

CHAPTER 7

Lifestyle

In this chapter, you will:

- Learn about the importance of rebuilding your social life.
- Learn to adjust your social skills to accommodate changes.
- Read about when and how to have a driver evaluation done.

Survivor Matters

The New Lifestyle

Each family responds to the changes brought by the brain injury in its own way and at its own pace. It can take a long time. It is also complicated because you cannot predict what abilities you will eventually have. Instead, you will be making adjustments throughout the different stages of recovery. One of the most helpful things you can do is allow yourself to grieve for the losses. As your grief is expressed, it will become easier to move forward and establish a new life.

Energy Levels

In the beginning, you will not have the energy to maintain a busy lifestyle. While you may or may not regain your pre-injury level of activity, most people's overall energy level will gradually increase. 'Gradually' is the key word. It may seem that little is changing, but over the long term you will see a steady increase in your energy level. Fatigue will also be a factor for your family as their stress and responsibilities are greatly increased. Your whole family should consider simplifying its lifestyle. If your energy level does not gradually increase, consult your doctor.

Social Skills

Social skills are essential to maintaining friendships, yet they may be affected by the brain injury. You may have difficulty with making eye contact, or you might dominate conversations, or say the same thing every time you see someone. You might stand or sit too close to others, or you may seem very rude. You might have difficulty showing emotion, causing your general expression to remain the same, whether hearing happy or sad news.

Other common behaviours that affect social skills include: impulsiveness, distractibility, inability to read subtle or non-verbal behaviour, and decreased sensitivity to other people's needs or social situations. You may have acceptable social skills but lack the memory or capacity for abstract thinking that is needed to participate in social activities.

If you have children, they may be most distressed by your lack of social skills. Pre-teens and early teens, in particular, are easily embarrassed by their parents at any time, and often find a parent who has difficulty with social skills very embarrassing. It may help children to tell friends about your injury, although this may be difficult to do.

It is important for your family to provide non-judgmental feedback about appropriate and inappropriate social behaviours. It may help to practice different social situations with your family, or a professional counselor or coach, to help you relearn appropriate behaviour. You may have to repeat these lessons if you have difficulty remembering or with applying learning from one situation to another. With repetition and coaching, many survivors regain their social skills.

Building a New Social Life

When you first return home, a lot of energy will be spent adjusting to the new situation. At this point, it is important not to restrict your social life too much. This applies to everyone in the family. Because you may not have the physical energy or intellectual skills needed to maintain your previous social life, you may need to be creative in your efforts to build a new one. You could:

- Consult your family, or a friend you can trust, for direction in choosing safe social activities. If your judgment is impaired, it could lead you into unsafe situations. Your family's role is to encourage you to take risks, within reason, so you can gradually gain confidence in social situations.
- Meet people, in a familiar setting, doing a quiet activity. As you gain energy, you will be less tired and less easily distracted. You can then increase the complexity of social situations. Remember that crowds, noises, and some kinds of light can affect some survivors.
- Learn from past events. If a situation does not go well, ask yourself: What happened? How was it set up? Was there anything you

could have changed to make it easier? Be positive. Wisdom comes from experience, and experience comes from making mistakes.

Establishing New Friendships

Spending time with friends is one of the most rewarding parts of life, but changes caused by a brain injury often result in old friends drifting away. They may not understand your changed behaviour or may not accept the changes.

If your friends are drifting away, it is easy to be angry with them. Often we choose our friends on common interests, so it is not surprising that when the common interests disappear, so do the friends. You should make every effort to find new friends with new common interests. A good way to start is by finding new activities you enjoy doing. Leisure activities and volunteer work provide social settings where common interests may be discovered. Shared interests are the basis of new friendships.

Family Matters

Loss of friends is especially devastating for children and adolescents. Unfortunately, it is a common experience for young people with any type of disability. There are no easy

answers, but there are things you can do:

- Concentrate on the abilities your child has and use that to foster new friendships based on common interests.
- Emphasize abilities and do not be discouraged by the initial reaction of others.
- Provide your child with opportunities to interact with their peers just as you would any other child.
- Engage your child in activities they enjoy. If you need an extra pair of hands to enable them to participate, ask local church groups, Guides and Scouts, or mentor programs. For more suggestions, contact Children's Services about the provincial programs for children with disabilities or talk to your child's school.
- Look to your extended family. Your child's deepest friendships may be with cousins, aunts, uncles, or grandparents.

In your efforts to build new friendships for your child, concentrate on developing quality, rather than quantity, in relationships. For more information about supporting a child with a brain injury, see Chapter 10.

Staying Active

Since many people do not return to work following a brain injury, or work less than full time, it is important to find meaningful activity. Changes in your abilities can make this a challenge. Your family can be a great help by providing coaching, feedback, and instruction. There are also outside resources available, such as your local Alberta Brain Injury Network office (see Resources). Do not hesitate to seek assistance.

