CHAPTER 6

Family

In this chapter, you will:

- Find out about some anger management techniques.
- Read about how a brain injury in the family can cause changes in responsibilities, roles and relationships.
- Learn about the possible effects of all these changes, as well as some ways to cope with them.

Adjusting to the Changes

Good or bad, life experiences change our families. Marriage, divorce, birth, and death are some experiences that we may know well. Each brings new responsibilities, roles, relationships and feelings. The key to living with these changes is learning to adjust.

How well you and your family adjust depends on the experience and the impact on your family. Adjustment is easier when the experience:

- is something that you want (like having a baby);
- is short-lived (short-lived might mean weeks to months);
- leads to few changes in the home.

Adjustment is easier when your family:

- likes challenges and looks for change;
- has a positive outlook;
- has family and friends who are willing to help;
- accepts help;
- has few other problems (like alcohol abuse or unemployment).

Living with a brain injury takes a lot of adjustment. This is not to say that you and your family will have problems with adjustment. You may not. If you do, you should know that it is quite normal. You should also know that there are things that you can do to help yourself. Often, the first step is to try to understand the changes that have happened. Greater understanding usually leads to a sense of control. Feeling in control can reduce stress and help you to make better choices when dealing with the changes that come with a brain injury.

Changes in the Survivor

Changes to the family usually begin with you, the survivor. This is because it is what you can and cannot do that determines how the family must respond. Not all changes are alike, however. Some make a big difference to the family, while others do not.

Following is a list of common changes. You and each member of your family should go through the list that follows and check off those that apply. This will help paint a picture of the changes that you see in yourself, and the changes that the family sees in you. Hopefully, this exercise will help each member of your family understand how everyone views the situation.

- □ Aggressive
- \Box Angry and critical
- □ Attention problems
- □ Balance problems
- Double vision or wandering eye
- □ Easily distracted
- □ Easily lost
- □ Emotional (anxious or depressed)
- □ Forgets appointments, etc.
- □ Headaches
- □ Immature
- □ Impulsive
- □ Judgment is poor (bad decisions)
- □ Lacks initiation (does not try things)
- □ Lacks insight (unaware of problems)
- \Box Misunderstands what is said
- □ Moods are up and down
- □ Movements are uncoordinated
- □ Poor problem-solving
- Problems with reading or writing
- \Box Says the wrong thing
- Sensitive to noise
- □ Sexual interest changed (more/less)
- □ Sleep problems
- □ Stands too close to others
- □ Swears/Verbally abusive
- Talks too much
- \Box Tires easily
- □ Trouble making decisions
- \Box Worries too much

Anger Management

Anger is a completely normal emotion. But when it gets out of control and turns destructive, it can lead to problems—problems at work, in your personal relationships, and in the overall quality of your life. This section is meant to help you understand and control anger. You may want to talk to a counselor, a mental health worker or your Service Coordinator for more information on anger management.

Anger can vary from mild irritation to intense rage. Anger can be caused by both external and internal events. You could be angry at a specific person (such as a coworker or supervisor) or event (a traffic jam, a canceled flight), or your anger could be caused by worrying or brooding about your personal problems. Memories of traumatic or enraging events can also trigger angry feelings.

The goal of anger management is to reduce both your emotional feelings and the physiological arousal that anger causes. You can't always get rid of, or avoid, the things or the people that enrage you, nor can you change them, but you can learn to control your reactions. It's best to find out what it is that triggers your anger, and then develop strategies to keep those triggers from tipping you over the edge.

We can't physically lash out at every person or object that irritates or annoys us; laws, social norms, and common sense place limits on how far our anger can take us.

People use 3 main approaches to deal with their angry feelings: expressing, suppressing, and calming. Expressing your angry feelings in an assertive—not aggressive—manner is the healthiest way to express anger. To do this, you have to learn how to make clear what your needs are, and how to get them met, without hurting others. Being assertive doesn't mean being pushy or demanding; it means being respectful of yourself and others.

Anger can also be suppressed or redirected. This happens when you hold in your anger, stop thinking about it, and focus on something positive. The aim is to suppress your anger and convert it into more constructive behavior. The danger in this type of response is that if your anger isn't allowed outward expression, your anger can turn inward—on yourself. Anger turned inward may cause hypertension, high blood pressure, or depression.

