Dale Brain Injury Services
We build futures

Family and Caregiver Handbook

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Table of Contents

Family and Caregiver Handbook

A Guide for Family and Caregivers of Loved Ones With Acquired Brain Injury (ABI)

This Handbook was designed to empower you by offering a uniform source of information while instilling hope as you navigate life after ABI. Our aim is to provide accurate and useful information that is user-friendly and based on the needs of real-life families and caregivers from their experiences. Our goal is not only to give you the information you need, but also to offer reassurance and guidance as you set forth on this journey. You have been thrust into a new reality where you are asked to be the voice, ears, and eyes of your loved one. You must all-at-once act as an advocate, counselor, and nurse, all the while striving to maintain your role as mother, father, husband, wife, son, daughter, sister, brother, and/or friend.

Take Care of Yourself

It is important to take care of yourself, so that you can take care of your loved one.

DO: Take time to rest and eat well.
DO: Talk about your feelings with a family member, close friend or a health care provider on the team.
DO: Get information and support from other families who have had a similar experience by joining one of our family and caregiver support groups.

If you become depressed or overwhelmed by your feelings, we have a consulting psychologist and a clinician that can provide family and caregiver support. This type of support can help you and your family learn to cope with this crisis in your lives.

This may be a stressful time for your family

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Having a loved one who has had an ABI, either recent or years ago, can be very stressful. You and your family may be feeling many emotions and family members may have different reactions to this situation. You and your family may be feeling:

- Shock and disbelief
- Helplessness
- Hope
- Fear and anxiety
- Guilt
- Frustration or anger
- Changes in relationship roles
- Relief that your loved one is alive and recovering

All of these feelings are normal

SECTION 1 – CAREGIVING

Caregiving Basics: What is a Caregiver?

A Caregiver is any family or support person(s) relied upon by a person with ABI who assumes primary responsibility for ensure the needed level of care and overall well-being of that person.

How Important is Caregiving?

Family and caregivers play an important role in recovery. Your job is to offer guidance and help your loved one and you are part of our team at Dale Brain Injury Services (DBIS). Many people, like us, who work with individuals that have had an ABI believe that having family or a caregiver just like you is one of the most important aids to recovery. Use this guide: It provides tips on how to manage caregiving. Ask questions of those providing treatment and care. Support groups and counseling may also be helpful.

Keeping Organized:

The more organized you are, the better. Being organized will help you:

- ✓ Have more control in making decisions and having access to accurate information
- ✓ Reduce your stress
- ✓ Have all the care-related information you need in one place
- ✓ Keep all the important documents deeded together

Suggestions for Organizing Information:

A notebook helps an individual with ABI and their family or caregiver keep information they need together in one place. You should keep all medical information together and maybe even enter it into a computer file. Your notebook should include:

Personal Information – emergency contacts, health card number and current letter code

Medication Log - drugs taken, dosages, dates, side effects/problems

Calendar of appointments - make sure there is enough room to include all of your appointments

Notes and questions - include a note pad to take notes at appointments

Resources and information - keep all the forms and information you received at appointments

Medical reports, tests, scans - ask for copies of reports, scans and tests

Paying Bills:

If your loved one with ABI can no longer handle paying the bills:

Consider online banking and bill paying

Consider Power of Attorney (see Resources on the last page)

Advocating:

You can learn to build on the problem solving skills that you already have to become an advocate. Advocacy is all about knowing what you want in a situation, getting the facts, planning your strategy, being firm and persistent, and maintaining your credibility.

The basics of speaking up for your family member:

1) Identify yourself. State your name and identify yourself as a family member or a caregiver.
2) Be specific. Clearly describe the issue and state your goals.
3) Make it Personal. Give the issue your individual voice. Use personal examples and speak in your own words.
4) Be Confident. You may know more about the issue than the person to whom you are advocating. You can offer yourself as a source of information.
5) Be Polite. Always work on the basis that the person you are speaking to is open to reason and discussion. If you are rude your message may not be received.
6) Be Brief. Communication that focuses strongly on one argument is the most effective. Keep it to one issue.
7) Be Timely. Your message is more likely to be considered if it is immediately relevant.
8) Be Factual. Use facts and statistics. Make sure the information you provide is accurate.

Taking care of yourself:

Caregiving requires you to take on new roles. Keep in mind that all of these new demands may happen at the same time, and that you and your family are coming to terms with the impact of ABI on your loved one.

You want to give the best possible care and support for their recovery which means that you may find yourself spending all your time and energy dealing with your loved one's needs. This may leave you feeling drained. You may be tempted to put your own

It's important to recognize when you need help - and ask for it

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As a family member or a caregiver, you may find yourself in situation where you need to advocate for your loved one with ABI or for yourself. It may not be something you are comfortable doing, but it is important.

Advocacy involves basic communication skills:

Listening to what other people have to say.

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Talking about what is important to you.

needs on hold, but it's not wise to do this. You won't be able to give the best care or cope with your new tasks if you do not care for your own needs.

How Can I Stay Emotionally Healthy?

You may move through a series of stages as you come to terms with the changes in your loved one. In the first couple of months, you may be feeling happy that your loved one is alive and hopeful that they will recover fully and quickly. As time goes by, progress may slow and you may feel anxious and scared. Sometimes you might think that a full recovery would happen faster, if only they would work harder at it. As recovery progresses, you may find yourself feeling discouraged and depressed or even guilty that you just don't know how to help your loved one get better.

Feelings of depression may progress into feelings of despair and a sense of being trapped, if recovery slows down over time. If you loved one has sustained a severe ABI and recovery is difficult, you may find yourself experiencing a period of grief and deep mourning. Eventually, and this may take up to two years or longer, you may find yourself stepping back from the pain, accepting what is, and finding peace in your family's situation. You may not go through these stages exactly like this. Knowing what many family members and caregivers go through as they adjust to life after ABI may help you to know that your reactions are "normal," although there can be harmful effects if you focus all of your attention on your loved one.

If you do find yourself suffering from caregiver burnout or compassion fatigue, the following is a list of what you can do:

1. Find a friend or family member to talk about your feelings or join a support group with other families or caregivers affected by ABI. Talking with someone can relieve stress and reduce anxiety.

You may experience caregiver burnout

If you do not take care of yourself emotionally and physically, you may find yourself:

- Being harmful to yourself
- Feeling listless, isolated, or bottled up
- Using alcohol to cope
- You may have poor hygiene
- Prone to emotional outbursts

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These are all signs of caregiver burnout and compassion fatigue. Compassion fatigue is an outcome of chronic, unrelieved stress.

2. Dale Brain Injury Services offers support groups for family members and caregivers.
3. If stress, sadness or anxiety begins to feel out of control, seek professional help from a counselor, therapist, religious/spiritual leader, psychologist or social worker.

How Can I Stay Physically Healthy?

Healthy behaviours can keep you well. They can help you cope with the stress of caregiving. This section contains some healthy lifestyle tips. The more you take care of yourself, the better you will feel, and this will enable you to better care for your loved one.

Sleep. If you don't get enough sleep, you are likely to be tired and irritable during the day. You may also find it hard to concentrate. Studies show that people who do not get enough sleep are less productive, tend to overeat, and are even more likely to get in accidents.
Try these tips for getting a comfortable night's sleep:

1. Establish a routine for when you go to bed and when you get up every day.
2. Establish a relaxing bedtime routine e.g. take a bath, read a book.
3. Go to bed when you are tired and turn out the lights. If you can't fall asleep, get up and do something else until you are tired.
4. Don't exercise close to bedtime. It may make it harder to fall asleep.
5. Avoid too much alcohol and caffeine. Too much of either usually reduces the quality of sleep.
6. Have someone stay over to take over the care duties during the night.

Eat a healthy Diet. A healthy diet is one that is low in fat, high in fiber from whole grains, fruits and vegetables, an includes lean cuts of meat, poultry, eggs and other protein sources. It can be tempting to overeat. Do not use food as a comfort when you are stressed and sad. A healthy diet will help you manage stress more effectively and elevate your mood.

Exercise. Exercise can relieve stress, reduce depression, make you feel better about yourself, help you maintain a healthy weight and give you some alone time.

- It doesn't have to be strenuous. A 30-minute walk on most days is usually enough to protect your health. You can break the 30 minutes into shorter 10 minute segments, if that's all the time you have.
- If you already have an exercise routine in place, try to stick with it. Doing things that was important to you before the ABI can help you cope. You will be a better caregiver.
- If you are new to exercise, check with your physician and start out slowly. Remember to include stretching and strength building in your routine.

- There are may exercise videos that you can use at home. You don't need to find the time or money to go to a gym.

Strategies for Self Care

Problem solving

Learning how to be a good problem solver can help you cope with stress and reduce anxiety. Here are some simple problem-solving steps:

1. Identify the problem. If the problem has many parts, break it down into one problem at a time.
2. Brainstorm solutions. Think of as many possibilities as you can.
3. Assess options. Consider the pros and cons of each possibility.
4. Choose a solution that seems to fit best for you.
5. Try the solution out, if it didn't work, try another solution until you find the one that works.

