driving ability. If you are worried about safety, do not let them drive until you have them checked by a doctor. Talk to your doctor about your concerns. There are special driving programs that can test their driving safety (see Driver's Rehabilitation Services in Appendix).
- Show them around new places many times. Do not send them to new places alone.

**SLOWED THINKING AND RESPONDING**

- Takes longer to answer questions.
- Takes longer to understand things he understood easily before.
- Takes a long time to react to things (this may be dangerous in emergency situations or when driving)

**WHAT TO DO ABOUT SLOWED THINKING AND RESPONDING:**

- Allow extra time for them to answer questions, read things, or learn new information.
- Your family member may react more slowly to other cars when driving. Limit their driving and talk to your doctor about it. Sometimes persons with injury will insist on driving no matter what you tell them. If this happens, take them to the driver's license agency and let them take the driving test. If they fail the test, the blame will be taken away from you.
- Your family member may think less quickly in an emergency situation. Write down emergency procedures and stick them on the refrigerator, by the phone, etc. For example, you could make a drawing that shows what to do in case of fire or in case a child gets hurt.

**My name is Mrs. Brown. My daughter, Alice, had a head injury resulting from a diving accident. Since her injury, she can't think as quickly as before. This makes me worried about what she will do in an emergency, so I've talked to her about emergency situations. We also have a checklist of what to do posted on the refrigerator.**



- Encourage your family member to ask others to slow down or repeat information if they have trouble understanding what has been said.

## PROBLEMS WITH ORGANIZATION

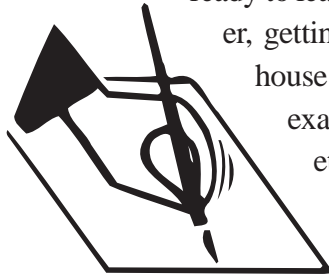
- Difficulty organizing their time to get things done (e.g., may tell someone they can be at a party at the same time they have a doctor's appointment)
- Trouble setting goals, planning the correct steps to reach a goal, or completing the steps to reach a goal
- Trouble completing tasks in the correct order (e.g., does not put soap in the washing machine when washing clothes)
- Trouble getting ready for daily appointments, school, or work

### HOW TO HELP WITH ORGANIZATION PROBLEMS:

- The memory book described in the memory section can help with organization problems as well. Have them use it to keep track of their daily schedule and things that they need to do. It is important that they check it every day. Checking the book should be part of their routine. For example, they could check it during every meal.

- Break activities down into smaller steps. For example, getting

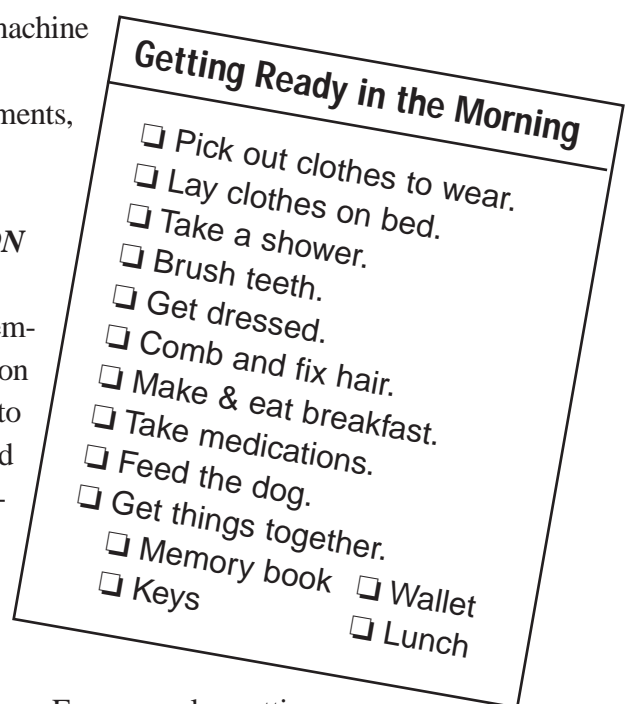
ready to leave the house in the morning can be broken down into taking a shower, getting dressed, eating breakfast, getting stuff together, and leaving the house. For some people, the steps may need to be broken down further (for example, putting on underwear, then shirt, then pants, combing hair, etc.)



- Use checklists to help them organize activities. The check list can be used to organize daily activities, such as household chores. It can also be used to keep track of the steps for a particular chore.

A check list can be made for different kinds of activities. They can check off the steps as they do them.

- If your family member has trouble getting organized to leave the house in the morning, have them get some things ready the night before. For example, they can choose what they will wear the night before and lay the clothes out. You can also use a check list to



help them get ready in the morning. Put all the things they have to do on the list and have them check each thing off as it's done. A sample check list for getting ready in the morning is shown on page 9. You can change this list to fit your family members' needs.

### TROUBLE SOLVING PROBLEMS

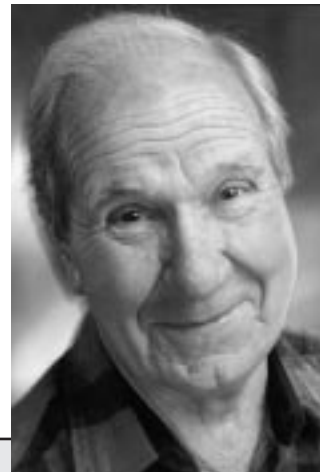
- Makes quick decisions without thinking about what will happen
- Seems to get stuck between different choices and can't pick between them
- Seems to get stuck on one idea and can't consider other choices
- Tries to solve problems in ways that don't make sense

#### *HOW TO HELP WITH PROBLEM SOLVING:*

- Help your family member to work through the problem solving steps shown in the back of the book. Teach them to think this way whenever they have a problem to solve or a decision to make.
- Talk with your family member about the fact that they may have difficulty solving problems and making important decisions. Encourage them to ask for help.

