

CHAPTER 5

Rebuilding Skills

In this chapter, you will:

- Discover how you and your family view the changes that have occurred.
- Learn ways to avoid conflicts.
- Find out what tools you need to rebuild skills and learn how to work on them.

Getting Help

Survivor Matters

Everyone needs help at one time or another. After a brain injury, you and your family will probably need help. It can be hard to accept that you have lost some skills and independence after a brain injury. On the other hand, it is also hard for your family to accept that they may now have to take care of you, even though you used to be able to take care of yourself. Because this is such a difficult situation and there are so many issues to talk about, this chapter is divided into sections for you, the survivor, and

sections for your family. However, we hope both you and your family will read both sections. This may help you begin to understand each other.

The question of helping is not always clear-cut. How much help should your family provide? How much help are you willing to accept? You and your family should consider these things:

Family Matters

Prior to injury did the survivor tend to be independent or dependent, trusting or cautious, easy-going or difficult? How much has this changed since the injury?

Has their ability to think been affected? For example, do they have memory problems, has their thinking slowed down, do they show poor judgment?

After their stay in hospital, does the survivor expect others to cater to them? This can affect their willingness to do things for themselves.

Survivor Matters

How do you feel about the changes in your life? Are you angry or depressed? Do you understand the changes?

Does your family expect you to follow their goals for your recovery instead of your own? Are they willing to give you the help you think you need? Does your family understand that their level of help might need to change from day to day, depending on how well you are doing on that day?

It is not surprising there are no simple answers to questions of how much help should or will be provided to you. The fact is, there is no “right” answer. The amount of help that should be provided depends on you and your family’s circumstances.

The Science of Rebuilding Skills

Since this is a difficult and emotional time for both you and your family, it might be helpful to lay down some ground rules to encourage

compromise and avoid conflict. The first suggestion is to approach helping like a scientist. Scientists always test their ideas; you can do the same while you are trying to rebuild skills. Testing is important because although you may feel like you are capable of doing the same things you could do before the accident, this might not be true. Testing is a safe way of assessing and improving your skills.

An added benefit of acting like a scientist is that helper and survivor can distance themselves from their emotions. Putting things to the test can lead to mutual co-operation between helper and survivor.

Rules to Remember

When putting things to the test, remember the following three rules:

1. The test must be safe. A good rule is to start small. This will set you up for success. If you want to cook a full meal, consider starting with a breakfast of toast and cereal, or a lunch of grilled cheese sandwiches and soup. The results will give you and your family immediate feedback on any problem areas. If the test is a success, try something a little more difficult. If not, set more achievable

goals or keep practicing to improve skills.

Family Matters

2. Do not assist if you feel uncomfortable. If the survivor wants to do something you feel is too dangerous, simply say “no”. Saying “no” gives the survivor two important pieces of information. First, it lets them know what makes you uncomfortable, which helps them understand what to expect of you and others. Second, it helps them make safer decisions. Like many of us, the survivor may sometimes push too far. Your refusal can lead to negotiation and a safer test. Remember, it is always okay to speak your feelings and misgivings.

Survivor Matters

Listen to your family if they are uncomfortable when you try something new. It may be true that you will succeed in this task, but it is important to keep a good relationship with your family by trying to understand their fears. You can discuss a solution that you will both be happy with, such as, “If I can make grilled cheese sandwich three times without any mistakes, then I will be given a chance to make a pasta supper by myself.”

Family Matters

3. Natural consequences can be the best teachers. As a helper, it is important for you to allow natural consequences to follow actions, whether rewards or punishments. If the survivor waters the flowers, they enjoy credit for the beautiful blooms. If they burn the toast, they eat it burnt or throw it out and have to do it again.

The important point is that you do not bring on the rewards or punishments. When you let natural consequences occur, the survivor is less likely to blame you when things don't work out. It can also lead to fewer disagreements and an increased sense of self-control for the survivor.

Rebuilding Skills

Communication

Communication is an important part of being human. Communicating is not just speaking. It is also getting ideas across to others through signs, symbols, gestures, body language and written language.

Brain injuries often affect a person's ability to communicate. Some brain injuries cause

problems with speech called **aphasia**. There are two types of aphasia: Expressive Aphasia and Receptive Aphasia.

Expressive Aphasia

People with expressive aphasia may have difficulty finding the right words and forming sentences to communicate with others. They may also have difficulty in writing words and sentences. Some people with expressive aphasia say that they know what they want to say, but they can't think of the words to say it. Some people however, may not be able to think of what they want to say. Others may know what to say, but they are not able to control the muscles used in speech and voice production.