Stress Busters

- Practice deep breathing. Take a deep breath, hold it for a few seconds, and then let it out. Continue to breathe deeply until you feel yourself calm down.
- Relax your muscles. Lying down, begin by tensing your toes, then relaxing them. Then tense your ankles and relax. Continue up your body to your forehead, tensing and relaxing each set of muscles. Then lie quietly for a few minutes, letting your body melt into the floor.
- Find time to exercise. Exercise helps you brain release endorphins. It also gives you some alone time
- Try tai chi or yoga. Many people find these activities helpful to relieve stress.
- Manage your time effectively. Plan ahead so that you have enough time to arrive at appointments on time. Plan your day or week sensibly, so that you are not trying to get too much done in too little time.
- Find ways to relax and take your mind off your daily routine: read a book, watch your favorite move/TV show, or spend time with a friend.
- Try meditation. Select a quiet spot in the house and a time when you can be quiet for 15 minutes. Sit down and rest your hands in your lap. Close your eyes. Clear you mind. Breathe in deeply, then let your breath out while you say a word such as "one". Repeat continuously. Try to clear all thoughts from your mind as you do this. It takes practice, but you will find yourself able to do so for longer and longer periods of time.

Helping your Children Cope with ABI

Having a parent with ABI can be frightening for a child who looks to their parent to provide strength and safety. The parent with ABI may no longer act the same as they did before the injury. Your loved one with ABI may be angry, depressed, or uncertain. As a result, the special parent-child bond that existed previously has changed.

Children may be confused and upset about what is going on. This could be due to worry about a parent's condition or concerns about changes in their parents' relationship. It could also be due to financial strains, or simply adjusting to the new "normal."

It is important to recognize that your children are grieving, just as you are. They may withdraw from social activities with peers, have mood swings, become withdrawn or disruptive, do poorly in school, and show other behavioural problems. Children also need time and space to be kids. Communicate with your child that they are not to blame for the ABI.

Some children may need to take on some caregiving tasks for the parent or for younger children in the family. Children who care for parents or other relatives experience considerable conflict over the reversal of roles between parent and child. Make sure any tasks that your child takes on are suitable for their age. Strive as much as possible to find other adults to help you, rather than relying on your children to play a major caregiving role.

You can help your children by explaining ABI in a way that they can understand (see below). You may want to ask a professional (e.g., Psychologist) to speak with your children. Build new family routines, and watch for signs that your child is not coping well. If your child appears to be depressed for a long time or they begin taking on risky behaviours, see professional help.

How can I tell my child about ABI? It is difficult to explain ABI to a child, but it is very important to tell your child what is going on. Some adults try to protect children from the truth because they think they are too young to understand. Children of almost any age are aware that something is wrong and they want to know what is happening.

Communicate in an age-appropriate way what has happened to your loved one with ABI. Protecting your children by withholding information may backfire. Children have active imaginations that may create a scenario worse than reality. How to tell your child about ABI depends on the age of the child. The table on the next page offers strategies that you can use, depending on the age of your child.

Age and Stage of Development	Communication techniques for Parents
Age 2-3 Can differentiate expressions of anger, sorrow, and joy	• Communicate using simple words. • Use picture books. • Create simple books with pictures of family members and simple objects that the child understands (hospital, doctor, bed, rest). • Offer dolls to play with so they can recreate what is happening at home or at the doctor's office.
Age 4-5 More self-secure, can play well with others, tests the rules, 'magical thinking'	• Select books with stories that mirror families like yours to help your child relate. • Familiarize your child with pictures of objects and concepts related to medical care and health (hospital, gown, doctors, flowers, bed, coming home from the hospital). • Incorporate play with a child's 'doctor kit' to familiarize your child and symbolize what is happening.
Age 6-7 Capable of following rules, enjoys having responsibility Uncertain of the relationship between cause and effect; parent is the primary source of self-esteem	• Use interactive communication—reading books and creating stories with your child. • Help your child create their own "this is our family" album and talk about the photographs and memorabilia. • Watch movies with story lines similar to what your family is experiencing.
Age 8-11 Has a better understanding of logic and cause/effect, less centered on self, able to understand others' feelings, can empathize	• Listen to your child's thoughts and opinions. • Ask questions that go beyond yes and no. • Depending on your child's level of development and understanding, speak with direct, reality-based explanations that include facts. • Include the sequence of events involved, and what to expect.
Age 12-17 Experience puberty and physiological changes, seek freedom and independence, acceptance by peers is extremely important, develop more intimate relationships, more thoughtful and caring	• Speak honestly and realistically. • Give facts, what is expected to happen including the diagnosis, prognosis, treatments, and expected outcomes. • Talk with your children, not to them. • Check in and offer time to discuss concerns frequently. • Listen attentively. • Ask questions that can be answered with more than 'yes' or 'no.' • Stay alert for risky behaviors, acting out, or noticeably withdrawn (if this is a new behavior). • If risky behaviors are present, seek professional help.

Suggestions for how to explain ABI to a child:

- The brain is similar to the command station of a spaceship. If a meteorite hit the command station, the crew would not be able to control what the space ship does. If the brain is hurt, it may send out the wrong signals to the body or no signals at all. A person with ABI may have a hard time walking, talking, hearing or seeing.
- The brain is the computer for the body. When injured, it doesn't boot up properly, runs slower, has less memory, etc.
- A broken bone will usually heal and be as good as new. A brain injury may not heal as completely. Even though the person with the injury may look the same, they may still be injured. These injuries might include having a hard time paying attention or remembering what you told them. They may get tired easily and need to sleep. They may say or do things that seem strange or embarrassing. They may get angry and shout a lot.
- Many people show anger because of the effects of damage to the brain. In other words, parts of the brain that normally stop angry flare-ups and feelings have been damaged and do not do their jobs as well. The parent with ABI may be mad because they cannot do the things they used to do. Their feelings may be hurt because others treat them differently than before the injury.
- A cut may take a few days to heal, a broken bone a few weeks. Getting better after a brain injury can take months, years, and sometimes the person will not get 100 percent better.
- Brain injury changes people. These changes can be confusing. Try to remember that the changes you see are caused by the brain injury. You can still love and care about the person.

Tips for helping children cope:

- Provide information to your children about what to expect before they are reunited with their parents with ABI. For example, explain in advance what they may see. Describe how their parent may look, behave and react before they meet.
- Be flexible. Take your cue from your child about when they want to resume their normal routine. Encourage children to stay involved with friends and school activities.
- If your children choose to attend their activities, ask friends or relatives to take them there. Ask friends to take over caregiving when you need to go to watch your child taking part in an activity.
- Encourage your children to talk about their fears, hopes and worries. Allow safe and appropriate ways for your children to express their emotions.
- Meet with your children's teachers to explain what has happened and the effects on the family
- Encourage other family members, friends, or other important adults in your child's life to share time with your child and to act as a sounding board if needed
- Your children may say upsetting things to you. Just listening can be the best support for them
- Re-establish routine for your children. Consistent dinner and bed times may help

- Encourage your children to talk about what familiar characteristics and behaviour of their parent they are starting to see.
- Be easy on yourself and your children. A certain amount of stress is normal.
- Be careful not to set a timeframe with your children for when recovery will occur. Children want it all to happen quickly, and it is hard to predict recovery after ABI.
- Stay alert for changes in their behaviour. Get counseling for your child to help them cope with grief, especially if the child appears depressed or is adopting risky behaviours.
- Recognize that some children may pull away for a while. Others may regress to younger behaviour, becoming very dependent, demanding constant attention, or exploding in temper tantrums. These behaviours should return to normal over time as the child adjusts.
- Teenagers may be embarrassed about their parent with ABI. Rehearse with them how to respond to comments or questions about how their parent looks, behaves, and speaks.
- At the same time that you are providing factual information about ABI, don't' forget to include reassurance that you are still a family and love one another.

Giving up is easy. Holding it together through hard times is true strength.

Building stronger family ties. Set time aside each week for your family to spend some fun time together, and move the family focus away from ABI. The following are some ideas on how to do this:

- Have a family meeting. Explain that you plan to hold a family time every week, and ask for ideas for when and what to do (if family members are old enough to participate). Family members could take turns choosing activities.
- Turn off the video, cell phone, email, etc. during family time. Your goal is to interact with and enjoy each other.
- Try activities that everyone in the family can enjoy. This might include doing things like playing board games, taking a walk or run, or baking cookies. Find activities where everyone in the family can play a role.
- In addition to family time, schedule some individual time with each family member. Children need to have time alone with their parent(s). This helps them feel heard and appreciated. Plan an activity with each child and schedule it on a regular basis.

- To build closer family ties, encourage the children to play simple games with their injured parent. Such games may also help the injured parent practice skills to help in recovery.
- Think about your family rituals/celebrations and keep them on the schedule. You may want to think about keeping your plans simple.