### CHANGES IN BEHAVIORS AND EMOTIONS

Family members often complain that their loved one is just not the same person after injury. A piece of them seems to be missing—a piece that was important to making them the person they were before. Family members often find it difficult to accept these changes in their loved one's personality. The first step in adjusting to these changes is to realize that they are due to the brain injury. Your family member is not trying to act in a different way, and they cannot make themselves return to the way they were before injury. Following are some of the most common changes in behavior and emotions. Keep in mind that your family member may not have all these problems, and that they may have some which are not on the list.



**My name is Joe Johnson and my wife, Judy, was also injured in a car accident. The hardest thing for me was that she didn't seem to be the same person after her injury. At first, I thought she was being difficult on purpose and could change if she tried hard enough. Her doctor helped me to understand that the personality changes were due to her injury, and she could not make herself be the way she was before.**

## **LACK OF MOTIVATION AND TROUBLE GETTING STARTED ON THINGS (DECREASED INITIATION)**

- Seems to sit all day staring at the T.V.
- Doesn't seem interested in the things he or she liked to do before
- Needs to be reminded to bathe or brush their teeth
- Knows what needs to be done, but just doesn't seem to be able to get started

### ***HOW TO HELP YOUR FAMILY MEMBER BE MORE ACTIVE:***

- Accept that this problem is a result of the brain injury. Your family member is not being lazy.
- Come up with daily activities for them to do. You may ask them what activities they would like to do, but don't be surprised if they say they don't want to do anything. You may have to choose activities for them at first. Give them a choice among 2 or 3 different activities. Make the activities a part of their routine, so that it will become a habit for them.
- Make checklists (see Figure on page 9) to help them complete activities.
- Find something that they really like, maybe a certain food or a T.V. show. Use it to reward them for being more active. For example, if they take a walk around the block in the afternoon, they can have some ice cream.
- Get them involved in a support group for persons with TBI. Get them involved with doing volunteer work at a church, neighborhood clinic, etc.

## **DENIAL OF PROBLEMS/LACK OF AWARENESS**

- Never seems concerned, as if nothing is different.
- Insists that they can do things just as well as before the injury. Or wants to do activities that you know they can't do.
- Complains that the doctors and you "don't know what you're talking about."
- Blames other people for the things they can't do (e.g., "I can go back to work, but the doctor won't let me").

### ***HOW TO HANDLE DENIAL OR LACK OF AWARENESS:***

- Be patient with your family member. Your family member is not ignoring problems on purpose. Sometimes the brain injury makes a person unable to recognize problems. Other times denial is a way of dealing with what they have lost.
- Point out problems when they occur, but do this in a kind and calm way. Do not yell or get angry with them.
- When it is safe, let them make mistakes on their own. This may sometimes be the only way to make them see what problems they have. Remember to talk things over with them after they make the mistake. Help them think of a way to get around their problems next time.

## DEPRESSION

- Seems sad a lot of the time and keeps to him or herself. Doesn't seem to be interested in talking with other people.
- Has lost interest in things he or she once enjoyed.
- Has difficulty sleeping or sleeps too much.
- Seems to have no energy.
- Has little appetite.
- Says things like "It would have been better if I had died in the accident."

### **WHAT TO DO ABOUT DEPRESSION:**

- Understand that feeling sad is a normal part of your family member trying to deal with what they've lost. Depression can be a good sign because it means that your family member has become aware of the problems they are facing.
- Talk with your family member's doctor about the possibility of depression and whether medication might help. Keep in mind that many signs of depression are also symptoms of the brain injury. Just because your family member has one of these problems doesn't always mean that they are depressed. These problems are more likely to mean depression if they happen months after the accident rather than soon after it.
- Offer to talk to your family member about their feelings. Let them know that you support them and that you realize how much the injury has changed things.
- Get your family member involved in activities that will take their minds off feeling sad. Activities where they can help others may be especially helpful, but any increased activity would be a good thing. Exercise can be especially good.
- Have your family member see a professional that understands brain injury, such as a rehabilitation doctor.

## INAPPROPRIATE OR EMBARRASSING BEHAVIOR

- Tells strangers about personal matters that people are usually quiet about.
- Asks personal questions of others he does not know well.
- Makes embarrassing sexual comments or gestures in public.
- Cusses a lot.