You can control your anger by calming down inside. This means not just controlling your outward behavior, but also controlling your internal responses, taking steps to lower your heart rate, and letting the feelings subside.

Relaxation

Simple relaxation tools, such as deep breathing and relaxing imagery, can help calm down angry feelings. There are books and courses that can teach you relaxation techniques, and once you learn the techniques, you can call upon them in any situation. If you live with others who may also be hot-tempered, it might be a good idea for everyone to learn these techniques.

Some simple steps you can try:

- Breathe deeply, from your diaphragm; breathing from your chest won't relax you.
 Picture your breath coming up from your "gut."
- Slowly repeat a calm word or phrase such as "relax," or "take it easy." Repeat it to

yourself while breathing deeply.

- Use imagery; visualize a relaxing experience, from either your memory or your imagination.
- Non-strenuous, slow, yoga-like exercises can relax your muscles and make you feel much calmer.
- Practice these techniques daily. Learn to use them automatically when you're in a tense situation.

Cognitive Restructuring

Simply put, this means changing the way you think. Angry people tend to curse, swear, or speak in highly colorful terms that reflect their inner thoughts. When you're angry, your thinking can get very exaggerated and overly dramatic. Try replacing these thoughts with more rational ones. For instance, instead of telling yourself, "oh, it's awful, it's terrible, everything's ruined," tell yourself, "it's frustrating, and it's understandable that I'm upset about it, but it's not the end of the world and getting angry is not going to fix it anyhow." Be careful of words like "never" or "always" when talking about yourself or someone else. Negative or angry statements can alienate and humiliate people who might otherwise be willing to work with you on a solution.

Remind yourself that getting angry is not going to fix anything, that it won't make you feel better (and may actually make you feel worse). Remind yourself that the world is "not out to get you," you're just experiencing some of the rough spots of daily life. Angry people need to become aware of their demanding nature and translate their expectations into desires. In other words, saying, "I would like" something is healthier than saying, "I demand" or "I must have" something. When you're unable to get what you want, you will experience the normal reactions—frustration, disappointment, hurt but not anger.

Problem Solving

Sometimes, our anger and frustration are caused by very real and inescapable problems in our lives. To address everyday problems, make a plan, and check your progress along the way. Resolve to give it your best, but also not to punish yourself if an answer doesn't come right away. If you can approach your problems with your best intentions and efforts and make a serious attempt to face them head-on, you will be less likely to lose patience and fall into all-or-nothing thinking, even if the problem does not get solved right away.

Better Communication

Angry people tend to jump to—and act on conclusions, and some of those conclusions can be very inaccurate. The first thing to do if you're in a heated discussion is slow down and think through your responses. Don't say the first thing that comes into your head, but slow down and think carefully about what you want to say. At the same time, listen carefully to what the other person is saying and take your time before answering.

Using Humor

"Silly humor" can help defuse rage in a number of ways. For one thing, it can help you get a more balanced perspective. When you get angry and call someone a name or refer to them in some imaginative phrase, stop and picture what that word would literally look like. If you think of someone as a "dirtbag" or a "single-cell life form," for example, picture in your head a large bag full of dirt (or an amoeba) standing in front of you. There are two cautions in using humor. First, don't try to just "laugh off" your problems; rather, use humor to help yourself face them more constructively. Second, don't give in to harsh, sarcastic humor; that's just another form of unhealthy anger expression.

What these techniques have in common is a refusal to take yourself too seriously. Anger is a serious emotion, but it's often accompanied by ideas that, if examined, can make you laugh.

Changing Your Environment

Sometimes it's our immediate surroundings that give us cause for irritation and fury. Problems and responsibilities can weigh on you and make you feel angry at the "trap" you seem to have fallen into and angry at all the people or things that made that trap. Give yourself a break. Make sure you have some "personal time" scheduled for times of the day that you know are particularly stressful.

Do You Need Counseling?

