

**STRATEGIES HANDOUT:
A SELF-HELP GUIDE
FOR INDIVIDUALS WHO HAVE ACQUIRED A BRAIN INJURY
AND THEIR FAMILIES AND FRIENDS**



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STRATEGIES HANDOUT

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(1) INTRODUCTION TO THE STRATEGIES HANDOUT

This handout provides a short description of strategies that may be useful to individuals who have acquired a brain injury and their families and friends. It is not meant to be comprehensive or to replace services provided by health professionals. It may help you cope with some of the problems you may be experiencing.

These strategies will not cure your problems but should decrease the frustration you may experience. You will have to actively work on them. Don't get discouraged if you don't see immediate results. It will take time and practice.

More information or material can be obtained from health professionals or the following agencies:

Ontario Brain Injury Association (OBIA)

P.O. Box 2338
Station 'B'
St. Catharines, Ontario
L2R 7R9
1-800-263-5404
905-641-8877
www.obia.on.ca

Brain Injury Association of Quinte District (BIAQD)

249 William Street
Belleville, Ontario
K8N 3K4
613-967-2756

Brain Injury Association of Southeastern Ontario

613-536-1555

(2)

WHAT IS A BRAIN INJURY

Head Injury:

A head injury includes injuries to the head, face, and neck area as well as symptoms caused by damage to the skull, scalp, soft tissues or peripheral nerves. A head injury may or may not result in a traumatic brain injury.

Brain Injury:

An acquired brain injury is defined as damage to the brain, which occurs after birth and is not related to a birth disorder or a progressive disease (such as Alzheimer's disease or multiple sclerosis). The injury may be caused by a violent movement of the head (resulting from a motor vehicle or other traffic crash, a fall, an assault, a sports injury, etc.) or it may be due to a non-traumatic cause such as stroke, tumour, aneurysm, anoxia (lack of oxygen to the brain), or an infection (e.g. encephalitis). A mild traumatic brain injury can occur even without loss of consciousness although a brief loss of consciousness is common. Many individuals who have acquired a mild traumatic brain injury are sent directly home from the emergency room or the hospital.

An acquired brain injury can have multiple effects including physical, communication, thinking, behavioral, and emotional difficulties. The exact nature of the difficulties for each person is unique and will depend on how and where the brain was injured, as well as age and personal characteristics.

The strategies presented in this handout are appropriate for all levels of brain injuries.

(3)

PAYING ATTENTION

The problem:

People who have acquired brain injuries are often distractible. If they are interrupted while doing an activity, they may not be able to pick up where they left off, but may have to start from the beginning again. They may have difficulty doing more than one thing at a time. They may not be able to carry out a conversation if the TV or the radio is playing in the background, or if they are in a large group of people.

What you can do:

- Work, read, study, or watch TV in a quiet area.
- Don't try to do two or more things at once.
- Finish one activity before starting another.
- Don't work when fatigued, if at all possible.

What family members/friends can do:

- Keep the noise level down.
- When talking to your family member/friend, it is best to discuss one issue at a time and to reduce other sources of distractions (e.g., radio, TV).
- Avoid interrupting your family member/friend, unless it is necessary.

(4)

LEARNING AND REMEMBERING

The problem:

Individuals who have acquired brain injuries often report memory problems. They may forget to do things and they may lose things. They may miss important appointments. They may get lost in conversations because they forgot the topic. They may begin an activity and, halfway through, may forget the purpose of the activity.

What you can do:

- Write information down as much as you can. You may also use checklists for activities you want to do in a day. It is best to keep all the checklists together in one day planner, notebook, or binder.
- Make sure you check off each activity on your checklist as you complete it.
- If you are using a watch alarm, you may set it to go off every hour (or so) to remind you to check your day planner.
- Always carry a notebook so you can write down information as it is given to you.
- Try to avoid interruptions when you are concentrating on a task.
- Develop habitual and safe places for keeping things (e.g., for keys, glasses).
- If you tend to forget to take things with you, place them where you will almost trip over them.
- Develop a routine of activities and responsibilities and stick to this routine as much as possible.
- Use “stick it” notes around the house to act as reminders.
- You may want to talk to an occupational therapist who can help you design a system for your needs.

What family members/friends can do:

- Keep the house tidy. Don't change things around unless it is planned and necessary. Discuss the changes made with the family member/friend. Cues placed around the house may act as a reminder of the changes.
- Keep a schedule of family activities on a family calendar in a visible place.