**After the injury, I didn't want to take Richard around other people because I'd never know what he might say to embarrass me. But we worked out a system so that if I gave him a signal he would stop talking. Then he would get a special reward when we got home.**

***WHAT TO DO ABOUT INAPPROPRIATE OR EMBARRASSING BEHAVIOR:***

- Calmly let your family member know that this behavior is wrong and bothers other people. Do not yell or lose your temper. That may cause your family member to act in a more inappropriate way.
- Come up with a signal that you can use to let your family member know when he or she is acting inappropriately. For example, you could hold up your hand to signal “stop”, shake your head no, or say a special word you have both agreed on. Make sure that you practice this with your family member so that they know what the signal means.
- Set up a reward system for your family member. If they go on an outing without doing anything inappropriate, they can have a reward of their choice. Remember that the injury makes it hard for them to always act appropriately. The goal should not be to have no inappropriate actions at all. You can start off with the goal of not more than one. Or you may make the goal that your family member will stop inappropriate talk or actions when you give the special signal. As time goes on you can increase the goal, so that it is eventually, no inappropriate talk or actions. Be sure to praise your family member whenever he or she goes on an outing and acts appropriately.
- If you get into a situation where your family member is embarrassing you by acting inappropriately, stop whatever activity you are doing. For example, if you are in the mall, return home immediately. This will help your family member to learn that they can only go out with you if they act appropriately.
- Don’t let this behavior run your life. Don’t avoid going out with your family member in public. Use some of the above techniques to help you deal with the problem.

**ANGER AND TEMPER TANTRUMS**

- Becomes angry at things that never bothered him or her before.
- Yells a lot.
- Uses bad language.
- Throws objects or slams fists into things, slams doors, etc.
- Threatens family members or others.
- Hits, pushes, or otherwise hurts family members or others.

***HOW TO HANDLE ANGER AND TEMPER TANTRUMS:***

- Understand that being irritable and getting angry easily is due to the brain injury. Try not to take it personally.
- When possible, ignore bad behavior like yelling or cussing. Paying too much attention to it can sometimes make the behavior worse.
- Set some rules for communication. Let your family member know that it is not acceptable to yell at, threaten, or physically hurt others. Let them know that you will not talk

to them when they act this way. Tell them that it is O.K. to let you know when they're upset about something, but that they need to do it in a calm way.

- Refuse to talk to your family member when they are yelling or throwing a temper tantrum. Go to another room where you can close the door and be separated from them. Or go to a neighbor's house if you feel O.K. leaving your family member alone. Before going, let them know that you will come back in 5 or 10 minutes and will be willing to talk to them if they are calm and pleasant, but that you will leave again if they are not. When they have calmed down, you can discuss the matter that made them angry if you think it's still important. Sometimes, persons with brain injury fly off the handle at little things that might not be worth bringing up again. You can make the decision.
- Reward your family member for discussing the problem that upset them in a calm and pleasant way. Let them know how pleased you are, and let them know that what they think is important.
- If you feel afraid that your family member may hurt you, your children, or anyone else, discuss this with your doctor or psychologist. You may need to consider having your family member live somewhere else.



**When Alice is angry or upset, me yelling at her seems to make it worse. It works much better if I leave the room and come back to talk to her later, when she is more calm.**

### **OVERLY EMOTIONAL (LABILITY)**

- Seems like they can be laughing one minute and crying the next
- Laughs at things that are not funny; for example, laughs when someone is hurt or dies
- Cries easily at things that would not have upset them before

#### ***HOW TO HANDLE OVERLY EMOTIONAL BEHAVIOR:***

- Do not yell at your family member-it is not their fault.
- Do not pay too much attention to the behavior. For example, if they begin crying loudly during a television show, try to ignore it. Paying attention to it may increase the behavior.
- If possible, remove the thing that they are reacting to. For example, change the topic of the conversation, change the television station, etc.
- This problem will be worse in times of stress. Try to avoid putting your family member in stressful situations.

**IMPULSIVITY (ACTING QUICKLY WITHOUT THINKING)**

- Says whatever comes to his or her mind, without thinking first
- Does whatever he or she wants to without regard for what happens
- Does things that are dangerous (e.g., walks into street without looking for cars)

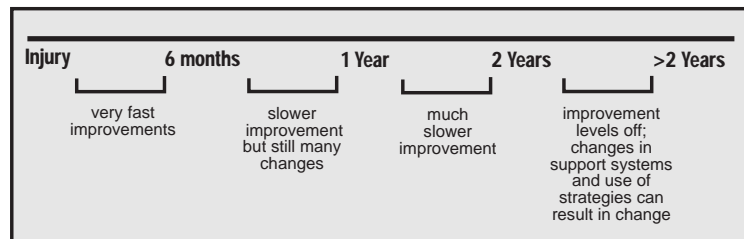
***WHAT YOU CAN DO TO HELP CONTROL IMPULSIVITY:***

- Stop them when they are acting without thinking. Talk calmly to them about the consequences of what they are doing.
- Develop a special signal that will let them know when they are doing something inappropriate (e.g., holding up a finger or saying a special word).
- Give them a reward when they think before acting. Let them know that they will get this reward if they act in an appropriate manner.
- Remove items that could be used dangerously. For example, hide the car keys if you think they will drive when they're not supposed to. Avoid keeping guns, knives, or other weapons in the house.

## CHAPTER 3

### How Long Will These Problems Last?

**Y**ou probably noticed that your loved one made a lot of gains in the first few months after injury. In the hospital, you were probably relieved and hopeful the first time he or she walked, talked, or showed any



improvement. Your family member may still be improving, but not as fast as earlier. Many family members have questions about what they can expect in the long term. Below are some general “rules of thumb” about what improvements to expect. Please keep in mind that everyone is different and that your family member may show somewhat different improvement.