If you feel that your anger is really out of control, or it is having an impact on your relationships or on important parts of your life, you might consider counseling to learn how to handle it better. A psychologist or other licensed mental health professional can work with you in developing a range of techniques for changing your thinking and your behavior.

Increased Responsibilities

After a brain injury, the survivor may not be able to do all the things he/she used to do. Other family members may have increased responsibility for chores or duties to keep the home working smoothly. How much more your family has to do can be a measure of how big the change has been.

Family Matters

Shifting Responsibility

Sometimes the survivor is not able to do things that they did before. The family's work increases because the survivor's responsibilities shift to other family members. Here are some examples of shifting responsibilities:

- The survivor used to handle the money. Now they make a lot of errors when doing the math. As a result, another person may have to balance the cheque book.
- The survivor used to help with meals. Now they forget simple things like how much

water to put in the rice. When they have problems like this they just do not cook. The result is that you end up cooking all the time.

- The survivor used to watch the children when you went bowling. Now the survivor is losing their temper with the children all the time. You give up your bowling so that you can stay home and watch the children.
- The survivor used to take the kids to everything. Now the kids think the survivor says embarrassing things and they either go alone, or ask you to take them.

New Responsibility

Some responsibilities may be totally new to your family. These are usually chores or duties the survivor did for themselves before the injury or illness. Things that you might already have found yourself doing for the survivor include:

- taking care of them, such as getting them dressed, bathed, or on the toilet;
- supervising the survivor;
- dealing with medical needs, such as giving medications or reminders about

appointments;

- correcting the survivor or helping them to relearn skills;
- dealing with out of control emotions and behavior.

A helpful exercise might be to write a list of new responsibilities as you think of them.

Changes in Roles

Survivor Matters

Changing responsibilities lead to changing roles. Roles are made up of groups of chores that we do. For example, the role of homemaker includes cooking, cleaning, watching the kids, and so on. But there is more to a role. Being in a role means making decisions and taking authority. The homemaker not only does the cooking, but decides what to cook and when. They also direct others to do things, like set the table.

Family Matters

Each member of the family might try making a list of the new roles that they and others have taken on. Do not forget to include how these new roles make you feel. For instance, roles bring work, but they also bring status. Status makes us feel better about ourselves. The family member who does more often gets more credit. This can lead to feelings of being valued and important.

Survivor Matters

It may be the reverse for you. You may do less and feel like you are valued less. You might react to this in a number of ways:

- grief as you feel you are not needed;
- anger at not being valued (especially if you have poor insight);
- apathy because of your inability to change things around you;
- relief because you can let go of responsibilities.

Write down some of your feelings.

Family Matters

How the family feels about the survivor's loss of roles is also important. Many families feel guilty. This often happens when the survivor is unhappy with the changes. Other families struggle with the dilemma of how to include the survivor. If they make the decisions alone, they risk the survivor's anger. If they let the survivor decide, they might not be able to live with the decision. Both options can lead to feelings of frustration, anger, and resentment. Write down your feelings about this.

Finally, there is one change in roles that spouses say is uniquely difficult; the shift from spouse to caregiver. A caregiver is a person that feeds, dresses, and otherwise cares for another person. It is a common role for parents of young children. Being a caregiver for a spouse is unusual and can be very unrewarding. Spouses need a give and take relationship in their marriage. Many do not get that when they are a caregiver. Write down your feelings about this.

Changes in Relationships

Three things change relationships after brain injury:

- shifting roles;
- changes in the survivor's personality; and
- less time spent with other family members.

Shifting roles change relationships between the survivor and family members. A child who watches over his father might not give him the same respect. A wife who cannot banter with her husband and turn to him for advice may not feel she has a partner.

Personality changes often alter how much you like the survivor. Likeable changes can strengthen the relationship, like when a gruff father becomes warmer and kinder. However, the changes can often lead to a less likeable person. At its worst, the survivor changes so much that they seem like another person. A wife described her experience as being widowed and married at the same time... and to someone she would never have had as a friend. A son said he could handle it if his dad had died, and he could handle having a strange man in the house, but that the strange man was in his dad's body was more than he could take.