(5)

COMMUNICATING EFFECTIVELY

The problem:

Following a brain injury, people may have trouble understanding spoken or written information. Some may have difficulty finding the right words to express themselves, whereas others tend to talk in circles and go on tangents during conversations. They may not be able to read or write as well as before. They may have difficulties recognizing and using body language, facial expressions, and tone of voice. They may not be aware of their communication problems.

What you can do:

- Take your time when you listen, speak, read, or write.
- Ask for repetition or clarification when needed.
- Ask people to speak slowly and/or write information down on paper.
- Stop and think about what you want to say before saying it. Writing down your ideas may be helpful.
- Keep eye contact with your listeners and watch for their reaction and body language.
- When you can't find the word you want to say, try to describe it with words or gestures. For instance, if you can't find the word "watch", you might say "you can tell time with it and you wear it on your wrist." Alternatively, you may point to a watch. You can help others to guess what you want to say.

What family members/friends can do:

- Take your time to listen and observe carefully to note any communication problems.
- Speak clearly, slowly, and in short phrases. Pause between phrases.
- Provide accurate feedback gently to your family member/friend regarding communication difficulties in a non-judgmental manner. Be specific and use concrete examples.
- Reduce background noise (e.g., TV, radio, street noise) whenever you can.
- Ask specific questions or restate previous points to help your family member/friend stay on topic.

(6)

KEEPING FIT AND HEALTHY

The problem:

Following a brain injury, many people have a period in hospital of very little physical activity. Once they return home, many find that they are out of shape and not involved in regular physical activity.

What you can do:

- Choose a physical activity you like and one you have easy access to.
- Do this activity regularly, three to five times a week for a minimum of 20 minutes, but only if the activity does not result in pain. If you are having pain, talk to your physiatrist or physiotherapist.
- Start slowly. Set goals you can achieve.
- Use a chart or your day planner to keep track of when you exercise.
- One of the best exercises you can do is walking. It's free and you can do it alone or with a friend.

What Family members/friends can do:

- Help your family member/friend choose an activity that he/she enjoys.
- Join your family member/friend in the activity.
- Remind and encourage your family member/friend to keep up the activity.
- Remind your family member/friend to write it down on his/her chart or day planner.

Physical activity can relieve stress and promote a sense of well-being.

(7)

CONTROLLING MOVEMENT

The problem:

Injury to the brain can cause the following types of problems with movement: weakness, decreased balance, stiffness (spasticity), and decreased coordination.

What you can do:

- **Weakness:** Do any exercise that a therapist has recommended in the past for your weakness. Walk, if possible, to increase your endurance. **Don't** squeeze a ball to strengthen your grip; this often leads to increased stiffness in the fingers instead of increased strength.
- **Balance:** Slow down. Remove obstacles such as rugs that you might trip on. Make sure the area is well lit. Use any aids that have been recommended to you, such as a walker or a cane.
- **Stiffness:** When you stand, make sure you keep your weight evenly over both feet. When you sit, make sure you sit so that you have your weight on both sides of your bottom.
- **Decreased Coordination:** Practice an activity over and over. Work on precision first and only then work on increasing your speed in that activity. There are aids that can be used for fine movements such as buttonhooks to help button a shirt. Remember safety first. If pouring hot drinks is a problem, consider using the microwave to heat one cup at a time.

What family members/friends can do:

- **Weakness:** Encourage your family member/friend to keep up their exercises and to be active. Go for walks with them, even inside the house if they are not up to walking outside. **Don't** give them a ball to squeeze.
- **Balance:** Remind your family member/friend to slow down, to stand up and pause before beginning to walk. Clear the house of obstacles which might cause someone to trip. Make sure the area is well lit. Encourage your family member/friend to use their walkers or canes consistently.
- **Stiffness:** Remind your family member/friend to stand with their weight on both feet and to sit with their weight distributed evenly on their bottom.
- **Decreased Coordination:** Encourage them to slow down. Praise success and encourage them when they are feeling frustrated. Encourage them to repeat activities or movements which are not well coordinated.

(8)

CONTROLLING BEHAVIOUR

The problem:

Brain injury can affect a person's ability to control his/her own behaviour. People with brain injuries often say that they react without thinking and do and say things that they would not have done or said before they were injured.

What you can do:

- Remind yourself to “**stop and think**” before you speak or act.
- Slow down. Take your time.
- Think ahead. Practice in your mind how you will handle a situation that is frustrating or upsetting.
- Take a break. When you start to feel yourself losing control, leave the situation and take a few minutes to settle down.
- Avoid places that are busy, noisy, and confusing.
- Get enough rest. Problems are more likely to arise when you are tired.