Receptive Aphasia

Receptive Aphasia can cause problems with understanding what others are saying to you. Some of these people may be able to speak well, but they may not understand when someone speaks to them. Sometimes receptive aphasia affects a person's ability to read words. They may be able to repeat what someone says to them but this should not be confused with understanding.

Brain injuries can affect the ability of the brain to send messages from the brain to the muscles of the mouth and throat that are involved in producing speech. This can cause problems with pronouncing words and/or using the voice to speak.

What you can do

Communication problems are very frustrating for both the person with aphasia and the person without. The following are ideas that can help communication with someone with aphasia:

If you have aphasia...

- slow down, take your time;
- be patient with those trying to understand you;
- keep a journal handy with common words and phrases which you can refer to when needed;
- ask someone who understands you to help you communicate;
- practice talking and forming words;
- use eye contact and body language to help you communicate;

- don't give up.

If you are communicating with someone with aphasia...

- try to eliminate background noises and other distractions;
- make sure you have the person's attention;
- speak slowly and clearly;
- check for understanding;
- encourage the person to keep trying;
- don't interrupt or fill in missing words;
- do not talk down to the person or use baby talk. Treat the person as the adult he or she is.

Where to get help

Professionals called speech-language pathologists are able to help people with aphasia. They can determine whether the problem is caused by the brain-muscle system or if it is a receptive problem or expressive problem. They can give you exercises and routines to help you with speech. They can also help you develop your own way of communicating with pictures, printed sheets and other symbols.

Some communities may have support groups for people with aphasia. These groups, usually led by speech-language pathologists, are designed to give people an opportunity to practice communicating in a supportive environment.

You can call your Health Authority for information about how to get in touch with a speech language pathologist, or ask your doctor for a referral.

Memory

The material in this section was adapted from the *Memory Management Handbook: Useful Strategies for Survivors of Brain Injuries*, available from the Edmonton Brain Injury Relearning Society (EBIRS).

Family members, friends, and support workers can play a key role in helping survivors cope more effectively with memory problems. Based on individual situations and strengths, many of the following strategies can be used that are best suited to your personal situation. Each time you introduce a new strategy, remember that the survivor may need specific instruction on how to use it. Take the time to review the strategy on a number of occasions if needed.

The following memory aid tips may be helpful:

- keep important items in a special place (i.e. keys can be left on a small table next to the door);
- label cupboards and drawers so the contents are known;
- post instructions on how to use equipment such as VCRs, microwaves and televisions nearby;
- put checklists, schedules, calendars, bulletin boards, and other memory aids in a convenient, highly-visible place;
- keep a note pad and pen or pencil close to the telephone;
- post important telephone numbers by the telephone;
- telephone numbers can be programmed to telephones that have the capability;
- use alarms, watches, automatic shut-off devices, tape recorders, electronic timers for lights, computers and electronic signaling

devices (i.e. keys that beep when you clap your hands);

- check appliances before leaving home and make sure everything is turned off before you leave.

Make Lists...

- of housekeeping duties;
- of groceries or various items to buy;
- of questions you want to ask your doctor or service coordinator;
- of bills to pay, etc.

Use Calendars...

- to remember to pay bills;
- to remember appointments;
- to remember addresses;
- to keep track of work and social dates, etc.

Remembering Names...

- say the name out loud or ask for the name again;

- ask a question using the name;
- use the name in a conversation at least once;
- say goodbye by using the name again.

Many survivors can learn to be more independent through repetition, practice, and use of memory compensation strategies. In addition to those already mentioned, there are a number of techniques that can be used to aid the survivor in rebuilding their memory skills. We encourage you to investigate further methods by speaking with your regional Service Coordinator to find out about additional resources.

Survivor Matters

Insight

Insight is a sense of one's own abilities. For example, knowing you can jump down three stairs, but not ten, is insight. The brain injury may affect your insight. Insight may be slightly less than it was, markedly less, or, as is the case of a small number of survivors, virtually gone. This is called lack of insight.

If you suffer from lack of insight, you may need help seeing the consequences of your actions. Regular and ongoing results of tests done with a helper can provide this. For example, you

could put up a chart in the kitchen and add check marks each time you successfully make toast. This provides you with clear, objective feedback and can help make up for your own lack of insight.

Initiation

Initiation is also necessary for people to rebuild their skills. Initiation is the drive that pushes us to do the things we want to do or feel we should do. Some survivors of brain injury lose their drive. They are less interested in doing things for themselves than before their injury. This is called lack of initiation.

Family Matters

As a helper, you may often find yourself doing a lot more than you would like for the survivor. Or you may find the survivor does things around you, but not without you. Ask yourself, what needs to happen to get the survivor to do things for themselves. Here are some suggestions:

- Find something that motivates the survivor. Praise can be a very powerful reward. People are more likely to work at something if they know that others appreciate their effort. You should also offer bigger rewards for

completing tasks that are more difficult or tasks that the survivor particularly dislikes.