Relationships between all family members can change when the survivor demands a lot of time. Time spent on the survivor means that others in the family need to do more for themselves. This can be good or bad. In families that have a child with a disability, about half of siblings become more mature. They care more for others, are more independent, and develop a strong sense of helping others. The other half become jealous and resentful. They say that they missed time with their parents. Couples with either a spouse or child survivor may also go either way. Some pull together and become stronger. Others fall apart entirely.

Common Responses

Your reaction to the changing family is very important. How have you felt? What do you experience? What has been your and your family's reaction to the changes? Make a list of your thoughts, feelings, and reactions.

Effects of Changing Responsibilities, Roles and Relationships

Most people see very quickly that things have changed greatly since the injury or illness. The family has much more to do now than before. You might have to expend much more effort on even the simplest tasks. What you might not notice right away is how your feelings have changed. If you feel the change has been particularly difficult and unrewarding you might:

- resent the unfairness of it;
- grow frustrated with the process of regaining skills;
- simmer or rage at others who do not understand;
- fear letting your family down;
- wish the injury had never happened, or wish that you had died;
- feel that you have been returned to a role you thought you left behind. As an adult, you may fear being treated like a child for the rest of your life.

It is important to realize that these feelings are normal. They are part of adjusting to the new family situation.

It is easy to feel unappreciated. Many of the things you do can go unnoticed. Many of the difficulties you face are unseen by others. Brain injury has been called the invisible injury. It is its invisibility that often leads others to underestimate what you have to do to manage.

Denial

No one wants to believe that they are in denial, but denial is common. It is a normal part of the healing process. When you do not deal with issues that must be dealt with, denial becomes a problem. This can mean that you or your family are ignoring a problem until it becomes dangerous; it can also lead to trying something that is unsafe.

Denial can be the result of a misconception. You may think, "If I have a brain injury I am useless to my family; so I cannot have a brain injury." Sometimes all you need to do is change the misconception in order to put denial behind you, "A brain injury means that I may have more difficulty in some tasks than I did before the injury, but that does not mean that I am not an essential part of my family."

Depression

Another common difficulty after brain injury is depression. This may include feeling "down in the dumps" or even thoughts of suicide. These feelings are normal and nothing to be ashamed of. It can take amazing strength to cope with a brain injury. Sometimes your ability to cope is simply overwhelmed.

It is important, however, to know if and when you need help. The following are signs that you may need to seek help from a professional counselor or doctor:

- Do you find yourself crying uncontrollably for no reason?
- Are you beginning to feel hopeless, like there is nothing you can do to make things better?
- Do you find that you have lost interest in things that you used to enjoy?
- Are you tired and listless?

- Are you having trouble getting to sleep or waking up early and unable to get back to sleep?
- Have you had a serious change in appetite?
- Are you having thoughts of hurting yourself or thoughts of suicide?

If you are experiencing any of these, especially thoughts of hurting yourself or suicide, you should see a counselor or doctor right away.

Coping Ideas

Look over what you have learned about changes in your family. Look over what you have written in the last few pages or in your journal and then ask yourself these questions:

- Has there been much change?
- Has that change led to good feelings, bad feelings, or mixed feelings?
- In what parts of my family's life have I seen change?
- What changes have led to very strong feelings?

Below are some coping strategies that may help if the changes in your family have become a concern to you or any of your family members.

What you found

Too many new responsibilities, or difficulty keeping up with tasks that were simple before the injury.

Suggestions for coping

The key to coping here is to reduce demands on your time. You might try the following:

- Simplify your life. Things are not going to pick up where they left off. Do not do anything you do not have to for awhile.
- Find out if you can pay for help. Home Care, private companies, and live-in nannies or housekeepers are some possibilities. You should check if the cost of this service will be paid by your insurance.
- Pass some duties to a family member, advocate, or close friend. Try to spread out the duties between several people to keep everyone from feeling overburdened.

What you found

New roles are overwhelming. A lot of stress in roles comes from being responsible. The idea here is to let go of your role for a while to take the weight off your shoulders.