- The fastest improvement happens in about the first 6 months after injury. During this time, your family member will likely show many improvements and may seem to be getting better all the time.
- You will still notice some improvements happening between 6 months and 1 year after injury. However, the changes may not happen as fast as the ones you first saw, and you may notice that the changes are smaller.
- The period between 1 and 2 years after injury is different for different people. Some people show more improvement. This may be especially true if they had a lot of medical problems during the first year that get better in the 2nd year. Other people start to level off and show very little improvement between 1 and 2 years. For people who show improvement, the changes usually happen very slowly.
- Most professionals agree that people usually show little change after 2 years. Most people continue to have some problems, although they may not be as bad as they were early after injury. Some common problems that tend to last longer are slowed thinking, memory and attention problems, and problems getting organized. However, many people are able to return to their activities in spite of problems. For example, people may go back to work, return to school, take care of their household, or return to other activities that they did before injury.
- What makes the difference in who can do these activities? Part of it is due to the type of injury and how severe it was. This is the part that you and your family member cannot control or change. However, part of it is also due to whether your family member can use your help to get around the problems. Two people with the same problems may have different outcomes depending on how they go about getting around their problems. The amount of support they have can also make a difference. For example, a person with a boss who is understanding and willing to help is more likely to go back to work and keep their jobs. Having support from family and friends can also help. Many



people with injury become socially isolated. Their friends often stop coming around and they feel lonely. You can help them to find other supports, such as friends, church groups, brain injury support groups, etc.

- Even when your family member improves, they may still need help with certain things from time to time. One of the things people often need help with is handling finances. They may need help remembering to pay bills or keeping up with their checkbooks. They may have difficulty with spending more money than they have or making financial decisions. If you are really worried about your family member's ability to handle their money, you may want to talk to a lawyer about obtaining legal guardianship. This means that you can make decisions for them in order to protect them from being taken advantage of.

<b>How well someone does after injury</b>	<b>=</b>	<b>how severe the injury is</b>
	<b>+</b>	<b>what part of the brain is damaged</b>
	<b>+</b>	<b>the strategies they use to get around problems</b>
	<b>+</b>	<b>the support they have</b>

## CHAPTER 4

### How Does Brain Injury Affect Family Members?

For most family members, life is not the same after TBI. We want you to know that you are not alone in what you are feeling. Other people who have family members with TBI may be having the same problems that you do. While everyone's situation is a bit different, there are some common problems that many family members experience.

- **Less time for yourself:** Since the injury, you likely have had very little time for yourself, to do the things you enjoy or to relax. Much of your energy has probably gone into taking care of your family member. You probably feel tired constantly, but can't get any rest.
- **Financial difficulties:** If your family member has not been able to return to work, you may have less money to support your household. You also probably have a lot of medical bills piling up. People also have difficulty applying for and getting disability income (SSDI).
- **Role changes:** People in your family probably no longer have the same roles. In other words, the same people don't necessarily have the same responsibilities they did before. For example, someone who stayed home to take care of the house before injury may now have to work. Someone who worked before may have to stay home to take care of the person with injury. There may not be enough people to help with chores, grocery shopping, etc.
- **Problems with communication:** People in your family may not talk to each other as well as they did before injury. They may seem to have trouble talking about their feelings. Things may be so busy that you just don't have much time to spend with other family members. It may seem that the family only gets together to solve the next problem, and not to just enjoy being together.
- **Lack of support from other family members and friends:** Soon after injury, you probably got a lot of help from other people. As time went on, the amount of help you received may have become less. Other family members and friends may come around less. They may not seem to understand what you're going through. They may not understand some of the changes in your injured family member. People may seem to be critical of the way you're handling things. They may give you a lot of advice that isn't really helpful.

These are just some of the problems that family members may face after injury. Your family may be facing other problems that we haven't talked about. Sometimes these problems can seem too much and you may become overwhelmed, not seeing any way out. Other people in your situation experience similar feelings. Here is a list of some common feelings that family members report:

- **Feeling sad or down:** Many family members report that they feel down a lot; sometimes, they are not sure why. They may not enjoy the things they used to. They may have a lot less energy. They may sleep too much or not be able to sleep at all. Some people cry more easily. They may start spending a lot of time alone, preferring not to be with other people.

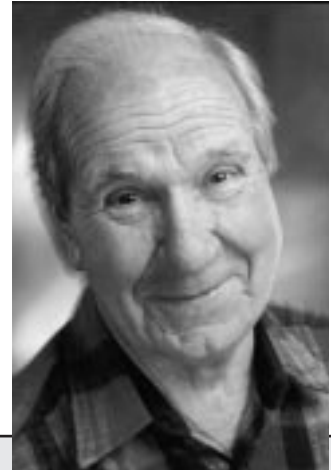
- **Feeling anxious or nervous:** Some family members report being nervous all the time. They may worry about something all the time. Some common things that people worry about are finances, the future, and the health and well-being of their injured family member. Other people may feel nervous all the time, without being sure why.

- **Feeling Angry:** You may be surprised to learn that many family members feel angry after the injury. They may be angry at many different people. Some feel angry at doctors or other

professionals who they don't think are providing enough care. Others feel angry at other family members or at friends who give advice but don't seem to understand what they're going through. Still others are angry at their injured family member for not trying hard enough or for not appreciating what is being done to help them. Some people are just angry at the world, questioning why this terrible thing has happened to them.