Family Needs

Everyone in the family is affected by ABI. As the primary caregiver your role within the family has changed. The role of your loved one with ABI may also have changed. Role changes can be emotionally demanding. Other challenges include learning how to balance work, family and your own needs, in addition to someone else. Changes in finances, social life, and relationships can also add stress to the family. Conflict among family members regarding the care and treatment of the injured family member may also occur.

Build on your family's strengths. You can learn to cope with the stress of ABI by finding and building on your family's strengths. No family is perfect. First think about your family's strengths. Then think about areas you would like to be stronger. Discuss these with your family members and choose one area that you can work on together.

Family strengths include:

- Caring and appreciation.
- Commitment. One way to build on commitment is to create and maintain family traditions.
- Communication. It's important to keep lines of communication open. Active listening is important. When the other person is telling you how they feel, try restating what they just said to see if you understand their position correctly.
- Community and family ties. Keeping close ties with relatives, neighbours, and the larger community can provide useful sources of strength and help in trying times.
- Working together. Sharing tasks and decision making will help your home run smoothly. When important decisions need to be made, all family members should share their points of view.
- Flexibility and openness to change. An ABI in the family means that everyone's roles and responsibilities will shift. Learning to manage change can be a challenge, but it can be done.

Use "I" statements to share your feelings, rather than "you" statements. For example, if you are upset because your brother didn't' show up to

Addressing family needs means paying attention to family members' emotional needs and addressing them drive you to the hospital on time, you might say: "I feel upset when you are late to pick me up. I am anxious to get this important medical appointment on to so that I have the doctor's full attention" instead of, "you are always late." The former states your feelings; no one can argue about your own feelings. The latter attacks the other person, making him or her feel defensive and more inclined to argue with you.

Preserving your relationship. ABI can affect the dating or marital relationship, just as it affects other areas of family life. In addition to the stress that caregiving may bring, the spouses of people with ABI may lose the intimacy with their partner that they once enjoyed. People with ABI may lose interest in sex, become impotent, or may not be able to have an orgasm. This is often due to biological changes or the medications that they may be taking. This is a common effect of ABI, so do not hesitate to talk with your physician about this. Some people with ABI may show their sexual interest in ways that are not socially acceptable. They may misinterpret social or vocal cues and therefore behave inappropriately. Seek professional counseling if you need it. All marriages go through ups and downs; there is no stigma in seeking help.

What if caregiving is just too much? It is helpful to know yourself and your limits. Your back-up plan may include finding temporary (relief) or more permanent residential care for your family member with ABI. Discuss quality of life issues with your family and health care professionals. Your choices may include:

- Give others permission to care for your loved one – accept help from other family members or friends, seek out relief services and look into in-home care, and outreach services.
- Seek assisted living facilities, in home care, and outreach services for those who have difficulty living alone but do not need daily care.
- Consider long term care homes or assisted living facilities for individuals who need 24hr care.

SECTION 2 – WHAT IS AN ABI?

What is an ABI?

An ABI is damage to the brain that occurs any time after a person is born. There are 2 types of ABI; traumatic and non-traumatic.

1. **Traumatic Brain Injury**

   A traumatic brain injury is the result of a physical force from outside the head, such as:
   - a fall
   - a bicycle or motor vehicle accident
   - a sports injury
   - an assault
2. **Non-traumatic Brain Injury**

   A non-traumatic brain injury is the result of a problem other than trauma, such as:
   - an infection, such as meningitis or encephalitis
   - blocked or interrupted blood flow to the brain, called a stroke
   - a swollen or ruptured blood vessel in the brain, called an aneurysm
   - not enough oxygen to the brain, such as in near drowning
   - a growth in the brain, called a tumour

Each person's brain injury is unique

Learning About the Brain

To understand the problems your loved one is having as a result of the brain injury, it may help to take a closer look at the brain and how it works.

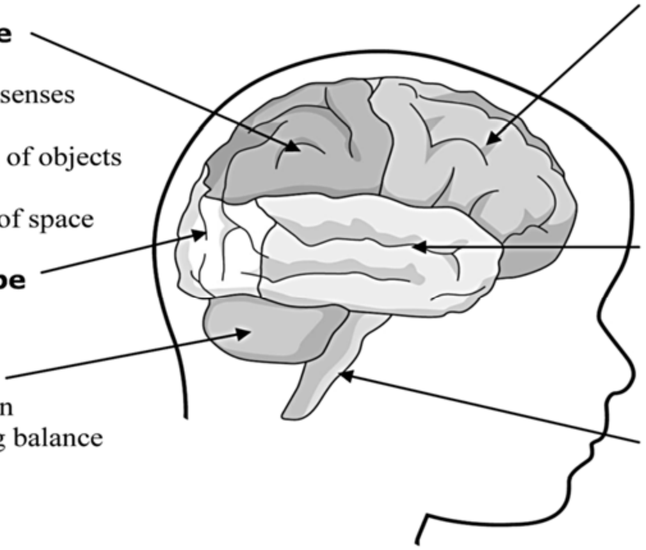
How Does the Brain Work?

The brain is the body's control center. The brain controls our movements, thoughts, feelings, senses (sight, hearing, touch, taste and smell), and communication (what we say or write to others, how we understand what others are saying, how we read).

What happens when the brain is injured?

The processing of new information may be affected. The brain takes longer to understand messages as they come in; what we see, hear and think, and how we move our limbs and body. Storing new information becomes difficult; the brain has a harder time learning new things. Some information becomes permanently lost; the brain can lose recent or past memories.

Each part of the brain has a different job or function



Parietal lobe
- perception
- integrating senses
- sensation
- recognition of objects by touch
- perception of space

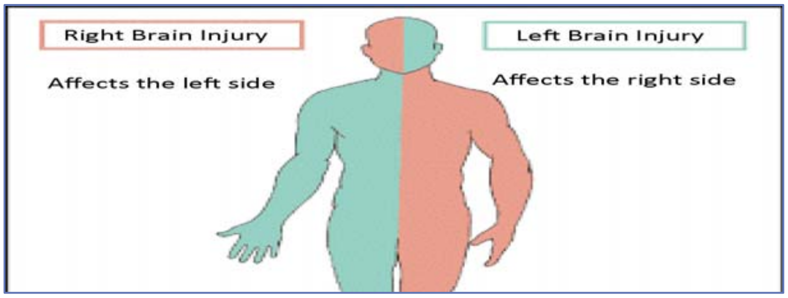
Occipital lobe
- vision

Cerebellum
- coordination
- maintaining balance

Frontal lobe
- control of attention, behaviour and emotions
- judgment
- problem solving
- movement

Temporal lobe
- memory
- hearing
- understanding language

Brain stem
- maintaining breathing and heart beat
- swallowing
- sleeping and wakefulness

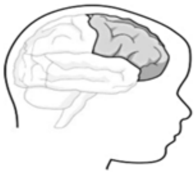


The Cerebral Cortex

The cerebral cortex is made up of 4 lobes (frontal, temporal, parietal, and occipital) and is divided into left and right sides. The sides and lobes have different functions

	What is it responsible for?	What may happen if this part is injured?
Left Side	• controlling movements on the right side of the body • how we use and understand language	Difficulty with: • movements on the right side of the body • understanding language • speaking and communicating
Right Side	• controlling movements on the left side of the body • how we use and interpret what we see in our environment	Difficulty with: • movements on the left side of the body • seeing and interpreting the environment

The Frontal Lobe



What is it responsible for?	What may happen if this part is injured?
• knowing what we are doing within our environment • responding to our environment • using judgement • responding with emotions • remembering how to do things • thinking before we act • controlling inappropriate impulses and behavior • controlling movement of our body parts	Difficulty with: • simple movement of various body parts • planning a series of movements to do a task • spontaneous interaction with others • flexibility in thinking • focusing on a task • problem-solving • speech and language Mood changes, impulsiveness Changes in personality and social behaviour

The Temporal Lobe

What is it responsible for?	What may happen if this part is injured?
• hearing • remembering things • putting things into categories • interpreting what we see • talking	Difficulty with: • recognizing faces • understanding spoken words • language and hearing • short-term and long-term memory • managing behavior • speaking and communicating

The Parietal Lobe

What is it responsible for?	What may happen if this part is injured?
• understanding the feeling of touch • paying attention to what we are doing • controlling movements • using different senses together	Difficulty with: • concentrating on more than one thing at a time • naming objects • locating words for writing • reading • drawing • telling left from right • mathematics • hand-eye coordination • focusing eyes on a task Lack of awareness of certain body parts

The Occipital Lobe

What is it responsible for?	What may happen if this part is injured?
• seeing everything in our environment	Difficulty with: • vision, identifying colours • locating objects in the environment • understanding what is seen • seeing objects or people clearly • recognizing words or pictures • recognizing movement of an object • some aspects of reading and writing

The Brain Stem

What is it responsible for?	What may happen if this part is injured?
• maintaining breathing • maintaining heartbeat • swallowing • reacting to sudden noises and sights • controlling sweat, blood pressure, digestion, temperature and level of alertness • sleeping	Difficulty with: • breathing • swallowing food or liquids • organizing or perceiving the environment • sleeping • relaying information between the brain and the rest of the body • eye movements Dizziness and nausea

The Cerebellum

What is it responsible for?	What may happen if this part is injured?
• coordinating our movements • maintaining balance • remembering how to move our body parts	Difficulty with: • coordinating fine movement of arms and hands • balance • walking • reaching out and grabbing objects • making quick movements Shakiness or dizziness Slurred speech

How Does the Brain Recover Over Time?