What family members/friends can do:

- Plan and pace activities to help avoid confusion and fatigue.
- Include your family member/friend in preparing for an activity and clearly define his/her responsibilities.
- Remind your family member/friend to rest, especially before activities that might cause problems.
- Give your family member/friend honest and supportive feedback, identifying successes and matter-of-factly pointing out mistakes.
- Choose quiet times and places for outings like shopping and restaurant meals.
- When attending a large gathering, arrive late and leave early.
- Help limit the time your family member/friend spends with large, noisy groups.

(9)

COPING WITH DEPRESSION

The problem:

People who have acquired brain injuries often find that it takes almost nothing to start them crying or to feel sad and discouraged. They can lose their interest in things, feel useless and have no hope for the future. Experiencing these feelings for brief periods of time is not unusual. However, when these feelings and beliefs become strong and hard to get rid of, we call them depression.

What you can do:

- Pay attention to your abilities. Look for the little signs that show that today is better than yesterday.
- Do not give up hope. Improvement is always possible.
- Plan and do activities that keep you active and make you feel good about yourself. Get involved in the community, visit friends and family, or develop a hobby.
- Keep active, but don't overdo it. Don't wait until you feel like doing an activity; just do it. The motivation for engaging in the activity will come later.
- Keep a diary of positive events. At the end of every day, write down one good thing that happened.

What family members/friends can do:

- Point out your family member/friend's accomplishments and progress. A pat on the back can go a long way.
- Support and encourage a balance between activity and rest.
- Do not give up hope. Do not hesitate to seek support for yourself or your family either through a friend or a counsellor. Enlist the help of positive people.

If depression seems serious, discuss the symptoms with your physician. Medication that may be helpful can be recommended.

(10)

COPING WITH STRESS

The problem:

People who have acquired a brain injury will experience many changes in their lives. Change is always stressful by its very nature. Changes call upon people to adapt and any adaptation can stress some parts of the body. Too many changes occurring too quickly in one's life can be extremely stressful. Excessive stress can cause apprehension, anxiety, fear, and sometimes the feeling of going crazy. Physical symptoms such as feeling uncomfortable with one's own body might also present themselves and need attention.

What you can do:

- Pay attention to your body. Are you tense? Is your heart pounding fast? Is your stomach in a knot? Becoming aware of how stress affects you is the first step in dealing with it.
- Try to identify your worries. Write down a plan of action to address each worry and refer to it as often as necessary. Remember that worries or concerns are made up of both facts and your feelings or reactions to these facts.
- Establish a daily routine and attempt to adhere to this daily routine as closely as possible. Write this schedule in a day planner.
- Pace yourself. Don't try to resolve all your problems at once. Stick with today's problems without letting your expectations for the future influence your immediate plans.
- Talk to yourself positively rather than negatively. For instance, instead of saying, "I can't handle this", say "One step at a time. I can handle this situation."
- Take some time to relax your body and your mind. Regular exercise, relaxed stretching, listening to music or taking a hot bath can help.

What family members/friends can do:

- Help your family member/friend talk to him/herself in a more positive way.
- Point out your family member/friend's strengths. Be supportive.

(10) COPING WITH STRESS (continued)

What family members/friends can do (continued):

- Discuss sources of stress and anxiety with your family member/friend.
- Get support for yourself, either from friends, support groups, or health professionals.

The problem:

Brain injury can affect a person's initiation and motivation. Individuals who have acquired brain injuries may feel that nothing is of any real importance. They may report a sense of inertia. They may be unable to make plans and follow through with them. Depression or previous failures may also contribute to their apparent lethargy and difficulties with initiation. Working towards goals and achieving them contribute to a sense of personal accomplishment and help keep a person motivated. An example of a goal may be to become involved in one fun activity per week or month for the next six months.

What you can do:

- Select two or three goals at most. Write them down in your day planner and review them every day.
- You may break down your goals into sub-goals. These goals will allow you to experience success more quickly.
- Goals must be "**SMART**".

Specific- You need to know exactly what it is you are trying to do.

Measurable- Ask yourself how you will know when you have reached your goal.

Achievable- Ask yourself whether you can accomplish a goal within the amount of time you have allowed. Remember that you may have slowed down since your injury. Make a plan of how to achieve your goal.

Realistic- Ask yourself whether your goals represent something important to you.

Time limit- Select a reasonable target time for completion.

► If you are having trouble achieving a goal, review each of the above steps and try to identify where the problem is. You may wish to talk to someone about this.