- **Feeling guilty:** Guilt is a common feeling that family members have after the injury. Some family members blame themselves for the injury, thinking that they somehow could have prevented it. Others feel guilty that they cannot keep up with the things that need to be done from day to day. Some family members feel guilty about the anger they feel; they tell themselves they should be glad their loved one is alive, and they don't feel they have a right to be angry. Others feel that the injury is a punishment for something they did in the past.

- **Feeling frustrated:** Frustration is a very common feeling among family members. There are lots of things to be frustrated about. Some of the things that most frustrate people are: not being able to get the services they need; not having enough time to do things; feeling that others don't understand what they're going through; dealing with the fact that their loved one cannot do the same things they did before.



**Since the injury I have been so grateful that Judy is alive. But I also feel angry at her because she is so demanding and doesn't seem to understand all that I'm doing for her. I really feel guilty for feeling this way.**

## CHAPTER 5

### Ways to Reduce Stress

Since the injury, your life has probably revolved around your loved one. Because you care about them, you try to make sure they have everything they need and that they are happy in spite of their problems. You may also have other people to take care of, maybe small children or elderly family members. You probably find that you spend most of your time working, caring for others, and trying to run the household. Very little time, if any, is spent caring for your own needs. You may say that you cannot afford to take any time for yourself. We would like to convince you that you can't afford not to pay attention to your needs. Here is why.



**For a long time after the injury I thought that if I worked extra hard I could get all the problems solved. Then I realized that the stress was making me have headaches and stomach aches. I ended up getting less things done because I felt bad. I decided to make taking care of myself a priority.**

Since the injury, you have likely been under a great deal of stress. A little stress is part of life, but stress that goes on for a long time can have a negative effect on the mind and body. Stress is related to medical problems such as heart disease, cancer, and stroke. Stress can make you do things less well because it affects your ability to concentrate, to be organized, and to think clearly. Stress also has a negative effect on your relationships with other people because it makes you irritable, less patient, and more likely to lash out at others. Stress can lead to depression and/or anxiety.

***Stress can have negative effects on the mind and body. You will be a better caregiver if you take the time to reduce stress.***

If you are under constant stress, you are not going to be as helpful to your injured family member or anyone else. If you do not take the time to rest and care for yourself, you will get fewer things done, which will lead to more stress. If you won't do this for yourself, do it for your injured family member. They will be better off if you are healthy and happy.

Here are some suggestions for ways to reduce stress, stay healthy, and enjoy your life more. These things have worked for many people, but not all of them may work for you. However, they may help you to think of things that will work. The important thing is that you begin thinking about ways to improve your life.

#### LEARN TO RELAX.

Taking a few moments to relax can help you be more ready for the things you need to do. Learning to relax is not easy, especially in your current situation. Even when you finally sit down at the end of a long day, your body and mind are probably not in a relaxed state. You are probably thinking

about what you need to do tomorrow or how to solve a problem. You need to train your body and mind to get into a relaxed state. Here are some techniques that may help. Find the one that works best for you.

- ***Focused breathing:*** When you are stressed or upset, your breathing becomes quick and shallow. You begin taking short breaths from your chest rather than breathing deeply from your diaphragm (the muscle between the chest and abdomen that helps with breathing). Taking full breaths from your diaphragm puts your body in a relaxed state. Try the following exercise (Caudill, 1995):

### ***Relaxation Exercise***

1. Lie down on your back in a comfortable place.
2. Put your hands just below your belly button.
3. Close your eyes and imagine a balloon inside your abdomen.
4. Inhale fully (but not too deep), and imagine the balloon filling with air.
5. Exhale slowly, and imagine the balloon collapsing (you can also imagine all the stress leaving your body).

Try this exercise several times during the day. Once you get the hang of it, you can do it sitting down or standing up as well as lying down.

- ***Muscle Tensing and Relaxing:*** The purpose of this exercise is for you to understand the difference between the way your muscles feel when you are tense and the way they feel when you are relaxed (Caudill, 1995).
  1. Lie down on your back in a comfortable place and close your eyes.
  2. Curl and tense the toes of one of your feet as you breathe in, then relax them as you breathe out. Notice the difference in tension as you relax. Repeat this with the toes of your other foot.
  3. Repeat this exercise with other body parts (see page 34 for instructions on other body parts).

- **Use a focus word or phrase:** This exercise can help you to clear your mind of negative thoughts and stress. Choose a focus word or phrase. Some people choose a word that has positive meaning for them (e.g., “peace”). Others choose something that’s just easy to remember, like a number (“one”). Take full deep breaths from your diaphragm. Say the focus word to yourself each time you breathe out.
- **Visual Imagery:** Lie down in a comfortable, quiet place and imagine yourself in a place where you feel calm and relaxed. It can be a place that you’ve been before or a place you’ve always imagined would make you feel relaxed. For example, you can imagine yourself on a beach, lying in the cool sand, feeling the sun on your face, and hearing the water lap against the shore. Try to imagine all that is there—the feel of the sand, the sound of the water, the smells of salt water. If a beach does not seem relaxing to you, pick another place.



In order to train your body and mind to relax, you need to practice often. Don’t give up if it doesn’t work right away. If you keep practicing these techniques, you will feel more relaxed in the long run, and you will find that you’re able to function better in all areas of your life.