No one completely knows what happens in the brain during long-term recovery from an ABI. Some researchers think that the healthy brain tissue learns over time how to do what the damaged brain cells used to do, which restores abilities. Others think that connections between brain cells rearrange themselves or become more efficient, which allows abilities to be regained.

The brain can repair itself more than people used to think were possible. Different things influence a person's ability to recover. They include:

- His or her age (younger brains often recover faster)
- How severe the ABI is
- Where the ABI is located

Each person's recovery is unique; progress is still progress even though it may be slow

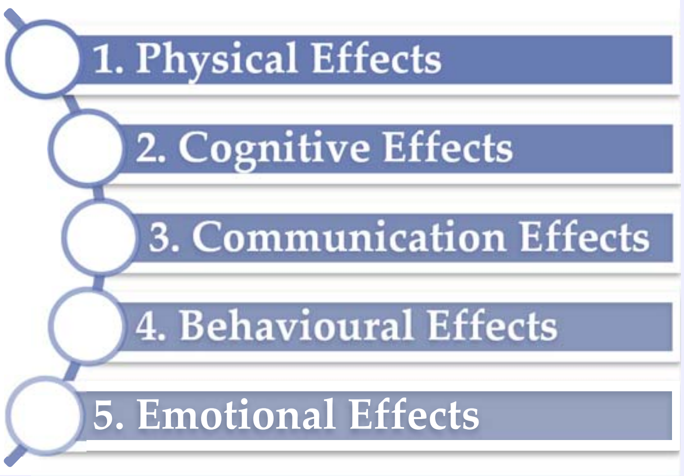
Rehabilitation

Rehabilitation services may be needed to help learn and practice everyday activities, and begin to get back into a daily routine. The goal of this stage is to help individuals become as independent as possible.

A small step towards recovery is great progress

Understanding the Effects of ABI

Five challenges that you may see after brain injury:



1. Physical Effects:

a) ***Headaches*** – Headaches are common following ABI. Some people have a headache all the time, and some people's headaches come and go. Fatigue, stress, and history of migraines make these headaches worse.

How you can help:

- Avoid bright sunlight (may need dark glasses)
- Avoid alcohol
- Avoid foods that trigger headaches
- Manage stress. Take breaks during activities, practice deep breathing exercises, exercise and have some fun
- Keep track of headaches in a journal. Note the time of day, the activity, and intensity of the pain
- Take medications at the same time every day

b) ***Sleep Changes*** – Altered sleep patterns are very common after ABI. Many people with ABI require naps, when before the ABI they did not. Some common sleep changes after ABI.

How you can help:

- Limit daytime naps (talk to your doctor first)
- Avoid caffeine after the morning
- Exercise during the day, avoid exercise too close to bedtime
- Avoid fluids two hours prior to bedtime
- Try to eat the last meal of the day four hours before bedtime
- Go to bed at the same time every night and get up at the same time every morning
- Avoid watching TV in the bedroom

What you might see:

- Difficulty falling or staying asleep (insomnia)
- Awake at night, sleeping during the day
- Frequent naps
- Sleeping too much or too little

c) ***Fatigue/Loss of Stamina*** – Fatigue is a common complaint of individuals that have experienced ABI. The body and brain need energy for healing re-learning skills.

How you can help:

- Set up a daily schedule and make sure it includes enough rest/sleep. Use a calendar to help your loved one follow the schedule.
- Reduce family and social demands.
- Help your loved one pace themselves.
- Ask your loved one to conserve energy for important tasks in the day.
- Help your loved one be active, consult a physical therapist for safe activities.
- Allow time for undisturbed rest during the day.
- Schedule important appointments for times of the day when your loved one is most awake.
- Learn the signs of fatigue in your loved one.
- Ask your doctor to rule out other signs of fatigue such as endocrine abnormalities, sleep disorders, mood disorders, diabetes, substance abuse, electrolyte imbalances and nutrition deficit.

What you might see:

- Frequent comments about being tired
- Need for sleep after a short activity, lack of energy
- Poor stamina
- Extreme fatigue after a busy stretch of hours
- Slurred speech
- Irritability
- Slower thinking speed

d) ***Dizziness*** – Used to describe everything from feeling faint or lightheaded to feeling weak or unsteady. An ABI can disrupt balance signals to the brain. The largest concern with dizziness is the risk of falls.

How you can help:

- Be aware of possible loss of balance
- Fall proof your home: Remove area rugs and electrical cords that someone could slip/trip on. Use non-slip mats on your bath and shower floors
- Have your loved one:
    - Sit for a few minutes before walking so the brain can adjust
    - Sit or lie down as soon as they feel dizzy
    - Avoid driving when lightheaded or dizzy
    - Use good lighting when getting out of bed at night
    - Avoid sudden movements or bending over
    - Walk with a cane, walker or other assistive device for stability

What you might see:

- Complaints that the room is spinning or moving (vertigo)
- Loss of balance, unsteadiness
- Nausea
- Lightheadedness
- Blurred vision during quick or sudden head movements

e) ***Balance Problems*** **(Tendency to fall)** – Often an early effect after ABI, but can go away with time and physical therapy.

How you can help:

- Encourage use of prescribed walking aids such as walkers, canes
- Supervision
- Remove throw rugs from your home
- Work with the physical therapist (if applicable) to learn how to assist your loved one

What you might see:

- Unsteadiness when walking
- Inability to walk or sit without assistance
- Falls
- Holding onto furniture, walls or other objects when walking

f) ***Muscle Tone, Strength and Coordination*** – Muscle tone is the amount of tension in a muscle when at rest. When muscle tone is normal, the limbs and body feel easy to move. A brain injury may damage the normal control of muscle tone. This may cause decreased muscle tone – the limbs feel floppy and heavy (hypotonicity) or more than normal muscle tone – the limbs feel stiff and tight. Both affect the person's ability to control movement.

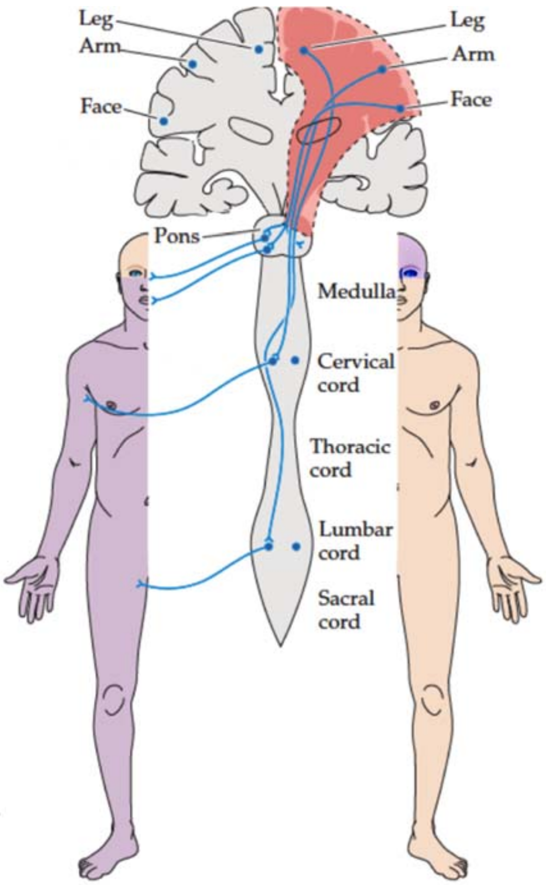
After a brain injury, muscles may show different degrees of weakness. Some muscles may be stronger in one limb than another. Damage to certain parts of the brain may result in slow, jerky, or uncontrolled movements.

You may hear the terms:

- ➢ Hemiparesis: muscle weakness on one side of the body only
- ➢ Hemiplegia: muscle paralysis (no movement) on one side of the body only

How you can help:

- Please talk to your healthcare provider about referrals to a physiotherapist or occupational therapist. They will be able to provide strategies on how to help someone who has physical changes after a brain injury.



g) ***Sensory Changes*** – When the brain is injured each of the senses (sight, hearing, taste, smell and touch) is at risk for change. There is often not much to be done about these changes. Doctors often use a "wait and see" approach with the hope that sensory changes will go away on their own before considering therapy and/or surgery.