- Use reminders around the survivor, such as lists or signs that say what to do next, or verbal cues from helpers. It is helpful to ask the survivor what kind of reminders would be most useful to them.

Survivor Matters

- Don't be afraid to reward yourself for doing tasks that you dislike or find difficult. For example, you can ask a family member or a good friend if they will go with you to a movie after you finally accomplish that big task that you were having trouble with.
- Use the kind of reminders that you find most helpful. If you prefer a computerized daily planner over a list stuck to the fridge, then that is what you should use. Experiment with different types of reminders until you find the way that works best for you. Other people may have good suggestions, but only you know what works best for you.

Motivation

Lack of initiation should not be confused with lack of motivation. People who lack motivation do not want to do what is asked of them.

People who lack initiation want to do something, but will not do it without encouragement.

Learned helplessness is one kind of lack of motivation. It occurs when a person cannot or is not allowed to escape a situation that is hurtful or difficult. From this experience, they begin to believe they have no control over their world and so lose motivation to help themselves. Some health workers believe learned helplessness can occur during the stay in the hospital. Survivors who have learned helplessness may appear listless, depressed, and/or uninterested in things around them. If this is the case you may want to:

- Try to do things for yourself, even if it is difficult or something you are not good at. This will help you regain a sense of self-control and help you remember that you can make a difference in your own life.
- Think about goals or desires that you would enjoy working towards and that would help you feel as if you were regaining control over your own life.
- Try to overcome any negative reactions over

your lack of motivation. If you focus on staying positive, it may help you become interested in trying new things.

Family Matters

Conflicting Goals

The survivor has to want to rebuild their skills; this desire is not always present. You may want the survivor to do things to ease the challenges of providing care, which can be very high, or health workers may recommend building certain skills. In both cases, the survivor may not want to do this. The result is that you become involved in a plan to build skills the survivor does not want.

Differences between you and the survivor may express themselves in two common ways: passive resistance, when they agree to work on a skill but do not practice it; and active resistance, when they argue or fight when you try to assist with the skill. Passive resistance is much more difficult to identify, but a key symptom is a feeling of dissatisfaction on the part of the helper. The reasons for your dissatisfaction will remain unclear until your differences are uncovered.

One way to reduce differences between you and the survivor is to involve them in planning the rebuilding of skills. Experience has taught health workers that a key to success is accepting the survivor's goals for treatment.

Accepting goals from the survivor may be even more important once they return home, but it may take extra effort. Survivors may be unable or unwilling to argue with health workers or caregivers. They may withhold their true feelings to keep the peace or because they do not want to offend. They may resist the whole process of planning to work on skills, because they want to do it on their own or because they are upset by suggestions from others, such as how to behave appropriately. Such resistance may be alleviated by certain techniques, (outlined in the following "Survivor Matters" section).

Survivor Matters

- You may have different goals for yourself than your family or helper has for you. These differences in goals can cause conflict. In this situation it may be a good idea to have a third person (someone who is not a part of this conflict) help you and your family or helper

talk about your goals, either separately or together. The third person can then bring both of you together to develop a new plan for building skills.

- You and the helper can write down the goals that are most important to you. Then, with discussion, a few goals can be chosen from each list with an agreement to try to work on them. This takes into consideration the needs of the family. Some of your goals must meet the needs of others.
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Family Matters

- How does your family want to continue providing support if the goals of the survivor differ from your own? This is usually more of an issue when caring for the survivor takes a lot of effort, and/or the survivor is resistant, lacking insight, or simply difficult.
- When differences produce increased strain and dissatisfaction in your family, consult a counselor, either as a couple or a family. Even if the survivor is unable to benefit from counseling, your family may. Counseling can

help you explore your commitment to the survivor and your concerns about providing care.

- A local brain injury society may be able to help direct you to a support group. Several of these brain injury societies can be found in the Resources chapter.

The discussion of the challenges of providing care brings up an important issue. Should family members be the ones helping the survivor relearn skills? Supervision, especially after a severe brain injury, can be required 24-hours a day. This can create relationships that lack the usual give-and-take, or where contrasting roles, such as lover and caretaker, form emotional conflicts for both the helper and the survivor.

In many cases, family members are the only ones available to help relearn skills. If community or financial resources are available, you may want to explore whether someone else can do this work. Someone from outside the family will not experience the same stress and strain and may be able to provide the necessary direction and supervision without the emotional turmoil. Success at finding such a person can be difficult, and the resource is often time-limited or places a heavy financial burden on the family.

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