***Practice relaxing. Don’t give up if it doesn’t work the first time.***

### **LEARN WHICH COPING STRATEGIES WORK FOR YOU.**

No matter what was going on in your life before, the injury has caused changes. You are coping with these changes the best way that you know how. The way that you cope with these changes likely depends on how you’ve coped with other difficult situations in your life. You probably tend to use strategies that have worked for you in the past, and this is a good thing to do. However, you may never have experienced anything similar to the injury, and some of your usual coping strategies may not work in your current situation. The best thing that you can do for yourself is to be open to trying new ways of coping. You may have to try several different things before you find the best one. Also remember that different situations call for different strategies.

To help you find the best strategies for different situations, do the following exercise. Make a list of stressful situations that you are facing (you can use the “Evaluate Your Coping Skills” table in the Appendix). Next to each one, list the strategies you’ve used to cope with that situation. Next,

describe what happened when you tried that strategy. If the result was positive, then that strategy is probably a good one for you. If the result was negative, then you know that you should try another strategy. In deciding whether the result of a strategy was positive or negative, you should pay attention to what happened when you used it and to how you felt when you used it. Did you feel good afterward, or did it lead to more stress for you?

***Evaluate your coping skills using the chart on page 35.***

Researchers have asked family members how they've coped with injury. While every family member is different, here are some strategies that other family members have found helpful. Some might work for you, and you can add your own to this list.

**COPING STRATEGIES THAT OTHER FAMILY MEMBERS HAVE FOUND HELPFUL (Willer et al., 1991)**

- Taking time for yourself
- Participating in Support Groups
- Maintaining a sense of humor
- Being more assertive
- Trying to see things realistically
- Being careful not to blame everything on the injury
- Redefining roles and responsibilities

**LEARN HOW TO SOLVE PROBLEMS BETTER.**

Sometimes you may feel overwhelmed by problems. There may be so many problems that you're not sure which one to tackle first. You can only solve one problem at a time, so pick one. Use the problem solving steps below to find a good solution. Try to choose a smaller problem to solve first. This will give you practice and make you more confident of solving bigger problems. If you deal with problems in this way, they may seem easier to handle.

## Steps in Problem Solving

### **I. Identify the problem**

What is the problem? Define it as clearly and specifically as possible. Remember that you can only solve one problem at a time. In many situations, you will be faced with more than 1 problem, or with problems that have many different parts. Start with one problem. If that problem has many parts, it may be best to break it down into parts. For example, a problem may be that your family member cannot work, so you must find a job. But you are having difficulty getting started because your resume is 10 years old, you have nowhere to leave the children during the day, and your family member has weekly doctor's appointments. All these things may be preventing you from getting a job, but you can only attack one problem at a time. Pick the one that you think will be easiest to solve. That will give you confidence in yourself and make it easier to go after the tougher problems.

### **II. Brainstorm solutions.**

What can be done? Think of as many things as you can. Don't worry about whether they sound silly or realistic. This is the time to think about all possibilities, even the ones that you don't think will happen. Be creative.

### **III. Evaluate the alternatives.**

Now you will start thinking about the consequences of the ideas you came up with in Step 2. For each idea, make a list of positives on one side of the page and a list of negatives on the other side. If you want this to work, be honest about the positives and negatives. It won't work if you try to fix things so that your favorite solution "wins."

### **IV. Choose a solution.**

Pick the solution that had the best consequences based on your list of positives and negatives. Keep in mind that more positives than negatives is not always the best rule. Sometimes you will have 1 negative that outweighs many positives. For example, you may have come up with the idea of taking some courses to increase your job skills in order to solve your problem of needing a job. There may be many positive consequences of taking these courses. The one negative consequence may be that the courses will cost money and your financial situation is already bad. This negative consequence may carry more weight than all the positive ones.

### **V. Try the solution out.**

Try out the idea you have chosen. Give it more than one chance to work. If it doesn't work right away, try to figure out why. Was there some consequence you didn't think of? Is there another problem in the way that could be easily solved?

### **VI. If 1st solution doesn't work, try another one.**

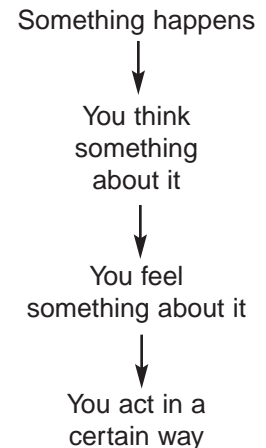
Don't give up. Everything doesn't always work out the first time. You can learn from your mistakes; they may help you to choose a better solution next time.



### LEARN HOW TO OVERCOME NEGATIVE THINKING.

Everyone has negative thoughts now and then. It is normal for you to have negative feelings about the injury and the unexpected changes it has caused in your life. However, negative thoughts can become a problem when they stop you from being able to reach your goals, hurt your relationships with other people, and lead you to feel badly about yourself and your life.

You can overcome negative thinking if you understand the effect that thoughts can have on what you feel and what you do. Take the following example. Your friend says to you, “I know a great hairstylist and I’ll give you the phone number.” How would you feel if you thought that your friend meant that your hair is looking terrible and you need some help? Now think about how you would feel if you thought that your friend was really excited about this great hairstylist and wants to share her with other people she cares about. In this situation, you would feel differently depending on how you thought about what was said. The way you think can also affect what you do. For example, you may tend to pull away from your friend if you have negative thoughts about what she said.