How you can help:

- A neuro-opthalmologist can evaluate visual changes. A neurologist can evaluate other sensory changes.
- Reinforce wearing of an eye patch or special glasses if directed by the doctor.
- Avoid alcohol. It may increase sensitivity to light and noise.
- Seek professional advice about whether or not it is safe for your loved one to drive if they are having a change in vision.
- Have your loved one's hearing checked. Use hearing aids, if needed
- Ask a dietitian about tips for eating if taste and smell are lost or altered.
- Make sure you have a working smoke alarm in the house if your loved one's sense of smell has been lost.
- Throw out any expired foods if your loved one's sense of taste and smell has been lost
- Try to be patient. Sensory changes can improve over the first several months or years after ABI. Keep track of how the senses are working and seek further evaluation and treatment options as needed.

What you might see:

- Vision changes, such as blurry vision, double vision, or sensitivity to light
- Hearing changes, including muffled hearing or ringing in the ears (tinnitus) in one or both ears
- Changes in taste and smell.

h) ***Visual Spatial Problems*** – Including blind spots and/or changes in the brain's ability to understand what the eyes see. The ability to perceive where you are in your environment might be affected by ABI. This is called special awareness. Usually, injury to the right side of the brain can lead to difficulties in these areas.

How you can help:

- Ask for a neuro-ophthalmologist to identify your loved ones specific visual and/or visual spatial problems.
- Stand on and place objects on the affected side and encourage your loved one to look to that side (this is called visual cueing).
- Remind your loved one to frequently look around the environment, especially toward the affected side (this is called visual scanning).
- Use visual cues (i.e. Dark line) on one side of a page to encourage visual scanning of the entire page.
- Arrange your house to make tasks easier. For example, have items to accomplish a task organized in one place.
- Show your loved one around new places several times. Avoid sending them to new places alone.
- Limit clutter in the house. Try not to move items around.
- Remind your loved one to use handrails when available.
- Provide gentle reminders that they are standing too close or too far away during social encounters.
- Seek professional advice about whether or not it is safe for your loved one to drive.

What you might see:

- Ignoring things on one side of the body
- Bumping into things on the affected side
- Difficulty finding their way around, especially in new places
- Difficulty recognizing shapes and telling the difference between shapes
- Turning their head towards the unaffected side
- Cutting words in half while reading or beginning to read in the middle of the page
- Mistaking the location of a chair when sitting down
- Misjudging distance i.e. Missing a cup while pouring
- Standing too close or far from others in social situations
- Right left confusion
- Reporting impaired vision

Keeping calm during stressful situations helps you make good decisions.

i) ***Seizures*** – Seizures happen when many brain cells in the brain fire at the same time repeatedly. Seizures can be frightening to watch. They can be temporary or chronic. Seizures are usually diagnosed by a neurologist and treated with medications. Ask your doctor how to recognize a seizure and what to do if one occurs.

How you can help:

- For a first seizure, call your doctor as soon as possible.
- If not a first seizure, alert the doctor. Make an appointment to have anti-seizure medication and blood levels checked.
- Talk to the doctor before adding or stopping medications or herbal treatments. These can change the blood level of the anti-seizure medication and make it ineffective.
- During a seizure **DO**'s:
  - ✓ Keep calm
  - ✓ Loosen ties or anything around the neck that makes breathing hard to do
  - ✓ Clear anything hard or sharp from the surrounding area
  - ✓ Put something flat and soft under the head
  - ✓ Turn the person gently onto one side. This helps keep the airway clear
  - ✓ Stay with the person until the seizure ends
- During a seizure **DON'T**'s:
  - X Don't hold your loved one down
  - X Don't try to stop their movements
  - X Don't try to force their mouth open
- **Call 911** if your loved one experiences:
  - ✓ Difficulty breathing during or after a seizure
  - ✓ The seizure lasts more than five minutes
  - ✓ A second seizure happens immediately after the first seizure
  - ✓ There is difficulty waking up from the seizure or a second seizure without waking up in between

What you might see:

- Generalized shaking or jerking of the arms and legs
- Loss of consciousness
- Altered attention, emotion, sensation or movement
- Reports of strange odours or sensations

Some things are triggers for seizures. Triggers can include stress, overuse of alcohol and/or other drugs and being overworked and/or tired. Help your loved one to avoid these triggers.

2. Cognitive Effects:

A. ***Confusion*** – Most people that have suffered an ABI have some confusion after their injury. Sometimes the confusion lasts only minutes and other times it can continue. Keeping your loved one safe and offering reassurance are important during this stage of recovery.

How you can help:

- Keep your loved one oriented. Use calendars, clocks, family pictures and/or signs.
- Use a notebook to plan for and log events. Have your loved one refer to it for details of daily events.
- Limit changes and provide structure in a daily routine.

What you might see:

- Disorientation (by location, time or sequence of events)
- Staring blankly or seems in a fog
- Confusion times and/or tasks in scheduled activities
- Confusing past and present events
- Making up stories to fill memory gaps (this is called confabulations see P. 44 to learn more)

B. ***Slowed Speed of Processing*** – Many people with ABI complain that their thinking and processing of information is much slower than it used to be. Slowed speed of processing can add to confusion.

How you can help:

- Slow down and simplify information
- Break complex tasks and activities down into smaller steps
- Allow extra time to respond to questions and to comprehend and learn new information
- Avoid situations that are overstimulating (i.e. noisy, crowds)
- Help your loved one choose activities or topics that are able to grasp and follow
- Encourage your loved one to ask others to slow down and repeat information

What you might see:

- Taking longer to answer questions
- Taking longer to understand things that were easily understood before
- Taking a long time to react and respond

C. ***Attention Problems*** – The ability to focus, to pay attention for a long time, and to do more than one thing at a time is controlled by the brain. ABI can and often does affect all forms of attention. Attention is important because paying attention is the first step to learning and remembering. It is common for a person with a severe ABI to only be able to attend for a few minutes at a time.

How you can help:

- Focus on one task at a time
- Be sure you have your loved one's attention before beginning a discussion or task
- Reduce clutter at home and in the work environment
- Perform tasks in a quiet environment
- Remove distractions and noises that you don't need
- Use notebooks, calendars, checklists (on paper or devices) to help with completion of tasks
- Refocus attention to the task at hand if attention waivers
- Expect a short attention span. Schedule breaks and/or stop an activity when you notice drifting attention
- When signs of distraction arise, insert a rest break ("Let's do this for another 5 minutes and then take a 15 minute break.")
- Present verbal or visual information in limited amounts

What you might see:

- Short attention span, sometimes only minutes in duration
- Easily distracted
- Difficulty in attending to one or more things at a time
- Inability to shift attention from one task or person to the next
- Difficulty completing tasks

Remove distractions wherever possible to help your loved one focus

D. ***Difficulties with Memory*** – Memory problems happen after ABI. Past memories or long term memory is nearly always intact. Recent memory, called short-term memory is much more often affected. Short-term memory often gets worse as fatigue increases, and it usually improves over time. Memory compensation means learning to use memory tools, such as a calendar, planner, organizer or memory notebook. Signs with instructions, lists, and notes are other effective memory compensation tools.

How you can help:

- Get your loved one's attention when you are trying to teach, do, or discuss something
- Break new information down into categories or "chunks". List and review them in order
- Set up a routine of daily tasks and follow it
- Help your family member use memory aids on a regular basis. Write down tasks on a clendar or notebook. Check tasks off when done.
- Explore the use of "high tech" memoryaids. Wristwatch alarms,tablets, and cell phone can remind your family member when to do a task, such as taking medication.
- Have the pharmacy separate medications into a blister pack that includes date and proper time to take the medication
- Keep personal and houshold items in the same place
- Try to pair new information with things the person is able to recall
- Provide verbal cues for recall and help fill in memory gaps
- Talk to your loved one about the activities and events of the day to help build memory
- Have your loved one review plans for the following day
- Learn and use a cueing system (see section on cueing at the end of this chapter)
- Present information in more than one way, including hearing, seeing and doing - each person has a different learning style
- Role play in order to reinforce new learning

What you might see:

- Your loved one can't remember information from day to day about people, conversations, places, events, appointments, dates and telephone numbers
- Keys, wallet, etc. are frequently lost or misplaces
- Repeating questions or the same story over and over again
- Your loved one can't learn new information and use it in everyday life

Post lists of items or tasks in convenient locations where they can be easily seen when needed

E. ***Planning and Organizational Problems*** – Organization and planning skills are often affected by ABI. These skills can improve over time. You may need to remind your family member again and again to use the skills they learn until they become habit.

How you can help:

- Begin with small, realistic tasks
- Work with your loved one to get organized at home. Keep a family calendar posted on a wall. Use reminder notes and cue cards
- Have a place for everything and keep everything in its place. In particular, keep your loved one's belonging in certain places
- Turn off the radio/TV or other distractions when tasks need to be done
- Use memory aids such as calendars and notebooks to plan, write down and check off tasks when done
- Use a tote bag or backpack to organize needed items for the day
- Work with your loved one to decide which information or activity has the highest priority

What you might see:

- Problems organizing time to get things done
- Problems understanding which tools are needed to complete a task and getting them together
- Problems breaking down complex tasks into smaller steps
- Having a hard time getting ready for work, school and appointments
- Being late for work or school and appointments
- Having a hard time starting a task
- Problems making plans and completing them
- Problems setting goals
- Trouble prioritizing
- Looking disorganized

Try to remember that it's due to the brain injury, not an intentional action of the person

F. ***Decision Making and Problem Solving*** – Making decisions and solving problems take a lot of thinking. Both can be hard for people with an ABI.