Recreation and Leisure

The brain injury may affect what you do for fun. For example, fatigue may affect your ability to participate in some leisure activities, while a loss of social skills may affect your ability to enjoy these activities with others. To adjust to the changes affecting your leisure activities try:

- being open to participating in new ways. For example, if you enjoyed curling before the injury but are no longer able to curl, consider getting involved as a spectator or volunteer.
- modifying an activity you enjoy to fit your current abilities. For example, if you loved playing cards but now have memory and

concentration problems, look for card games where chance is more important than memory.

Family Matters

Find a “leisure buddy” to accompany the survivor to various activities. In addition to helping the survivor develop self confidence, a leisure buddy can give you a few hours’ rest.

If you need guidance, contact your local Alberta Brain Injury Network office (see Resources) and ask them to direct you to a recreational therapist. If you live in a larger community, call the municipal recreation and/or leisure services department, and ask about services and facilities in your area.

Volunteering

Once you are physically able to do more, it may be helpful to participate in volunteer activities. Volunteering will give you a chance to do something for others, and it can boost your self-esteem and help you get back into a structured daily routine. Some survivors have said that volunteering is critical for bridging the space between recovery and work. Check out the volunteer opportunities in your community. Just be sure to look for volunteer opportunities that match your activity level and social skills.

Your local brain injury association (see Resources) may provide a volunteer program to help you get started.

If you hope to return to work eventually, you will need to work on regaining as many skills as possible. For example, social skills and energy levels are critical to a successful return to work. Begin by developing a daily schedule that includes meaningful activities (such as leisure and volunteering) as well as activities designed to help you practice and improve your skills. This will help your recovery by providing structure to your day. You should probably begin with just one or two hours of structured time in your day and slowly increase this. This will also help you work on your organizational and time management skills, and it will help you discover what your best “daily method of operation” is. For example: Do you work best if you take a five-minute break to stretch once every half hour? Does a computerized daily planner work better for you than a booklet? Do you work better first thing in the morning or late in the evening?

For more information, refer to Chapter 10, “Work.”

Maintaining Your Family's Social Life

Family Matters

It is important for family members to maintain social contact with others. If you are the caregiving spouse:

- do not quit your job unless absolutely necessary;
- balance your need to talk about the stress of your situation with your need to talk about other things;
- schedule social activities for yourself and follow through;
- arrange for respite care to give yourself a rest (see the "Housing" chapter).

Studies have consistently shown that people with strong social networks manage stress much better. If friendships disappear, establish new ones by participating in one or two social interests or hobbies, or by joining a support group for families of survivors of brain injury. Your local brain injury association (see Resources) should be able to direct you to one of these support groups.

Driving

Survivor Matters

Upon discharge from the hospital, many survivors of brain injury should not be driving. Reflexes are slow, decision-making is slow, and judgment is impaired. You may also have light sensitivity and visual problems that you did not have before. These changes, however, may be subtle. It is not uncommon for them to go unnoticed at first, by yourself, your family, and your doctor. In fact, it may take time to realize that you should not be driving or should only drive in light traffic. You should be careful to evaluate your driving skills and decide whether you should wait before beginning to drive again. It is especially important considering that your brain is still in very delicate condition and even a small accident may be dangerous for you. You may want to contact your local Alberta Brain Injury Network office (see Resources) to find out if there is a driver-retraining program available in your area.

Alberta law requires that if you have a condition likely to affect your ability to drive, you must notify your insurer and the Alberta Driver Control Board.

On discharge from the hospital, your doctor will usually advise you and your family on whether it is safe for you to drive. In either case, the Alberta Driver Control Board must be notified.

To notify the Alberta Driver Control Board, you can either contact them directly (310-0000), or contact your nearest license and registry office (check the yellow pages) and explain your situation. They will provide forms for you and your doctor to fill out. They will then review the information from your doctor and determine if you may drive. When leaving the hospital, if the doctor tells you that it is safe to drive, it is legal for you to continue driving until the Alberta Driver Control Board makes a determination.

Family Matters

Because you deal with the survivor every day, you may realize it is unsafe for them to drive even though your family physician believes it is safe. This can be stressful if you are advocating having the survivor's license removed against their wishes and those of other less involved family members. In this case, a driver evaluation may prove useful.

You may call the Alberta Driver Control Board (310-0000) and make an anonymous request to

have the survivor evaluated for their ability to drive.

For many survivors, losing their driver's license is a major blow to their independence, especially if they live in a rural area. You and the survivor may need support to work through the process. Get in touch with your local brain injury association (see Resources) or other health professionals in your area, or talk to other families of survivors.

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