What family members/friends can do:

- Help your family member/friend by encouraging him/her to set realistic and achievable goals.
- Help make a plan for achieving these goals.
-
- Remind your family member/friend to check his/her goals every day.
- Give your family and member/friend gentle feedback on his/her progress towards a goal. Be supportive and positive.

(12)

MANAGING TIME AND ENERGY

The problem:

People who have acquired brain injuries often try to accomplish the same number of activities within a day as they used to prior to their injuries. However, they become fatigued much more quickly. When they are fatigued, performance is often affected and may lead to increased frustration and a sense of failure.

What you can do:

- Don't fight fatigue.
- Pace yourself; don't overdo it.
- Rest before you feel tired. Frequent short breaks are more effective in reducing fatigue than infrequent long breaks.
- Schedule some breaks or quiet time for yourself. You may like to listen to music that is relaxing to you.
- Each evening, set up some time to plan and write down your schedule for the next day. Make sure the schedule allows you sufficient time for each task.
- It is important that you follow your schedule. You may find it helpful to prioritize your activities. Low priority activities may be left unfinished if you are running short of time. What doesn't get finished today can be continued tomorrow.

What family members/friends can do:

- Remind your family member/friend that he/she needs more rest than before his/her injury.
- Schedule activities for times when your family member/friend is most rested.
- Help your family member/friend set up a schedule for the next day.
- Help your family member/friend estimate how much time each activity will take.

(13)

COPING WITH FRUSTRATION

The problem:

Frustration can be defined as an emotional reaction, such as anxiety or anger, when goals or expectations are NOT achieved. People who have acquired brain injuries can often be impatient and may get easily frustrated when things aren't going their way. They may also get frustrated with themselves if they can't be as accurate or as efficient as they feel they used to be.

What you can do:

- Identify which expectations or goals are not being achieved. Reassess whether your expectations are realistic.
- Identify the activities that are most frustrating to you. Break down the initial activity into smaller steps and identify which of these smaller steps are frustrating to you.
- Approach a frustrating task from a different angle and look for alternative solutions. Ask for help to identify alternative solutions.
- Switch to another task and return at a later time when you are not as frustrated.
- Ask for feedback from others about your performance.
- Recognize that some things are essentially outside your control and that there are things you just cannot change.

What family members/friends can do:

- Help your family member/friend identify which aspects of an activity are frustrating to him/her.
- Help your family member/friend recognize when he/she is beginning to become frustrated. It is good to discuss this beforehand and to agree that your task is to point out the beginning of your family member/friend's frustration and his/her task is to be receptive to this.
- Help your family member/friend adjust their expectations.

(14)

COPING WITH CHRONIC PAIN

The problem:

A number of individuals who have acquired a brain injury have also sustained other bodily injuries. Chronic pain is often experienced by many.

What you can do:

- Try to educate yourself about pain. There are many good books on pain. Alternatively, discuss the rationale behind treatment with a health professional. Be prepared for discomfort before any gains are made. Be patient if you don't make immediate progress and, as difficult as it is, keep trying.
- You may use relaxation techniques that can help you identify the parts of your body that are tense. Pay attention to the tension in your body as it often precedes the onset or worsening of pain. When you feel the tension coming on, take a break.
- Remain active, but don't overdo it. When pain forces you to quit an activity, you have gone too far and you have not paid attention to the build-up of tension in your body. It is important to stop any activity before the worsening of your pain.
- Be very careful when engaging in activity which makes your pain worse. Pace yourself. Measure how long it takes for your pain to get worse from the activity. Start practicing that for half of that time two or three times a day. For instance, if your pain is triggered after 30 minutes of an activity, engage in that activity for 15 minutes two or three times a day. If you still experience an increase in pain, cut down the duration of the activity, but continue to practice it two or three times a day. You must build up your resistance to pain gradually. Wait a few weeks before increasing the duration of the activity and increase it by a small amount at a time.
- Use good body mechanics when doing physical activities. Maintain good posture in sitting and standing.

What family members/friends can do:

- Chronic pain sufferers often feel depressed, and speak of feeling hopeless or powerless. Try to maintain your own perspective and encourage your family member/friend to remain active without overdoing it and to pace him/herself.

The problem:

The family as a unit and as individuals are affected by one member's brain injury. Roles and responsibilities change and what used to happen naturally, now needs time, planning, and organizing. Everyone may be feeling that they are carrying many additional responsibilities. It is important to recognize that this is happening and acknowledge any feelings of anger, resentment, and even guilt which may follow. These are natural reactions to have when faced with changes and adjustments, so don't berate yourself.