How you can help:

- Avoid having your loved one make decisions when tired, hungry or under stress
- Help your loved one weigh options and consequences of a decision
- Give your loved one time to make a decision. Be patient and talk them through possible options
- Limit the number of possible choices. Two or three choices are best. Too many choices are often overwhelming and can increase indecisiveness
- Avoid making last minute decisions
- Practice identifying a problem and following through with evaluating the options

What you might see:

- Taking a long time to make a decision
- Making inappropriate and/or potentially harmful decisions
- Problems reasoning
- Responding impulsively to situations
- Having a hard time recognizing problems
- Slow to think of alternate solutions to problems
- Tendency to be "concrete" in terms of problem solving, that is, difficulty making inferences
- Taking things literally

G. ***Confabulation*** – Confabulation is a memory problem. It happens when a person with an ABI makes up false memories. These memories could be about past events that never happened, or they could be memories of actual events that the persone puts in the wrong time or place. Sometimes these memories are very detailed and the person honestly believes the events happened. Confabulation is the direct result of the injury to the brain and may go away on its own.

How you can help:

- DO: Gently help your loved one become aware that this memory is not accurate
- DON'T accuse your loved one of lying

What you might see:

- Making up convincing stores to fill memory gaps

Common Cognitive Strategies:

Cueing - means to give a signal to begin a specific action. Cueing prompts your loved one to stop and think before acting. The goal of progressive cueing is to move your loved one from having to be "told what to do" by you and to being able to independently cue, or remind, him or herself what he or she needs to do. Learning how to self-cue will help increase independence. Consistency in approach increases success.

Try the following methods for cueing your loved one with ABI:

- ✓ Guide your loved one by asking questions. Ask questions that will help the person find a solution, such as "What could you do to help yourself next time?" Avoid asking questions that do not help solve the problem, such as "Why did you do that?"
- ✓ Provide verbal or nonverbal cues. For example say "Stop and think, what else could you do?" or pausing/not acting immediately to help the person recognize the need to use a strategy such as Astop and think," or you could use a signal you have agreed upon ahead of time, such as a raised finger or a head nod.

Types of Cues

• • •

Direct: *a specific prompt. For example "Did you look in your calendar?"*

Indirect: *a general prompt: for example: "Where could you find that information?"*

Self: *a self-prompt "Where could I find that information."*

CUE CARD – Preparing a Meal

- Decide on a menu
- Count number of people eating
- Look at the needed ingredients
- Look in the pantry for what you have
- Prepare shopping list and shop
- Follow recipe instructions and organize time
- Serve and eat meal
- Clean up

Problem Solving – Learning how to be a good problem solver can help you and your loved one cope with stress and reduce anxiety. The following simple problem-solving steps can be effective in helping to break down problem solving into a more manageable task. Writing down the answer can be helpful and allow the person to better "see" options. Reinforcing use of this technique is one way you can help with problem solving.

1. Identify the problem. If the problem has many parts, break it down into one problem at a time
2. Brainstorm solutions. Think of as many possibilities as you can
3. Evaluate the alternatives. Consider the pros and cons of each possibility
4. Choose a solution, the one that seems to fit best for you
5. Try out the solution
6. Evaluate the solution. If it didn't work, try another solution until you find the one that works

The Problem	Potential solution	How it worked
Sally has to be at school at 8:15 and Don's appointment is at8:30 across town. I can't be in both places	Ask Terry's mom if I could drop off Sally at her house early and she could drive Sally and Terry to school together	Worked great!
I can't remember what the doctor told me to do about John's memory problems	Ask again at the next appointment	I still forgot—he's not the only one with memory problems!
Nothing's changed—I still can't remember what to do	Next appointment, I will take a notebook with me and write down his answer	Now I can refer to my notes and don't feel so worried about it

3. Communication Effects:

Communication skills are very important in everyday life. Your family member may not be able to use words to express themselves well. This can be very frustrating. Many people with ABI can do well speaking in non-stressful situations. But your loved one may not be able to use these speaking skills during a stressful situation at school, work, home, or in the community.

Language problems can lead to miscommunication and confusion. This may make it harder than it used to be to make new friends and maintain old relationships. A positive note: Most people with an ABI can make notable progress in communication over time.

Sometimes with ABI the individual may be able to speak, but may need training to understand and remember what is being said as well as to express needs, wants and ideas clearly to others.

Speaking Clearly

How you can help:

- Tell your loved one that you did not understand what they said. Ask them to say it again, but this time more slowly
- Use a consistent cue or gesture to let them know you did not understand
- Allow time for your loved one to express themselves

What you might see:

- Slurred speech
- Speaking too loudly or softly
- Speaking too fast

Problems Starting a Conversation

How you can help:

- Ask a leading question such as, "What do you think about….?"
- Encourage your loved one to talk about topics of interest or familiar topics
- Ask open-ended questions (i.e. questions that cannot be answered with a "yes" or "no") such as: "Tell me about your day."
- Give your loved one your full attention
- Give your loved one time to organize their thoughts
- Use redirection, if necessary (e.g., "so what do you think about….?)
- Reinforce all efforts to start a conversation. Show that you value what your loved one has to contribute to conversations

What you might see:

- Your loved one may be unable to start or is slow to start conversations
- There may be long pauses
- Your loved one may have problems explaining what they mean
- They may not respond to another's questions or comments

Word Finding

How you can help:

- Give your loved one time to locate the word they are looking for
- If they cannot locate the word after some time, guess at what they might mean or ask them to write it down.
- Try and be patient. It can be very frustrating for your loved one when they know what they want to say but cannot locate the right word or phrase
- Encourage them to use another word that is close in meaning
- Suggest they use gestures to help get their meaning across

What you might see:

- Problems finding the right word to describe what they are trying to say

4. Behavioural Effects:

You may notice changes in the way your family member acts. People with ABI may have many emotional and behavioural effects. That is because the brain controls the way we act and feel. An injury to the brain – usually an injury to the frontal lobe- causes changes in emotion and behavior. The life changes that happen after an ABI also affect how people act and feel.

Changes in behavior may include:

- Frustration, increased anger/aggressiveness
- Impulsivity or difficulties in self – control
- Decreased ability to initiate conversation or activity
- Repetitive behaviours (perseveration)
- Less effective social skills
- Changes in sexual behaviours
- Impaired self-awareness about how ABI impacts them and others

Emotional effects may include:

- Depression
- Increased anxiety
- Mood swings (emotional lability)
- Changes in self-esteem

A. ***Frustration, Anger/Aggressiveness*** – After an ABI, many people become frustrated more easily than before. Your loved one may not be able to do things as easily as they did before. Sometimes they may not know what others expect which can be frustrating. You may notice a quicker temper. Loss of independence, fatigue, overstimulation or cognitive problems can also lead to feeling of frustration and anger.

How you can help:

- Develop a plan to manage frustration or anger. This might mean taking a walk or going to another room and turning on the television
- Remain calm. Encourage your family member to recognize when they are becoming angry or frustrated. Help them learn to ask for a break or some space to calm down
- Reinforce all efforts to use effective anger management strategies
- Prepare your loved one for challenging situations when possible
- Simplify tasks and provide a consistent, structured environment
- Try to avoid surprises. People with ABI do better when they are prepared and can anticipate a change in plans.
- Try to consistently react to certain behaviours in a certain way. Often, a consistent approach helps to manage difficult behaviours.
- Rehearse and role place specific situations to boost confidence in managing life outside the home
- Approach challenges calmly and allow yourself to take a break when necessary
- Depersonalize as much as possible. Frustration and anger may seem as though it's directed at you, however it is the result of the brain injury.

What you might see:

- A strong reaction to minor annoyances or sources of frustration
- A general lack of patience
- A low tolerance for change
- Unexpected outbursts of anger
- An increase in irritability
- Verbal or physical demonstrations of anger
- An increased tendency towards anger when tired, in new situations and during high levels of stress

B. ***Impulsivity*** – Many individuals with ABI react before thinking. "Stop and think" is a good way to help a person make up for various cognitive problems. It allows the person to stop, slow down, pause, and take the needed time to think about something before doing it. This allows time to develop a reasonable plan or response.

How you can help:

- Use redirection (i.e., suggest a different activity or topic of conversation)
- Develop a special "stop and think" signal that you can use to alert your loved one when they are doing or saying something inappropriate
- Suggest that your loved one slow down and consider options
- Praise and reward desired behaviours, discuss consequences in private after the fact
- Avoid comparing past and present behaviours

What you might see:

- Your loved one may say whatever comes to mind without thinking about how it might affect them or someone else
- Your loved one may act without thinking about potential consequences (i.e. Crossing the street without checking traffic)
- Your loved one may make inappropriate comments to or about others

C. ***Lack of Initiation*** – Your loved one may seem to have lost interest in activities they used to enjoy. You may find yourself offering frequent reminders to do simple tasks, like brushing teeth or taking a bath. Your loved one may not begin activities on their own. This is not laziness. This is due to their brain injury.