Suggestions for coping

Try the following:

- Pass some duties back to the survivor. Family members find themselves doing a lot for the survivor because they fear for the survivor's safety or dignity. Letting the survivor try things is the way to pass these duties back to them. Suggestions for how to do this can be found in the chapter called "Rebuilding Skills" (Chapter 5).
- Make time for fun or relaxation. It does not have to be a lot. It could be 15 minutes of listening to music, coffee with a friend, or an evening playing ball. The thing is to drop the load you are carrying for a little while and have fun.
- Take one day at a time. When you feel overwhelmed, take one hour at a time.

What you found

New roles are upsetting for the survivor or other family members.

Suggestions for coping

You should acknowledge the survivor's feelings even if you cannot deal with the problem right away. When the family is ready to deal with the difficulty of new roles you might try the following:

- The survivor and family should develop a plan together when making decisions about the recovery goals. Both the family and the survivor should list their worries and problems. You may want to limit the list to each family member's top three worries so that no one feels overwhelmed or attacked. The key is to avoid letting your worries build up until you explode at the other person. You may want to have a professional involved when you do the planning. This will help avoid a situation where one family member feels teamed up on.
- Write down all family members' new roles. Make sure that everyone in the family has a role that makes them feel like an important member of the family. These roles should be

defined and clearly understood by all family members. Keep in mind that these roles can and should change as the recovery process goes on. Again a professional might help here.

What you found

The survivor is like a new person.

Suggestions for coping

This can be a difficult experience. It is often best dealt with by talking to others who understand. You might try the following:

- Go to a brain injury caregiver support group. Sharing your experience with others who know firsthand what you are going through can be helpful.
- Talk to a counselor who knows about brain injury. Talking to someone knowledgeable about such changes can help you understand your feelings and help you make life decisions.

What you found

You or another family member appears depressed.

Suggestions for coping

 If you or a family member show serious signs of depression, you should see a professional. You can start with your family doctor. Your Service Coordinator might be able to direct you to a private counselor or a support group.

What you found

Denial is leading to difficulties in your home.

Suggestions for coping

If it is your family who is in denial, they may be pushing you beyond your limits.

• Talk about changes that you have noticed. This can be very effective, though sometimes the help of a professional is needed.

If it is the survivor who is in denial, it may lead to them trying something unsafe.

• Help the survivor to see what they can and cannot do. (Use experiments to help them understand this concept.)

What you found

You are unsatisfied as a caregiver.

Suggestions for coping

This is likely the most uncomfortable issue to deal with. This is because this situation may lead to separation or divorce. The following are possibilities:

- Try to make a change in your thinking. If your choice is to stay, it is helpful to find a way of thinking that helps you feel better.
 For example, some see caregiving as an honorable way to spend one's life.
- Find someone to talk to about your feelings. This could be a counselor, a friend, or a support group.
- Look at other living arrangements.
 Sometimes the best choice for the family is to have the survivor live with someone else.
 For more information on your choices, read Chapter 9, "Housing."

What you found

Some family members seem to be getting too little attention because most attention has been directed at the survivor.

Suggestions for coping

The idea here is to see if you can make time for yourself and your family. You might try the following:

- Set up regular activities just for those family members. It should be a special time for you and them. Some families have found that relatives and family friends can also sometimes provide this quality time.
- Explore respite services in your health district. Respite is discussed in Chapter 9, "Housing."
- Plan a family getaway. This may include leaving the survivor with someone else.
- Let the survivor get away for awhile. If the survivor has a close friend or family member that they can visit for a week or two, it can help ease everyone's tension.

One way to cope with all the changes in your family is to seek out a support group. Your Service Coordinator may be able to help you to find out about one in your area.

Separation, Divorce, and Placing the Survivor Outside the Home

Leaving the survivor is a sensitive issue. Families have a lot of different feelings in these situations: guilt, because they feel they should continue to help the survivor or because they have wished the survivor dead; anger, because they feel health care professionals misled them into taking the survivor home or did not give them enough support after the survivor did return home; concern about how the choice to leave might affect the survivor and the rest of the family.

There is no universal answer to the question of whether the survivor should live at home or somewhere else. This is a sensitive issue and must be an individual choice for every family. It is a good idea to discuss this issue extensively with the survivor's doctor and other health care professionals, with a professional counselor, and with the survivor themselves before making any decisions.