The way you think has a lot of power in your life. The good news is that your thoughts are one of the few things you can control. You cannot always control what goes on in your life, but you’re the only one who can control how you think about things. What you say to yourself about things can make a difference. Here are some common thoughts that can have a negative effect on what you feel and do (Burns, 1989).

- **All or nothing thinking:** thinking that if things don’t go perfectly, it’s a complete failure; example: “I missed a day of exercise, so I may as well give up and not exercise at all.”
- **Overgeneralization:** seeing a single bad event as meaning that things have always been bad and will always be bad in the future; example: “My husband’s disability claim was denied the 1st time we tried. I guess we’ll never be able to get any financial help.”
- **Focusing on the negative and ignoring the positive:** People tend to pick on one negative event to remember, while forgetting all the positive things that have happened. For example, if you’ve gotten many compliments on your new haircut, you’ll still focus on the one person who said they didn’t like it. Even if most of your friends and family have told you what a great job you’ve been doing since the injury, you will likely focus on the one person who reminded you of something you forgot to do.

**What you say to yourself  
about things can make a  
difference.**

- **“Should”, “Have to”, and “Must” statements:** These are things people say to themselves that are not true or rational. Some examples are: “I should not make mistakes.”; “I have to reach all the goals I set for myself.” “Everybody must be happy with me at all times.” Because these statements are not true, you are setting yourself up for failure. You will eventually make a mistake, events will prevent you from reaching all of your goals, and everyone will not be happy with you at all times. When these things happen, you may think that you are a terrible person, that someone else is a terrible person, or that life is awful. These thoughts will have a negative effect on what you feel and do.

To increase positive thinking, try to recognize when you are having negative and irrational thoughts. Then tell yourself something positive to replace the negative thought. For example, if you catch yourself saying “I should not have forgotten that doctor’s appointment this morning” stop for a moment. Instead, tell yourself “I have remembered all of the other appointments we have had this week. I have many more things to remember than I used to, and I am bound to forget some things at times. I will do better next time.” Use the chart

“Evaluating Thoughts” in the back of this book to identify common thoughts that you have and

**Track your negative thoughts by using the chart on page 36.**

replace them with positive ones. Remember, thinking is very powerful: changing your thoughts will allow you to better control your life. You will still have some negative thoughts, but they will not control your life.

**Replace negative thoughts with positive ones.**



I didn’t get everything done today that I wanted to.



I got a lot of things done today.

**LEARN HOW TO REWARD YOURSELF.**

Everyone needs something to look forward to. You’ll probably say, “I have no time; it’s impossible.” Just remember that you will be more ready to do the things you have to do if you take some time to do some things that you want to do. Even if you have very limited time, you can find some small way to reward yourself. Promise yourself a bubble bath at the end of a long day. Take a walk around the block. Or have a cup of your favorite coffee or hot chocolate. If your schedule is very hectic, you may need to write this time into it. This will also give you something to look forward to. Don’t be surprised if you feel guilty at first for taking



**Everyday I save 20 minutes to take a bubble bath. This reward helps me to get through the day.**

this time. This guilt is the result of negative thinking (“I should always be doing something for my loved one or getting something accomplished.”). Ignore the voice in your head that tells you this. You deserve to have your own time, and you will be a better caregiver if you take it.

### **LEARN HOW TO COMMUNICATE YOUR NEEDS TO OTHERS.**

If you’re like most people, you have a hard time asking others for help. This is because we often think we should be able to do everything on our own. However, the injury was something that you didn’t expect and it is natural for you to have difficulty handling everything by yourself. Many people might be willing to help, but they may not think to offer help. It is also important for you to let others know when you don’t want advice or help. Other family members or friends may constantly give you advice that isn’t useful because they don’t understand your situation. Others may even criticize the way you care for your injured family member. It is important for you to clearly communicate to them that you are doing the best you can and that things are more stressful for you when others criticize you. When communicating your needs to others, be clear and use words that won’t make them feel blamed. Use sentences that start with “I” rather than “You.” For example, say “I feel badly when you tell me I’m not doing a good job” instead of “You really make me mad when you criticize me.” Also let them know what would help you or make you feel better. For example, you could say, “I’m having trouble doing everything well because I have to do so many things at once. Is there something you’d be willing to help me with?”

## CHAPTER 6

### Will My Family Ever Get Back to Normal?

A brain injury can change the way the entire family functions. Your family is probably not exactly the same as it was before the injury. However, your family life can still be pleasant; it will just be different. Here are some common changes and what you can do to help adjust to them.

#### CHANGING ROLES

You may not have thought about it before injury, but everybody in your family probably had a special role that they filled. Some worked and earned money, some took care of the house, and some made financial decisions. Other roles may have been more emotional in nature. For example, someone may have been the person who made everyone else laugh in hard times. Someone else may have been the “rock” in the family, who everybody turned to in times of trouble. The injury has likely changed a lot of these roles. Your family member who was injured may no longer be able to fill the same roles. Other family members may try to take over those roles. Many times this leads to role strain, which means that each person in the family is trying to fill too many roles. Family members can become overwhelmed and can become sick, either physically or mentally.

- **What to do about changing roles:** Accept that roles must change after the injury. Get your whole family together. Discuss what needs to be done and how things can be divided up. Be sure to involve your injured family member in the conversation and have them take on some responsibilities. They need to continue to make a positive contribution to the family.