How you can help:

- Set up a regular schedule for your loved one to follow. This will allow them to learn a routine so well that it becomes automatic
- Post the schedule. Make sure the schedule is in your loved one's calendar or memory notebook
- Work with your loved one to develop a list of goals or tasks to be completed. Help them check off completed tasks so they can see their progress
- Encourage them to become involved. Having a purpose along with structure can help

What you might see:

- Your loved one remaining in bed until encouraged to get up
- They may spend most of the day sitting around, not actively engaged in activities
- They may not speak unless spoken to
- They may have problems completing tasks without a lot of supervision
- They may agree to do something, but then not follow through

D. ***Repetitive Behaviours* (Perseveration)** – Perseveration means getting stuck on one idea or one behavior and repeating it again and again. Injury to the frontal lobe of the brain can cause this behavior.

How you can help:

- Use redirection (i.e., try to change the topic or focus of interest to something else)
- Try engaging the person in a physical task if they are verbally stuck on a topic
- Try engaging the person in a conversation or thinking task if they are physically "stuck" on a task.

What you might see:

- Writing the same letters or words or repeating the same word or phrase over and over
- Repeating physical movements or tasks
- Getting "stuck" on one topic or theme (i.e. "When can I drive?" or "I need a cigarette")

E. ***Social Skills*** – Social skills are all of the things we do and say in order to fit in, get along with others, and read and understand the people and situations around us. Social skills form the foundation for relationships with others. They include:

- ✓ thinking of topics of conversation
- ✓ listening to the other person without interruption
- ✓ keeping the conversation going
- ✓ reading the facial and verbal cues that the other person sends and responding to them
- ✓ knowing when and how to end a conversation

How you can help:

- React calmly
- Role play or rehearse responses to social situations
- Use an agreed-upon signal to let your loved one know that they may be saying something inappropriate
- Use redirection (i.e., try to change the topic or focus of interest to something else)
- Praise and reinforce appropriate behaviour

What you might see:

- Lack of awareness of personal space and boundaries (i.e. talking about private family matters, asking questions that are too personal, flirting with a married person)
- Reduced sensitivity for the feelings of others
- Possible disregard for acceptable standards of conduct at home or out in public
- Use of vulgar language or behaviour

E. ***Changes in Sexual Behaviours*** – many people with ABI change how they act during intimate moments. Those with moderate to severe ABI may sometimes act in sexually inappropriate ways. These behaviours can often be managed over time. It takes patience, feedback and a consistent approach.

How you can help:

- Develop a "stop and think" signal to let your loved one know that they are saying something inappropriate
- Use redirection (i.e., try to change the topic or focus of interest to something else)
- Talk to your loved one about what is and isn't acceptable in public
- Let your loved one know that having sexual feelings is normal. Sexual behaviour, however, is a private matter
- Find a way for your loved one to express his or her sexual needs (i.e., in the privacy of their room).

What you might see:

- Hypersexuality (thinking about or wanting frequent sexual activity)
- Hyposexuality, or a lack of interest in sex
- Discomfort with intimacy
- Trying to kiss or touch strangers
- Making suggestive or flirtatious comments to or about others
- Disrobing or engaging in masturbation in front of others

F. ***Lack of Self-Awareness*** – Your loved one may not be aware of how the ABI has affected them. They may also not understand how it affects others. Self-awareness means understanding our own strengths and weaknesses. Our sense of self-awareness is derived from the frontal lobe of the brain. A reduced sense of self-awareness is common in ABI. Your loved one may say very little has changed. They are not deliberately denying there is a problem. People with ABI simply may not understand that they are having problems. Self-awareness usually improves with time and feedback from others. Individuals with ABI learn from their successes and failures, just as we do.

How you can help:

- Use safe "supported risk taking" techniques. This is allowing the person to try to do something that they think they can do but may be beyond their capabilities. The goal is to raise the person's awareness through real trial and error situations.

What you might see:

- Underestimating the problem areas related to the ABI
- Not understanding why rehabilitation therapies are needed
- Not following recommendations of professionals (i.e., driving restrictions)
- Unrealistic expectations about future plans or abilities
- Inaccurate self-perception or self-image

- Work with your loved one using problem solving techniques
- Give realistic and supportive feedback
- Help set realistic goals. Develop plans to take steps towards larger goals
- Use a memory notebook to track progress and setbacks
- Use redirection (i.e., try to change the topic or focus of interest to something else)
- Praise and reinforce appropriate behavior

5. Emotional Effects:

Emotions start in the brain. Emotional self-control may be more difficult following an ABI. ABI can affect the complex neurochemistry system in the brain. This can lead to changes in emotional functioning.

A. *Depression* – Many people with ABI become depressed. This depression comes from both the physical changes in the brain due to the injury and the emotional reactions to it. It is sometimes hard to tell the difference between symptoms of depression and the effects of the ABI.

Men and women often have different symptoms of depression. They also have different ways of coping with the symptoms. Men often report symptoms of:

Fatigue	Irritability/Anger
Loss of Interest in Pleasurable Activities	Sleep Disturbances

Men are more likely than women to use alcohol or drugs when they are depressed. They may engage in reckless, risky behaviour. Men also tend to avoid talking about their feelings of depression with family or friends.

What you might see:

- Low activity levels
- Sleep problems
- Difficulty controlling emotions
- Lack of initiation

Women are more likely to talk about depressive symptoms to others. They often report feelings of:

Persistent Sadness	Anxiety
Excessive Crying	Feelings of Guilt/Worthlessness
Decreased Energy	Increased Appetite
Sleep Problems	Weight Gain

In severe cases, both men and women may experience thoughts of suicide. If you suspect that your family member is depressed, ask a health care professional to evaluate their mental health. Depression can be treated with counseling and medication. If the depression is affecting the family, and/or marriage then family therapy can help.

How you can help:

- Offer emotional support, understanding, patience, and encouragement. Remind your family member that depression usually fades with time and treatment
- Talk to your family member and listen carefully
- Acknowledge feelings, point out realities, and offer hope
- Get your loved one involved in activities outside the house (i.e., walks, shopping, movies, church services, volunteering). If they decline, keep making gentle suggestions but don't insist

Remember, depression is common as a person struggles to adjust to the temporary or lasting effects of ABI. Being depressed is not a sign of weakness. It's not anyone's fault and help is available. Do not wait to call someone if you think your family member needs help.

Know the signs of a person thinking of suicide:

- Making a will
- Taking steps to get affairs in order
- Giving away personal possessions
- Sudden requests to visit friends or family
- Purchasing a gun or stockpiling medications
- Sudden and significant decline or improvement in mood
- Writing a suicide note

What you might see:

- Persistent sad, anxious, or "empty" feelings
- Feelings of hopelessness and/or pessimism
- Feeling of guild, worthlessness, and/or helplessness
- Irritability, anger, restlessness
- Loss of interest in activities or hobbies once pleasurable, including sex
- Fatigue and decreased energy
- Problems concentrating, remembering details, and making decisions
- Insomnia, early morning wakefulness, or excessive sleeping
- Overeating, or appetite loss
- Persistent aches or pains, headaches, cramps or digestive problems that do not ease with treatment
- Less attention paid to grooming and personal appearance
- Thoughts of suicide, suicide attempts

Call 911 immediately or bring your family member to the closest hospital if you have any suspicion about suicide. It is perfectly fine to directly ask the person if they have been having suicidal

thoughts. If yes, ask if they have a specific plan in mind. Having a plan for killing oneself is a serious sign to get help quickly.

B. ***Increased Anxiety*** – People with ABI often become anxious. Anxiety sometimes goes hand in hand with depression.

How you can help:

- Work with your loved one to recognize problems that they may be worried about. Use problem solving techniques (above) to address them. This can help put the issue into perspective
- Suggest that your loved one write things down or keep a journal. Sometimes this alone can be calming and can slow down racing and nervous thoughts
- Use redirection (i.e., try to change the topic or focus of interest to something else)
- Ask your loved one to talk with the doctor about medications for anxiety. Counseling may also help
- Other ways to reduce anxiety include: relaxation training, controlled breathing and meditation

What you might see:

- Constant physical tension
- Excessive worry, racing thoughts
- Feeling jumpy, irritable, restless
- Racing heart, dry mouth, excess sweating, shakiness, or feeling short of breath
- Feeling panic or having a sense that something bad is going to happen

C. ***Mood Swings*** **(Emotional Lability)** – It can be frustrating and embarrassing when you can't control your emotions. It can make it hard to participate in social situations.

How you can help:

- Reassure your loved one that you understand that their display of emotion may not match the situation. Be nonjudgmental.
- Help family and friends understand sudden shifts in your loved one's mood.
- Distract your loved one. Use redirection (i.e., try to change the topic or focus of interest to something else)
- If the mood swings are interfering with your loved one's everyday life, ask them to talk with the doctor. Medications may be helpful in managing mood swings.