What you can do:

- Try to imagine how other members of your family might be feeling. Check it out with them.
- Do not feel that you need always be in control of what is happening in the family. Talk it out with other family members.
- Try to spend time with each member of your family on a one-to-one basis. Write down the time and the activity in your day planner so you don't forget to do it. Group outings might be too overwhelming and frustrating for you.

What family members can do:

- Keep the home atmosphere as organized and calm as possible. Try to maintain family routines, customs or traditions when possible.
- Include your family member in decision-making and share responsibilities where and when possible. Encourage him/her to carry out designated tasks and try to stick to this.
- Maintain open communication. Allow yourself to say "No" when you are feeling that this is best for you.
- Set a time for yourself on a weekly basis to do something you enjoy (e.g., coffee with a friend, crafts, relaxation, walks, etc). Don't be afraid to seek out counselling services in your community for support.
- Children can be quite confused by the effects of one parent's brain injury on their lives. They can benefit from special attention and from information on brain injury. They need to be reassured that they are not responsible for either the injury or any ensuing difficulties.
- Work hard to maintain your friendships. Let your friends be as helpful as they can be. Tell them how much you value them.

(16)

ALCOHOL AND DRUGS

The problem:

People who have acquired a brain injury are more sensitive to the effects of any substance that affects the central nervous system, such as alcohol, caffeine, street drugs, and prescribed medications. A brain injury together with alcohol or any drugs other than those your physician has prescribed will decrease your abilities, slow down the normal recovery process of your brain, and increase the chance of epileptic seizures.

What you can do:

- Never stop or change your medication without first talking to your physician.
- Remember that you are more sensitive to the effects of caffeine than before your brain injury. If you have problems sleeping, cut down your caffeine consumption in the afternoon and evening. Consider switching to decaffeinated beverages.
- Avoid alcohol and street drugs. Let your friends know that medical advice recommends that you not use these.
- If someone offers you alcohol, say “No” like you mean it and propose an alternative, like “I’ll have a soda instead.”
- Change your activities. For instance, go to the movies instead of a bar.

What family members/friends can do:

- Limit the supply of alcohol available in the home. Let your friends know that medical advice recommends that your family member/friend stay away from alcohol and drugs.
- Start drinking decaffeinated beverages in the home.
- Propose alternative activities and go along with your family member/friend.

(17) **WHAT FAMILY MEMBERS NEED TO HEAR**

1. Anger, frustration and sorrow are natural emotions for close relatives of individuals who have acquired brain injuries.
 - Sometimes sad things happen to good people.
2. Caretaking persons must take care of themselves first if they are going to be able to continue giving the survivor good care.
 - Keep your sense of humour.
 - Don't expect perfection; this sets up failure.
 - Don't lose touch with yourself and your capacity for love and intimacy.
 - Set reasonable boundaries; do not get confused about where you stop and the survivor begins.
3. The caretaker must ultimately rely on his own conscience and judgment in conflicts with the survivor or other family members.
 - Situations change, depending on moods, time of day, and even within the same day.
 - Surround yourself with supportive, accepting people.
 - Our society tends to undervalue caregivers. It is important that you take care of your needs and take time for yourself.
4. The role changes that inevitably take place when an adult becomes dependent or irresponsible can be emotionally distressing for all concerned.
 - It is important to acknowledge these, to take stock, and to make needed adjustment. Change is difficult and we are often reluctant to make these changes. It is worthwhile discussing these changes and how you feel about them with someone.
 - Encourage autonomy as much as possible for both the caregiver and the survivor. Each little success increases self-confidence.
5. The family members can probably do little to change the survivor and thus need not feel guilty or inadequate when their care does not result in improvement.
 - You cannot be all things to all people. You are human. Do not fall into the trap of attending to whoever yells loudest.
 - Try to be accepting and tolerant of human reactions –your own and others.

(17) WHAT FAMILY MEMBERS NEED TO HEAR (continued)

6. When it appears that the welfare of dependent children may be at stake, family members must explore the issue of divided loyalties and weigh their responsibilities.

- Children need to know that they are not responsible for their parent's injury.
- Special times and outings are important for children to know that they are important, valued people.

Adapted from: Journal of Clinical Psychiatry, Muriel Lezak, Ph.D., 39:592-598, 1978

It is our hope that the information and suggestions in this handout will be helpful to all those who are affected by brain injury.

We welcome your comments and suggestions.



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