#### PROBLEMS COMMUNICATING WITH EACH OTHER.

Things have probably been so hectic since the injury that there is very little time to talk to each other. Often it seems that everything is about the injury now, and family members may not know what else is going on in each others' lives. Everyone may have similar feelings about the injury and what has happened, but they may feel alone in these feelings. Some family members may feel that it's not O.K. to talk about the injury. Even small children in the family will have feelings about what has happened and they need to feel understood. Sometimes the person with injury has problems that may make it hard for them to communicate with other family members.

- **How to improve communication:** Set aside times when family members can get together and share what's been going on in their lives. For example, you can schedule a sit down dinner together once a week. This will let you enjoy each other's company as a family again. Let all family members know that it's O.K. to talk about the injury, even if some of their feelings are negative. Find new ways to communicate with the injured family member that get around any problems they have. For example, if they have trouble speaking, have them write down what they want to say.

**LESS AFFECTION AMONG FAMILY MEMBERS:**

This problem may be related to communication problems. Family members have less time to spend together and talk to each other. Thus, they may show affection for each other less. Sometimes family members may feel less affection for the person with injury because of physical or emotional changes. For example, if the person with injury throws temper tantrums often other family members may feel less affection for them.

- ***How to increase affection in the family:*** The same suggestions for improving communication can work here. Set aside some time to spend with your family members doing things not related to the injury. A fun activity is to get some old picture albums out and look at those. This will allow you to remember the fun times you've shared as a family. Accept that it is normal to not feel affection for the person with injury at times. That doesn't mean that you love them any less.

## CHAPTER 7

### Where Can You Turn for Help?

Early after the injury, you probably had lots of help. Your loved one was still getting a lot of medical care. There were a lot of professionals around to answer your questions. You also probably had a lot of friends and family offering their help. As time has gone by, you may have less help. You may not know where to turn for certain services. Here is a list of places that you can go to for help with different things. Most of the places are in Houston, but if you call they may be able to tell you about a place closer to where you live. In addition to these places, local churches are often a good source of support.

## Resources

Information & General Help:	Phone or Website
<p><b>Brain Injury Association of America (BIAA)</b> Provides education, support and information for persons with TBI and their families</p>	<p>(703) 761-0750 (800) 444-6443 (toll-free) <a href="http://www.biausa.org">www.biausa.org</a></p>
<p><b>Local Resources</b> Call the National Brain Injury Information Center (NBIIC) Find BIA in your state</p>	<p>(800) 392-0040 (NBIIC) <a href="https://www.biausa.org//find-bia/find-bia">https://www.biausa.org//find-bia/find-bia</a></p>
<p><b>Brainline.org</b> Articles and fact sheets about brain injury and PTSD</p>	<p><a href="https://www.brainline.org/">https://www.brainline.org/</a></p>
<p><b>Centers for Disease Control and Prevention (CDC)</b> Provides information, publications, and resources regarding traumatic brain injury</p>	<p>(800) 232-4636 (toll-free) <a href="http://www.cdc.gov/traumaticbraininjury">www.cdc.gov/traumaticbraininjury</a></p>

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## **MUSCLE TENSING AND RELAXING EXERCISE**

- Flex your foot toward you head as you breathe in, then relax it as you breathe out. Repeat with your other foot.
- Extend your leg at the knee as you breathe in. Relax it as you breathe out. Repeat with your other knee.
- Tense your buttock as you breathe in. Relax it as you breathe out. Repeat with your other buttock.
- Tense your stomach muscles as you breathe in. Relax them as you breathe out.
- Flex your hand toward your shoulder as you breathe in. Relax it as you breathe out. Repeat with your other hand.
- Extend your arm at the elbow as you breathe in. Relax it as you breathe out. Repeat with your other arm.
- Tense you shoulder muscles as you breathe in. Relax it as you breathe out. Repeat with your other shoulder.
- Tense your neck muscles by bending your head back as far as it can go. Relax.
- Stretch your mouth into a big smile. Relax it.
- Wrinkle your nose. Relax it.
- Tense your forehead muscles by opening your eyes wide as if someone surprised you. Relax them.

Remember to take deep full breaths from your diaphragm. Try to imagine the stress leaving your body as you relax your muscles and breathe out.

## Evaluating Coping Strategies

Situation	What I did to cope	What Happened	Positive or Negative?
We needed to see the Doctor because my family member ran out of medications, but there was a 2 month wait list.	Yelled at the receptionist and told her that was a ridiculous amount of time to wait.	Appointment time was not changed. My family member still did not have his medicine.	Negative
	Did nothing- just waited until the appointment.	Appointment time was not changed. My family member still didn't have his medicine.	Negative
	Explained that he's out of medications and asked if he could get a temporary refill until the appointment.	Appointment was rescheduled. Medication was refilled.	Positive



# Evaluating Thoughts

Upsetting or Stressful Situation	Negative Thoughts	Why this isn't realistic	Positive, Realistic Thought
<p>Example: Your family member's application for Disability was denied.</p>	<p>“We will never be able to get any financial help.”</p> <p>“They should have approved our application the first time.”</p> <p>“No one cares about us.”</p>	<p>One instance doesn't tell you how things will be in the future.</p> <p>People are just following the rules and may not understand the details of your situation.</p> <p>This situation has nothing to do with people's feelings for you or your family member.</p>	<p>Lots of people are denied the first time. We will try again and explain our situation in more detail. If we don't get approved, we will look for other resources of assistance.</p>

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## References

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