What you might see:

- Laughing one minute, and feeling sad or crying the next
- An emotional response that does not "fit" the Frequent, unexpected shows of emotion

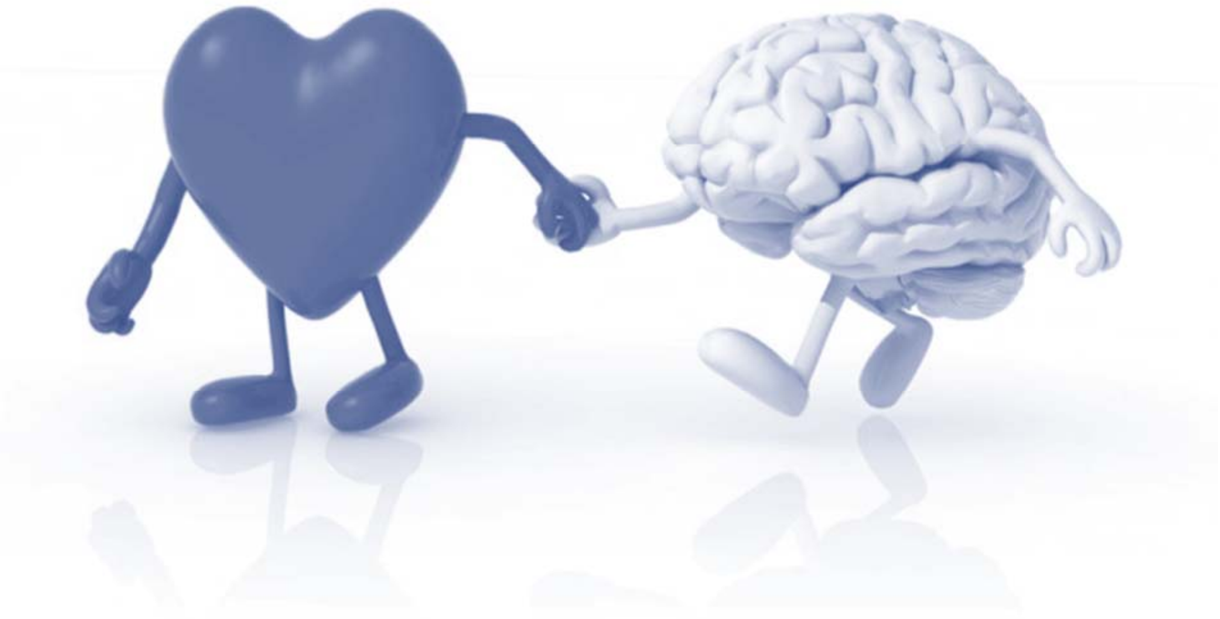
D. ***Changes in Self-Esteem*** – A person's view of themselves can be negatively affected by ABI. Feelings of low self-esteem go hand-in-hand with depression.

How you can help:

- Encourage your loved one to express their feelings. Try to redirect the person to more positive thoughts
- Encourage your loved one to spend time with others. Encourage them to take part in independent activities
- Help your loved one to set realistic, attainable goals. Help them choose activities that they can successfully complete.

What you might see:

- Negative self-statements: "I am worthless," "I'll never be normal again," "How can you love me like this?"
- Less interest in personal appearance
- Social withdrawal



Resources for Family and Caregivers:

What is a substitute decision-maker?

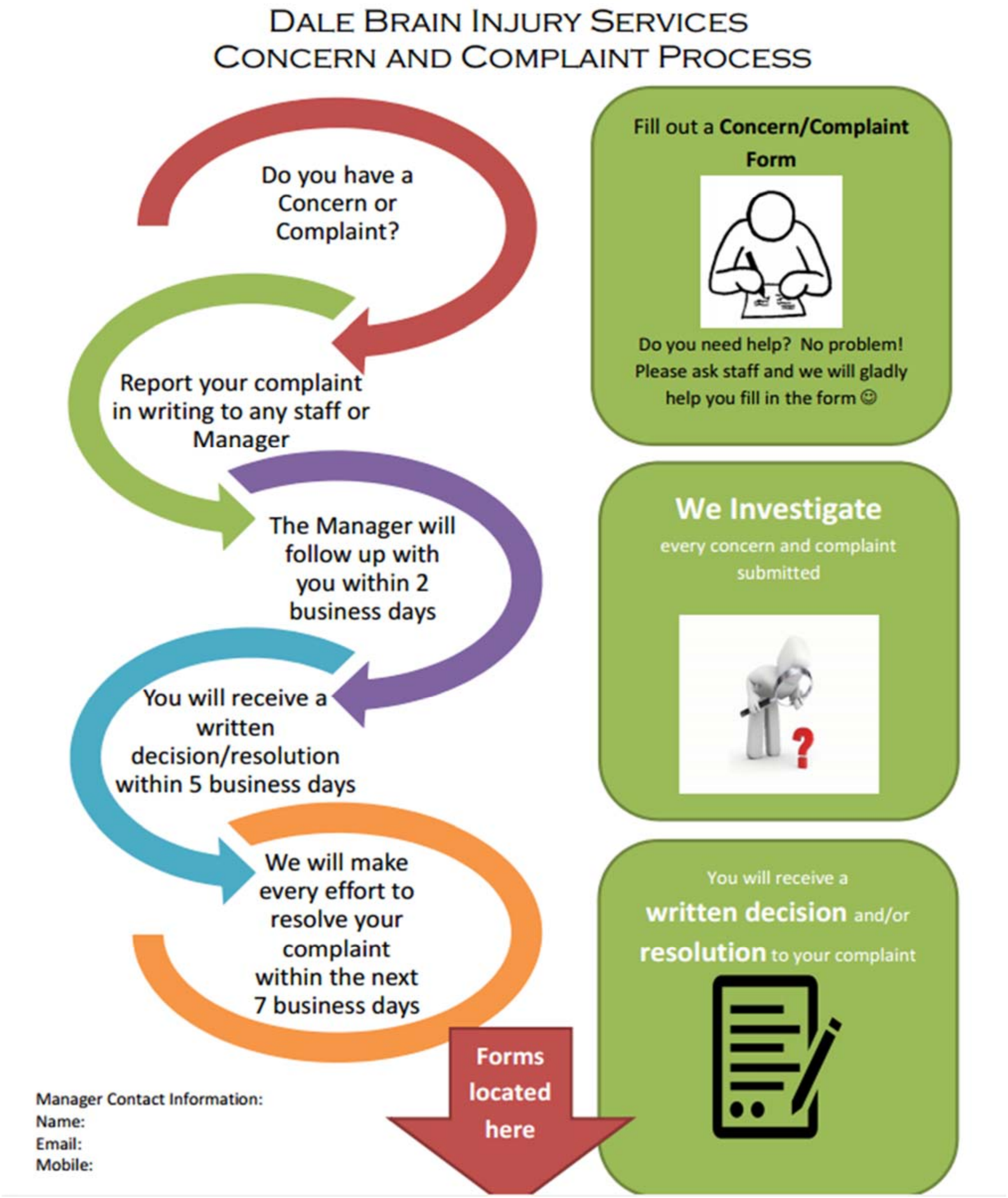
Critically ill patients are often unable to speak for themselves so identifying a Substitute Decision Maker is necessary. The selection of a Substitute Decision Maker is guided by the Health Care Consent Act in Ontario. A Substitute Decision Maker is appointed according to the following hierarchy:

1. Power of Attorney
2. Spouse (living together in a married or common-law relationship)
3. Parent or child
4. Siblings
5. Other relatives

Anyone can appoint an individual to act as a Substitute Decision Maker, prior to a need arising. A person appointed to make decisions about health care is called an "attorney for personal care". This appointment can be written into a legal document, called a "Power of Attorney". The person given Power of Attorney for personal care may be different than the person given Power of Attorney for financial issues. The appointment needs to be made when an individual is competent and capable of making this decision. Critically ill patients are often too ill or under the influence of medications that limit their ability to make informed decisions.

A Substitute Decision Maker must be willing, available and capable of taking on this responsibility. If the individual identified does not meet these criteria, then the next person on this list is contacted in order to identify the most appropriate Substitute Decision Maker. If a patient does not have a Power of Attorney for Personal Care or an appropriate family member, a guardian can be appointed by the court.

Client Complaint Process Information Sheet



DALE BRAIN INJURY SERVICES
CONCERN AND COMPLAINT PROCESS

Do you have a Concern or Complaint?

Report your complaint in writing to any staff or Manager

The Manager will follow up with you within 2 business days

You will receive a written decision/resolution within 5 business days

We will make every effort to resolve your complaint within the next 7 business days

Fill out a **Concern/Complaint Form**

Do you need help? No problem! Please ask staff and we will gladly help you fill in the form ☺

We Investigate every concern and complaint submitted

You will receive a **written decision** and/or **resolution** to your complaint

Forms located here

Manager Contact Information:
Name:
Email:
Mobile: