ABISS PERSONAL GUIDE

to Navigating Brain Injury

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Section 1

About Us

About ABISS

Acquired Brain Injury Survivor Solutions (ABISS) began as a social group for people living with brain injuries. It provided a place for us to practice social/communication skills in a group setting. Despite differences in age, gender, interests, and specific brain injuries, we found a commonality in many of our experiences after our injuries. Not only did it lead to an incredible support system, but it also led to the evolution of an advocacy focus within ABISS resulting in years spent challenging the injustices in the insurance industry. Refer to our website to learn about our initiatives www.abiss.ca.

About this Guide and Who it's For

Today, we continue to actively support fellow brain injury survivors and have developed this guide to help those new to brain injury navigate the often confusing and overwhelming recovering journey**. This guide is unique in that it has been written by people WITH brain injuries FOR people with brain injuries**. The information in this guide provides you with a unique perspective drawn from our lived experiences. It is not meant to replace any professional guidance.

"Your recovery may feel like a roller coaster. We've already taken the ride.

We are familiar with the pitfalls and highlights."

~ Ashley Tindall, ABISS

Recovery and rehabilitation can be a very busy and confusing time for both you and your loved ones. We have created this guide to help you through this difficult time. In it you will find strategies for living and coping with brain injury, tools to help you manage your own health information, and resources to build and advocate for a team approach with your rehabilitation support services. Our goal is for this guide to help bring you some understanding and organization to what may feel like a chaotic and confusing time.

This guide is meant for both the survivor and their care team as it covers a wide range of topics and useful tips and resources. This guide is by no means a replacement for advice and guidance from your healthcare team. As such, we encourage you to use this in addition to seeking medical advice from the appropriate medical professionals.

About the Authors

As the authors of this guide, most of us have suffered traumatic brain injuries (from car accidents, falls, blunt trauma etc.). However, we believe this guide applies to anyone with a brain injury of any kind acquired after birth known as "ABI".

Authors and Founding Members of ABISS
Jackie Cribb, Dave Gaylor, Sheila O'Reilly, Deanna Pelino, Ashley Tindall, Julie Wynen, Sheila MacDonald (ABISS Consultant/Facilitator)

Click here to read our stories

Section 2

How to use this Guide

This guide provides information and resources to help you advocate for your recovery. It is not intended as therapy or a basis for healthcare decisions, but rather a place to begin to get you started on your recovery. If you have concerns or questions, please direct them to your healthcare or support team. We hope it will give you some things to think about and give you some clarity. You are not alone.

> **Surviving an Acquired Brain Injury (ABI) and the aftermath can be incredibly isolating, so an important goal for ABISS is that people living with an ABI realize that they are not alone.**

- We made this book for you, survivors and caregivers.
- Everyone is different.
- Some have recently had a brain injury, and others had their injury years ago.
- Many have different combinations of physical, cognitive, communication and emotional difficulties.
- Some feel brain injury interferes with their daily life a lot and for others it interferes occasionally.
- Make this book yours; select the sections you need.

Brain injury Is a family injury. Some people in your circle may be more ready to read this guide than others. Use it in whatever way suits you and your support team.

- Some may not recognize the difficulties they are having so it may be their family or support people who benefit from the book. Personalize this guide. Read the sections you feel are relevant to you, in any order you choose.
- This guide is for information and general support only. If any of this information causes concern please speak with your team, health providers or a counselor of your choice.

There is a lot of material here. Pace yourself. Read a bit at a time.

Close your eyes and take breaks.

"People make the mistake of thinking that brain injury rehabilitation is like a linear path laid out with blocks, but it's not. With this injury, recovery is often non-linear, with the idea that you take two steps forward and then two steps back. Moving forward slightly sideways, if you will.

Brain injuries are often associated with multiple different traumas (physical, emotional, cognitive, communicative). Think of rehabilitation like a Jenga game. Each different injury is like balancing another block. So, the more injuries the more blocks on the tower. Each time you adjust a block, it has an effect on the whole tower...sometimes even bringing the whole thing toppling down.

Once you pile on emotional trauma and grief it becomes like playing Jenga while standing on a wobble board. Every movement now has a very good chance of knocking the tower off balance bringing it down. Pile pain and fatigue onto that and it's like playing Jenga on a wobble board in the middle of a wildfire. Pile the stress of a multitude of therapist, legal, and insurer appointments and it's like doing all the above and then having someone throw things at you to juggle...just for good measure.



And we are all expected to do this while fighting for our right to treatment, while educating politicians about the reality of this system, and while trying to help our families deal with and heal from their own traumas.

We cannot run through a cookie cutter system because we are people, not baked goods."

~Julie Wynen, ABISS

Section 3

About Brain Injury

Head injury or brain injury?

The term "head injury" used to be used to describe brain injuries but it didn't tell the whole story. It made people think that you had to hit your head or have a bruise on your head to have had an internal problem with the brain. Now we use the term "brain injury" to describe the problem of changes in brain functioning. These injuries may result in *visible* changes such as bleeding, skull fractures, or bruises on the brain but may also occur due to *invisible* injuries such as abnormal change in blood flow, unsteady electrical impulses, or a change in the chemistry or connections within the brain. A person can have a brain injury even if they did not hit their head directly. They can have a brain injury simply from having their brain shaken hard enough. They can have a brain injury even if they did not lose consciousness or pass out.

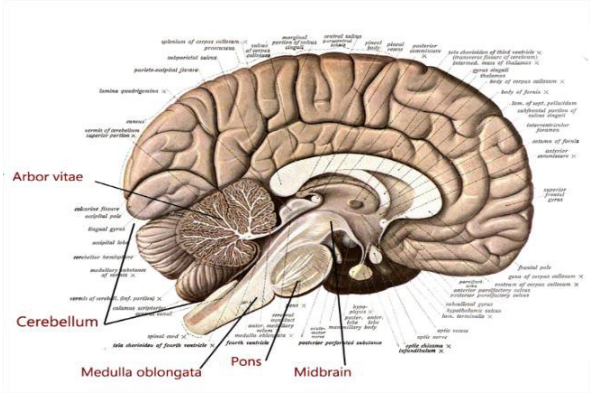
What is brain injury?

A brain injury is any disruption in how the brain functions due to injury on the *inside* of the skull. There are different onsets, causes, and severities of brain injuries.

Brain difficulties can occur ***before*** someone is born (e.g., autism spectrum disorder, attention deficit disorder, fetal alcohol syndrome), ***during*** birth (e.g., cerebral palsy) or ***after*** birth (e.g., acquired brain injury, multiple sclerosis etc.). Some types of brain injury are **progressive** meaning that conditions are expected to worsen over time, as is the case with Parkinson's disease, Multiple Sclerosis, or Huntington's disease. This guide will focus on "Acquired Brain Injuries" or ABI. Acquired brain injuries are those that occur after birth and are **non-progressive** in that some improvements are expected over time. The course of improvement after brain injury will depend on many factors. We will expand upon these below.

Causes of Acquired Brain Injury (ABI)

- ***Traumatic brain injury*** - A traumatic brain injury (TBI) occurs when there is force to the head or other body part that causes the brain to move rapidly. TBI can be caused by sports injury, motor vehicle collisions, falls, assaults, or other hits to the body or head. It is not necessary for someone to hit their head to get a brain injury. Any force to the body that is big enough to move the brain can cause brain injury, even if the person wasn't "hit on the head."
- ***Stroke*** - A stroke "occurs when a blood vessel that carries oxygen and nutrients to the brain is either blocked by a clot or bursts". For more information, click here.
- ***Infection*** - The brain's functioning can be disrupted by infections that affect the brain such as Lyme disease, encephalitis, or meningitis.
- ***Lack of oxygen*** **-** The brain does not like losing the oxygen it needs to function. Lack of oxygen can be caused by heart attack, severe blood loss, constriction of the neck, near drowning, carbon monoxide poisoning, or other poisoning. When the brain experiences lack of oxygen for a long time it can result in a type of brain injury called "hypoxic ischemic disorder" or "anoxia".
- ***Electrical Injury*** **-** Electrical harm to the brain is quite rare but can occur with electrical injuries or lightning strikes.
- ***Seizures*** **-** Severe seizures can cause injury to the brain. Epilepsy is the name for the neurological disorder in which the brain experiences abnormal activity causing seizures. See more information, click here.
- ***Brain tumour*** **-** There are many types of brain tumours and some are cancerous ("malignant") and some are not ("benign"). The Brain Tumour Foundation of Canada has an excellent website with detailed information about tumours. To visit the website, click here.



Severity of Brain Injury

Brain injuries can be mild, moderate, or severe. Depending on the type, location, and severity of the injury the person may experience some initial, and possibly long-term difficulties. These difficulties may include physical challenges, cognitive or thinking difficulties, communication difficulties, or emotional problems.

We cannot stress enough that no two brain injuries are alike.

Some people need help to re-learn how to walk, talk, and look after themselves . Others have fatigue that limits how much they can do in a day. And others may be able to function well in most aspects of life but have some difficulties when met with challenges at work or school.

The severity of the brain injury is determined when the brain injury first occurs or in the early stages using a 15-point scale called the Glasgow Coma Scale (GCS). Note, the GCS provides an initial picture and broad classification, but it is subjective, and ratings may fluctuate over time. Also, it does not predict outcome.

Mild - A score of 13 to 15 on the Glasgow Coma Scale classifies the person's brain injury as "mild". A concussion is a mild traumatic brain injury that may result from a sports injury, fall, hit, or motor vehicle collision. Although most people with concussion or mild brain injury will recover and be able to return to their daily work or school, some (about 15-20%) will have long term difficulties that require rehabilitation, support, and accommodation. Mild brain injury guidelines are available from the Ontario Neurotrauma Foundation and there are some very good resources for adults and children. To learn more, click here.

Moderate - A score of 9 to 12 on the Glasgow Coma Scale classifies the person's initial brain injury as "moderate". It is important to recognize that the initial GCS score is only a general number used to give health professionals some idea of the person's condition at the time of the injury or when they came into the hospital. These numbers provide a general picture of how things were at the time; they do not predict the long-term outcome. The score is an initial snapshot, but it is not a prediction. The best predictor of how someone will do in the long term is to evaluate their physical, cognitive, communication, and emotional abilities over time.

Severe - A severe brain injury is one in which the person's responsiveness is scored as 8 or less on the Glasgow Coma Scale. That is, if the person is unresponsive and their eyes are closed, they receive a lower score. Those who are minimally responsive, unable to talk or follow commands, may be in a coma or "minimally responsive state". These are called "disorders of consciousness" and there are different levels within it. If your loved one remains in a minimally responsive state there is a very helpful resource provided by physicians and rehabilitation professionals in the United Kingdom that you can access here.

Three Broad Levels of Brain Injury Cognitive Functioning

There are three main levels of cognitive functioning after a brain injury. There are more detailed levels of functioning called the Rancho Los Amigos Cognitive Levels of Functioning available here but for now we will limit our discussion to these three broad levels:

Minimally conscious – individual is minimally conscious after a severe brain injury. A person at this stage may have limited awareness of their surroundings or of what has happened. Keep in mind that there are different levels of difficulty with consciousness, and these are called "Disorders of consciousness", including: "coma", "vegetative state", and "minimally responsive". If your loved one is minimally conscious, please refer to your healthcare team for recommendations.

Fully conscious but confused – individual is fully aware but showing signs of confusion and/or agitation. When in confusion the person may not be aware of who you are or even who they are. They may have delusions. For example, one person is reported having told his young son that he got his injury in a war, this after having viewed a TV movie involving an American ship in WWII. Agitation involves saying or doing things before thinking. The person has cognitive or thinking problems due to the brain injury. It is a cognitive problem not a behaviour problem. It is common for confusion to occur early after injury, for agitation to last about two weeks, and for confusion overall to last less than three months. However, every brain injury is different, and confusion can last less or even more time depending on many individual factors.

Not confused but managing limitations – individual is interacting regularly but showing subtle difficulties (e.g. with concentration, memory, organization etc.). For some, these may be prolonged. The symptoms are more apparent when the person is overwhelmed, tired or when the situation is complex or new. Many activities take greater concentration and may be more difficult after brain injury. For example, driving, problem solving, learning something new, or technical or complex reading might become challenging. Those able to undertake these tasks may become fatigued more easily because of the extra cognitive effort required. They will need to take this into account when planning their day.

The more severe the injury the longer a person may experience or remain in any of these levels of functioning.

Initial Severity may be different from long term outcomes

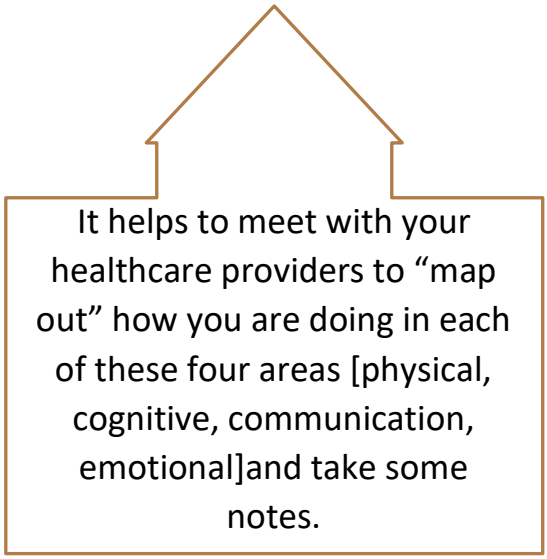
How your brain injury is classified in the beginning may not be the same as how you experience or feel about the brain injury. Someone with a classification of "mild" brain injury may find that their injury affects their day to day lives quite significantly**.**

That is, "mild" brain injury may not feel so "mild".

Stages of Recovery

As we said earlier, each brain injury is different and no two people with a brain injury are alike. However, there are some common themes and pathways. It helps to view physical, cognitive, communication, and emotional recovery as 4 related but different pathways. A person may improve more quickly in their physical recovery, for example but have ongoing difficulties in their cognitive or communication recovery. Some people have significant difficulties with their emotions and may lash out with anger or impulsivity that is not like them.

Cognitive and communication recovery tends to go through a series of stages that are well described by the Rancho Levels of Cognitive Recovery. This scale, often called "The Rancho Scale", was developed by speech-language pathologists Hagen, Malkmus, and Durham (1972). To read a version of it provided for families and friends of people with brain injuries, click here.



Long-Term Improvements and Neuroplasticity

It is not helpful, accurate, or constructive to tell a person with a brain injury that their recovery will stop after two years. Although the rate of change slows and becomes more subtle after the two-year mark, long-term improvements have been seen for many years post-injury. Neuroplasticity refers to the brain's ability to reorganize and rewire its neural connections and pathways in response to experiences and learning (Doidge, 2015). People with lived experience of brain injury emphasize that they see functional changes every year, and that it is not helpful to deny them the hope of change. As one person with lived experience of a brain injury said,

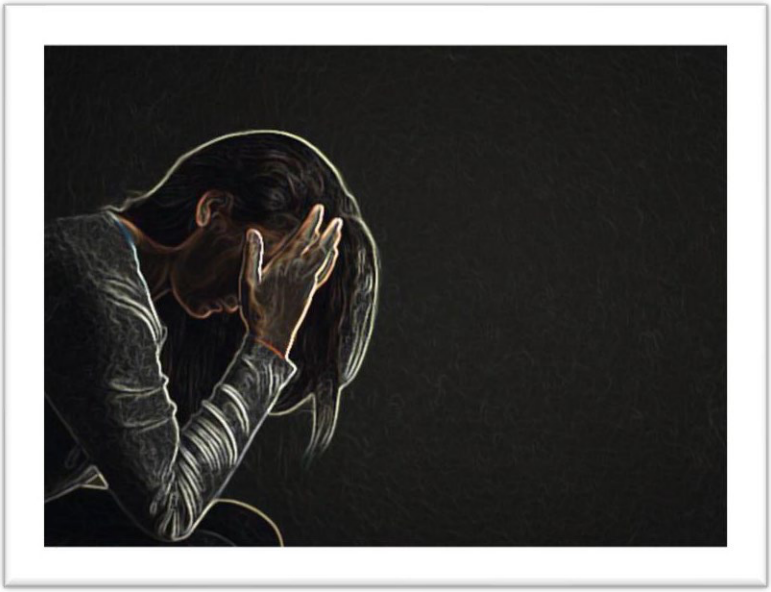
> "Some Doctors and therapists need to be taught that neuroplasticity is a thing!"

Therefore, healthcare professionals need to be mindful of balancing realistic predictions with the hope for ongoing development in daily life.

How it might feel to be the person with a brain injury

Early on the person with brain injury may not recognize that they have difficulties. Some feel "I'll be fine as soon as I get out of the hospital and go home". Others wonder why everyone is correcting them and they may feel "everyone else has changed". Some may feel that they are "glitchy" but cannot pinpoint the exact difficulties. Others may feel that it's "not that bad" until challenged by real life activities. Many try to "fake it 'til you make it" or to push on through without acknowledging or managing the difficulties. Some feel like they are operating very slowly or have the sensation of "walking under water."

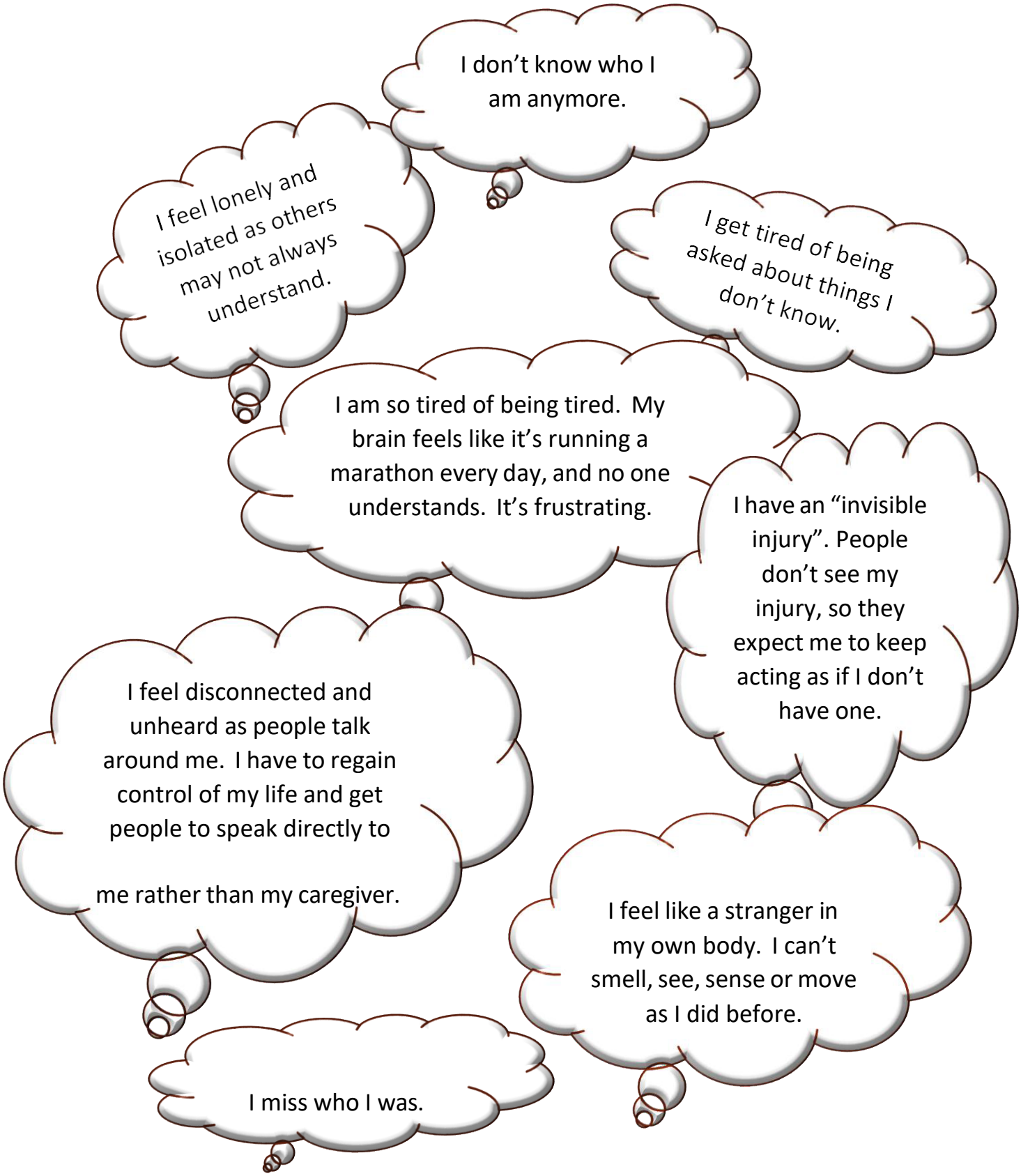
Meeting with a rehabilitation team is a very important step for both the individual and their support people. Read more about building your team here. The rehabilitation team can help the person with a brain injury to recognize their own difficulties, and this is called awareness. They can also help set specific goals designed for that person and help to develop an individualized rehabilitation plan. The difficulties become more apparent as they try to return to their daily activities.



As the person becomes gradually more aware of their difficulties, they can feel discouraged, terrified, frustrated, or overwhelmed. Meeting with a counselor to get help with managing these feelings and adapting to new circumstances is helpful.

Brain injuries happen not only to the individual but also to their families and support people. Family members may be realizing and experiencing the difficulties from a completely different perspective and along a different continuum of "recovery". To learn more about family, friends and support circle, click here.

Once the person is at home or living in the community, they meet with their challenges daily. At the point when they are very aware of their deficits, they must adapt to life with brain injury. Some of the feelings they might experience are:


I don't know who I am anymore.
I feel lonely and isolated as others may not always understand.
I get tired of being asked about things I don't know.
I am so tired of being tired. My brain feels like it's running a marathon every day, and no one understands. It's frustrating.
I have an "invisible injury". People don't see my injury, so they expect me to keep acting as if I don't have one.
I feel disconnected and unheard as people talk around me. I have to regain control of my life and get people to speak directly to
me rather than my caregiver.
I feel like a stranger in my own body. I can't smell, see, sense or move as I did before.
I miss who I was.

Some things we found to be helpful:

- Recognize that things have changed.
- Be patient with yourself. You need time to recognize, understand, and adjust to the changes.
- Approach one day at a time and go easy on yourself.
- Understand that you're as intelligent as you always were, just slightly less efficient.
- Think of one main thing or priority at a time. Ask, "What is my main priority today?" and reassure yourself, "I don't have to do it all at one time".
- Recognize that brain injury is an invisible injury: you wouldn't expect that someone who had a broken leg would go out and run a marathon the next day. It needs time to heal. Improvement happens by doing things gradually, with pacing, and with support as needed.
- Things will get better. Improvements are expected although they may not happen at the speed you want. One improvement needs to build upon the next and then the next.
- Recognize the small improvements and do not compare yourself to your pre-injury self. Changes are easier to see in the longer term as you look back.*
- Think of recovery as a continuum.*
- "Glitchiness" is a word we often use to describe how functioning feels after brain injury. In some moments you may experience more difficulties than others depending on the context or conditions (e.g. fatigue, pain, medication, cognitive challenge, stimuli, or things in the environment). All this can be overwhelming. The condition of being overwhelmed is common and can be debilitating. Acknowledge, accept, advocate, and adapt day to day.
- Remember every reaction you feel is completely normal.

Rehabilitation and Support

Take control of your rehabilitation. What's happening in your recovery will guide your future. Sit down with your team and family and tell them you would like some help designing your goals, priorities, and strategies. See the section on Building your Team here.



- Know that brain injury is a family and community injury. Work together.
- Meet with those who love and support you and develop a plan..
- Get visitors to sign a guest book when they visit. Have them print a few lines about what's new (e.g. visits, pets, family events, etc.). Ask them to sign the book and put their relationship to you beside their name. You and your family will find that this book is very helpful for memory, support, and encouragement.
- Work with your family or support team to personalize this guest book idea. What is best for you? Large print? Plain paper with no lines? Reading it aloud to you? A google doc you can all write in and read online?
- Think of the "Goldilocks" view of support… not too much, not too little, just right. Recognize that this will change from day to day depending on such things as how tired you are.

Advocacy

- Find ways to make the “invisible injury” visible. Gauge support by letting others know when you do and do not need help. Show those close to you how long things take you, and when you do and do not need support. Make lists together.
- Develop some scripts for how you describe your injury and think about words to use and not use. For example, do use words like “challenge”, “adapt”, and “strategies”, rather than words that are negative or critical.
- Look for motivational messages or inspirational sayings that you can repeat to talk yourself through things (e.g. one thing at a time, just keep swimming)
- Count all successes no matter how small.
- Use humour to help you and your loved ones get through. Give yourself and others permission to breathe and laugh.



Section 4

About You, Your Recovery, and Your Support

Each person is unique. Each brain injury is unique. We recognize your needs will be different depending on many things including the time since your injury and the severity and classification of your injury. This section of the workbook addresses the issues that can arise for you and how you might deal with them while recovering from your brain injury.

The following is a list of characteristics of brain injury. For more information visit the Ontario Brain Injury Association website.

Concentration may be much more difficult

You may forget what you were saying mid-sentence or find yourself searching for the right word.

You may be slower forming thoughts and may find it difficult to converse or keep up with what people are saying to you.

Being in a group discussion may be difficult.

You may tire far more easily and have less energy

You may have physical issues like pain, headaches, sleep issues, changes in sensation, vision, appetite, hearing, smell, or taste.

You may not be able to tolerate noises, flashing lights or quick changing scenes on a computer, phone or TV.

You may be easily distracted or get stuck on one issue.

You may have poor coping skills initially and need to learn new ones.

You may need a quiet space of prefer to talk to only one person at a time

Friends and family may tell you that your personality seems to have changed. You may be more emotional and express anger more than you did prior to your injury.

Even though these things may be happening to you, you may be completely unaware of it. This can cause some conflict with your loved ones if they notice changes and you do not.

Planning, organizing, and pacing yourself may be more difficult.

You may be more inflexible and find changing circumstances more difficult.

The way you experience the world emotionally may change. You may be more sensitive to stress or experience sadness. You may feel flat emotionally, experience a lack of happiness, or have little or no facial expression. On the other hand, you may have emotional outbursts or cry involuntarily. These emotions may change rapidly throughout the day. Therapists may use different words to describe what you are experiencing

(e.g. depression, anxiety, anhedonia, lability). Ask them to explain these words.

Early on you may be disoriented and not recall where you are, what you are doing or who you are seeing.

Remembering things and people may be more difficult

You might act or speak without thinking.

These experiences are completely normal

when it comes to brain injury.

Family members and therapists may be called upon to assist you with:

- Self-care tasks
- Household management tasks
- Driving a car
- Your social and/or hobby activities
- Balance, coordination, and walking
- Communication including listening, expressing, taking notes, reading, writing emails, or discussions
- Community interactions
- Your work or planning for return-to-work. Your school or planning for return—to-school.
- Management of information, including healthcare, legal and financial matters

In summary here are some things to know about you and your brain injury:

- It is difficult to make the necessary adaptations to deal with your brain injury on your own. It will be essential to seek the help of professionals, family members, and support people to provide the direction and structure you need.
- While you are fundamentally the same person, your brain injury has changed you and this can have an impact on your relationships.
- The effects of brain injury don't just impact you but everyone around you, thus the often-used expression "brain injury happens to families".
- Your family members are all people who will continue to experience their own life challenges. They will not always be at their best either.
- Challenges from brain injury may be long term. Pace yourself and get support.
- Meeting brain injury challenges, while difficult, will have its own rewards. Some things will be better than you remember preinjury.

Pacing and Adjusting for Fatigue

After a brain injury fatigue comes easily. Fatigue can be physical, cognitive, or emotional. It is critical for those recovering from a brain injury to learn to "pace" their day. This means taking frequent breaks throughout the day from activities, even if you are feeling ok. Think of it as "activity, then rest, activity, then rest". It's important not to overwhelm yourself and deplete your energy. Many people refer to brain injury related fatigue as running low on "batteries". Think of rest as whatever recharges your batteries.

Find ways to pace yourself and remember to take a break. Some people set alarms. Some use their phone, Google or Alexa or similar technologies. Pacing is needed to prevent or minimize cognitive problems, irritation, anger outbursts, or emotional reactivity. Pacing to reduce fatigue is critical.

- Many of us who have experienced a brain injury reflect on how difficult it was for us to come to terms with the need to pace and slow down.
- Just having a conversation can be tiring.

Having a brain injury is exhausting.

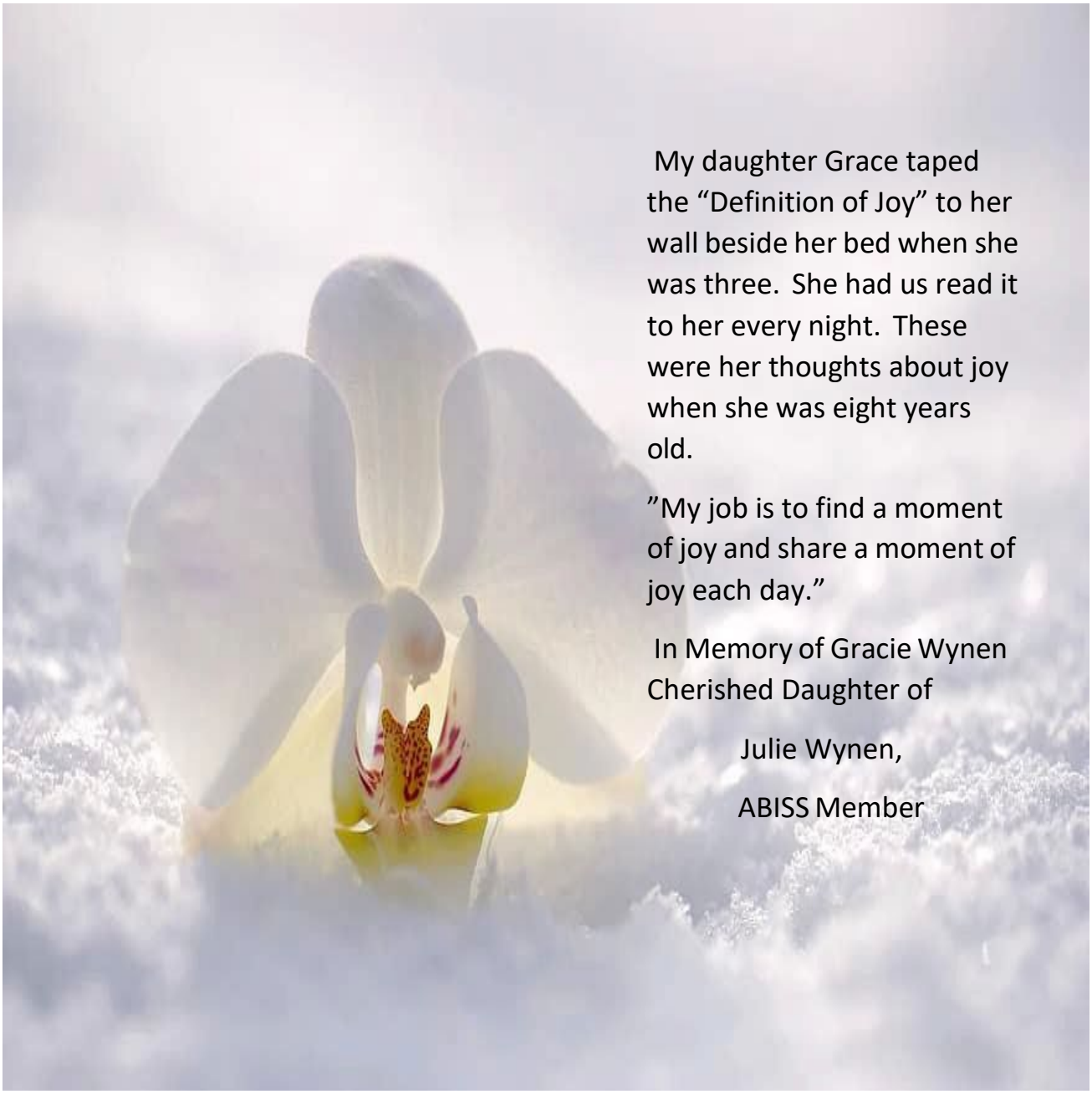
Simple tasks can feel overwhelming.

- When you injure a body part you are usually told to rest it. What do you do when you have injured your brain? Alternate activity with rest.

What is a rest? This is different for everyone. It may mean

- sitting for a few minutes in a quiet room without noise or stimuli
- meditation or intentional breathing
- sitting quietly with a cup of tea
- going for a walk
- watching a garden or fish tank
- listening to calm music
- spending time in nature

Rest can be for as little or as long as you need. At times you may need to rest for a lot longer. For example, after a cognitively intense activity or after a particularly busy day you may need an extended rest period.



My daughter Grace taped the “Definition of Joy” to her wall beside her bed when she was three. She had us read it to her every night. These were her thoughts about joy when she was eight years old.

”My job is to find a moment of joy and share a moment of joy each day.”

In Memory of Gracie Wynen
Cherished Daughter of

Julie Wynen,

ABISS Member

- Schedule accordingly based on your needs and the recommendations from your therapists. You might find that your need for rest changes throughout the day as you experience lower periods of energy and your "batteries" get depleted.

- Most individuals with brain injuries find that they need to rest in a quiet place in the middle of large gatherings, family, events, or activities. Help loved ones give themselves permission to take this time and to talk in advance with others about the need to plan for a break at some point. It will be helpful to find a quiet space ahead of time.

- Some people find it helpful to provide a list of pacing strategies to their family members so that they understand how to help.

Section 5

Building Your Team, Advocating for Your Needs and Managing Your Health Records

BuildingYourTeam

Who needs a team**?**	**Everyone with a brain injury needs a team.**
Who is at the center of your team?	**You are at the center of your team.** We are here to remind you that your team should always be communicating with YOU (or your chosen advocate). In the beginning it can be difficult to advocate for yourself. Ask a trusted person to act as your advocate to make sure you can communicate your needs and preferences.
Who is on your team	**Your team members will change over time** and will change in their importance in your day-to-day life. Some will be with you for a short time. Some will be with you for short periods over a long time. And some may be with you for life. Early on your team may have more of a hospital or medical focus. Later, as the team moves to your home and community, it will focus on your return-to-life participation.

Who are some other potential support people?

People you meet through community services (e.g. brain injury support groups - for a list of local groups, please click here) and various recreational opportunities (e.g. skiing lessons for people with a disability) may become part of your team too.

For those returning to school, teachers, educators, and school support personnel will be on the team. For anyone returning to work, supervisors, and co-workers may play a role on your team.

Please click here to access the Return to Work guidebook from Brain Injury Canada.

What is a team?

A brain injury team is a group made up of various medical and rehabilitation, professionals who are trained in brain injuries and will help identify therapies, and strategies to help you manage your new abilities and recovery journey. Your team should always be centered around you. Remember, your family, friends, and advocates (i.e. case manager, lawyer etc.) are part of your team.

A team should collaborate and coordinate, not duplicate and overlap (although there may be some minor overlap but usually because they are addressing the same challenge with different skills and approaches).



Why do you need a team?

As a person negotiating the world with a brain injury, you may struggle with certain things like speaking, reading, writing, comprehension, time management, organizational skills, memory, cognitive fatigue, physical fatigue, physical movement and sensation, personality changes, and all the FRUSTRATION that goes with any of these. Plus, you might be dealing with all of this while you are having to schedule more appointments than ever, keep those appointments straight, show up at the right place for them, on the right date at the right time, and know who you are seeing and why. To access a planning sheet for a doctor's appointment, click here. To access a planning sheet for a therapist appointment, click here.

It can take some time to assess your needs and find the best team members to fit them. You may need to self-advocate while trying to build this team. And that's okay. Take the time to choose these people carefully, because you are going to be spending a lot of time with them, and they will greatly impact your recovery.

How do you choose a team?

Determining your needs

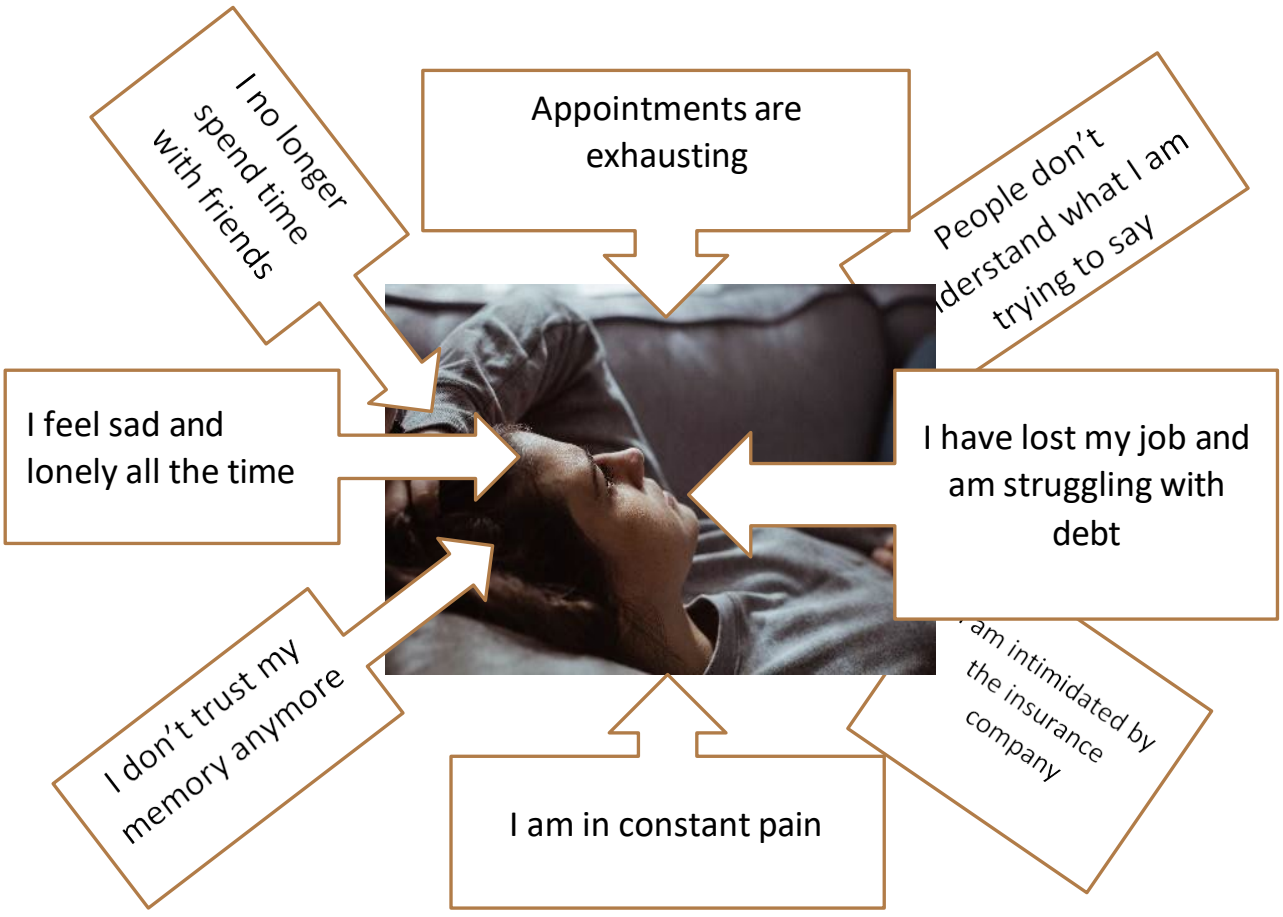
Consider your needs in all areas: physical, cognitive, communication, and emotional.

Listen to your healthcare team if you have one in the hospital. They will be able to list your needs and each of the professionals you'll need to help you with them. The hospital social worker, or discharge planner can usually help with making the initial team transition plan.

If you didn't begin in the hospital or if you haven't had a team assigned, list your needs, and begin by meeting with one of your health or rehabilitation professionals (e.g. family doctor or therapist). They can help you identify needs and help you source corresponding service providers in your community.

The key is to listen to the health and rehab professionals but also to listen to yourself and those closest to you as you progress. Communicate with your existing team, and continually ask if there is any professional you need to add. Partner these needs with your own available resources including financial, physical, and energy levels.

Ideally, a case manager with expertise in brain injury is the most helpful professional in forming a team that is tailored to your needs. Unfortunately, case management services are not always funded, and you may be left to do this on your own. If your case is quite complex and you need support, you could consider hiring a case manager for a short period of time to get you started.



Potential team members and their roles

Team Member	What They Do
Occupational Therapy	Occupational Therapy (OT) is "a form of therapy for those recuperating from physical or mental illness that encourages rehabilitation through the performance of activities required in daily life". After brain injury the OT may help you return to regular activities of daily living (e.g. dressing, laundry) or to independence in the community (e.g. taking transportation, banking) or to productive activities (work, volunteering. Adapted from: Ontario Society of Occupational Therapists
Physical Therapy (Physiotherapy)	Physiotherapy is "the treatment of disease, injury or deformity by physical methods such as massage, heat treatment and exercise rather than by drugs or surgery". PT's help with any aspects of your movement (e.g. arm, leg, balance, strength, co-ordination) and getting back to your physical activities (e.g. walking, running, lifting). Adapted from: College of Physiotherapists of Ontario
Speech Language Pathology (Communication Therapy)	Speech-Language Pathologists help people with all aspects of their communication (listening, speaking, reading, writing, and social interaction) and the thinking skills they need for communication (e.g. attention, memory, reasoning). "SLPs assess, diagnose and treat speech, language, social communication, cognitive-communication and swallowing disorders". Adapted from: College of Audiologists and Speech-Language Pathologists of Ontario and Speech-Language & Audiology Canada
Vision Therapy Optometry	Optometrists evaluate all aspects of your vision, diagnose visual problems, and recommend supports and vision therapy. Vision therapy after brain injury involves helping your eyes and brain to work together. Also called "Neuro-optometry", "Binocular Vision" Adapted from: Vision Therapy Canada
Social Workers	Social workers (SW or MSW or RSW) provide counselling and support to manage stress, resolve conflicts, or solve problems.

	They work by viewing the person within the context of their families, and other personal connections. Some social workers provide discharge planning or case co-ordination services. Adapted from: Ontario Association of Social Workers
Psychology and Neuropsychology	Psychologists study how we think, feel, and behave from a scientific viewpoint and they apply this knowledge to help people understand, explain, and change their behaviour. There are different kinds of psychologists. After a brain injury, you might see a Clinical Psychologist who helps with assessment and diagnosis of emotional difficulties and provides counseling. Neuropsychologists are psychologists with extra training in how the brain works. Neuropsychologists assess cognitive and emotional functioning and provide recommendations to guide your rehabilitation. Adapted from: Canadian Psychological Association
Physiatrist (Rehab Doctor)	A physiatrist is a medical doctor who specializes in rehabilitation. After brain injury this rehabilitation doctor can help to diagnose problems and provide recommendations for therapies, medications, and supports. Adapted from: Canadian Association of Physical Medicine and Rehabilitation
Neurologist	A neurologist is a medical doctor who has extra training in diagnosing brain disorders and prescribing treatments (e.g. medications, additional examinations, therapies) to help. Neurologists diagnose and treat nervous system disorders involving the brain and spinal cord and other nerve and conditions. Neurologists often consult and provide information to the rest of the team. Adapted from: Neurology Profile

Psychiatrist	A psychiatrist is a medical doctor with extra training in mind and behaviour. A psychiatrist can diagnose mental disorders such as depression, anxiety, post-traumatic stress disorder, dementia etc. After a brain injury, some people see a neuropsychiatrist who has additional training in brain and behaviour and mental health. They can prescribe medications, treatments, or specialized treatment programs. Adapted from: Neuropsychiatry
Audiologist	Audiologists are healthcare providers who specialize in hearing and balance disorders. They diagnose hearing loss or hearing changes (e.g. tinnitus, noise sensitivity) and provide treatment and work with other healthcare providers regarding hearing. Adapted from: Canadian Academy of Audiology
Rehabilitation Support Worker	A rehabilitation support worker is someone trained in general rehabilitation practices who can implement the recommendations from the regulated health professionals (e.g. SLP, OT, PT). They can help you reintegrate back into community and regular activities.

Choosing the best fit for you

As mentioned above, choosing the right team member for you – whether it's a therapist or a doctor or a personal support worker – is vital to the success of your recovery as you will be spending considerable time with them and depending a lot on their skills and abilities. Below are some criteria to help you figure out who is the best fit for you.

1. Being Heard

You need to feel that you are being listened to. If you tell a therapist that you keep having bad headaches after every appointment with them, how do they react? You want them to listen to your concerns and provide information and options for addressing them. For example, a helpful therapist might have suggestions such as pacing your day, planning a break before or after the appointment or changing aspects of the appointment. The therapist needs to work collaboratively with you to figure out the best plan going forward.



2. Rapport and Relationship

Research has shown that having a positive relationship with your support team improves the recovery path. It's okay to search for someone who is a good 'fit'. For example, one of our ABISS members said, "I needed someone with a good sense of humour. I needed to find some bright spots in my life at the time. I needed therapists who would laugh with me while they were helping me rehab, adapt, and accommodate for "*the absurdity that is my life now*." Having said that, some may prefer a different approach. It's all about finding the right fit for you. Both attitudes (and everything in between) are perfectly normal but having someone who "gets you" definitely helps the process.

3. Ask questions

Don't be afraid to ask questions. You have the right to ask, after all, it is your health. Some questions to ask when choosing team members are:

- What challenges will you address?
- Are you covered by OHIP, my employee benefits, auto insurance or other funding?
- Are you specifically trained in brain injury?

Communication, collaboration and coordination amongst your team

Remember, without you there is no team!

What is needed for a successful team is **effective communication** to coordinate, to help you solve, adapt, and accommodate and keep moving forward. Good communication can also help to streamline services and avoid confusion or too much overlap.

An example of **collaboration** would be if you have an injured arm: your physiotherapist may work on rehabilitating the injury itself and your occupational therapist may help you to accommodate and adapt to living with the injury while it is being rehabilitated.

An example of **coordination** is your team working to figure out who on the team is best suited to be the first to address a challenge you are facing. Perhaps you are experiencing challenges with returning to social life post injury. The speech-language pathologist (SLP) may help you with any communication issues, the occupational therapist may help to arrange transportation to a social function. The SLP may help to involve you in social groups or discussions. The OT may help you find new leisure activities to take part in. The physiotherapist may assist you with physical coordination and comfort during the social activity. The psychologist, social worker, or counselor may help with emotional adjustment to changes in your social life

Included in this guide are sample charts and tracking sheets that might help you stay organized and on-track with your recovery. To access a planning sheet for a doctor's appointment, click here. To access a planning sheet for a therapist appointment, click here.

Where is your team and how does it change over time?

Hospital

At the hospital your team may consist of a variety of professionals including doctors, nurses, a physiotherapist, occupational therapist, speech-language pathologist, social worker, psychologist, or neuropsychologist. Later a lawyer and their assistants may also be part of your team. Not everyone will have all these people on their team, and some may even have more people on their team depending on what other injuries they sustained. When you are leaving the hospital, a discharge planner may assist.

Home

Once you transfer back to your home, your team will probably change again and will continue to evolve and change over time. It can be very helpful to have a **case manager,** that is someone who can co-ordinate your team and help you find services. Case managers are not always paid for by the healthcare system and sometimes people hire them privately. You may still have **doctors** on your team but not in the same way as when you were in the hospital. You may still need to see some doctors after you are discharged. Or you may be discharged from their care at that point. You may be referred to new doctors in the community after being discharged from the hospital depending on your injuries or service needs. You may still have an **occupational therapist** to help you return to your activities of daily living and your transition from home to community. A **physiotherapis**t may help you reconnect your brain with your body and work on movement. A **speech-language pathologist** can assist you with cognitive and communication difficulties. Depending on the severity of your injuries, you may or may not have a **nurse.** You may also need help at home in the way of a **personal support worker (PSW)**, someone to cook meals for you, or someone to make any necessary changes to your home environment so that it is safe. You may or may not need a **lawyer** at this point if you haven't already engaged one. Once home other therapists may be added to your team. Click here for a list of possible team members and their roles.

Community

The end goal of rehabilitation is reconnection of the person with the community. This may look different depending on the severity of the injury. It can include such things as help with:

- re-engagement in the home environment
- attempts at independent living
- participation in community
- transportation and navigation
- engagement in recreational activities
- volunteering
- return to the workplace
- social engagement

The goals must be tailored to you, your needs and your preferences.

As you move into the community the challenge will be to find your new routine. You will begin to recognize the new you and learn how to interact with the world around you. You will probably be seeing fewer doctors (other than your family physician and possibly the occasional specialist). You may or may not have a Case Manager/Social Worker. This is when you may be adding a Recreational Therapist to your team, and you will probably have your Occupational Therapist playing a more active role on your team again. You may also be seeing your Speech-Language Pathologist more often as you work on community communications, social communications, academic pursuits, or workplace communications.

This is the time when your team expands to include community members, support groups (Ontario Brain Injury Assoc., brain injury support groups, etc.), and members of any activities you are pursuing. This is a great opportunity for you to practice advocacy skills for your recovery as the makeup of your team and your priorities are up to you. Remember, you are the focus of your recovery.

Team changes over time

As you progress, your needs will change, and your team will evolve to meet these changes. You may need your rehabilitation therapies (e.g. occupational therapist, physiotherapist, or speech/communication therapist) frequently in the beginning and then intermittently over your lifetime. Again, this depends on your needs. It can be challenging to find funding for ongoing needs.

Eventually, you may go years without needing anyone with a medical/ rehabilitation background.

You will probably find that you need your team during times of transition in your life (e.g. moving back home from the hospital, going back to work or school, starting a new job, a death in the family, a birth in the family, moving, school semesters, etc.). Please accept help when you need it.

> Do not associate needing help or reactivating support as a regression in your recovery. It's natural to bring support back in at various times along the path to recovery.

If you move from one place to another it may require additional physical, personal or organizational support. Plan your team ahead so that you are not 'lost in the chaos of change'. At times of change even consider planning for additional emotional support due to stress. Depending on how far you are moving, you may need help from your current team to help you establish a new team. Again, remember to be kind to yourself.

We encourage you and your supporters to advocate for the services and care you need. Needs for new services maybe identified in the following ways:

1. Other professionals may recommend you see someone for your particular challenges.

2. You may become aware of difficulties/challenges/struggles that YOU feel you need help with.
   Many people become aware of new needs over time.

3. Others around you may see you struggling and suggest help.

4. You may feel like you can and want to do more but need help figuring out what "more" is, and how to approach it.



Remember you had a brain injury, and your body is healing. You may feel exhausted. EVERYTHING feels like work. On the other hand, you might be able to accomplish a task and then feel tired or overwhelmed for some time afterwards. This is normal. Don't be too hard on yourself. Take breaks as needed. You may find it easier to stagger therapies and phase in different kinds at later times or even suspend therapies at certain times to conserve energy. This can be challenging when trying to balance your own capacity with the needs/requirements of the insurance companies. Seek advice from your team if you are struggling with this. Remember to advocate for yourself.

Never be afraid to ask for help when you are struggling or if you identify a problem.

Instead of thinking of asking for help as a step backwards, think of it as a move forward. You have moved forward by solving, adapting to, and accommodating for a great number of challenges, and are now able to get to those priorities further down the list.

The team members you need will fluctuate and change over time.





Who pays for your team?

This is a good question, and the answer is 'It depends'. We will answer what happens in Ontario, Canada.

- **Hospital services** - are usually paid by government funding such as Ontario Health Insurance Plan (OHIP).
- **Doctor services** - are usually paid by OHIP.
- **Rehabilitation Services** - these are paid by the government while you're in a hospital or an inpatient rehabilitation program. However, once you are out in the community, you usually must pay for private community services.
- **Home Health** - Some home health services such as personal support workers and nurses are paid by the government if you are confined to your home. Some are paid for under the heading of "Attendant Care" services through motor vehicle insurance. See funding options below.
- **Community Services** - Rehabilitation and health services in your home or in the community are usually private or 'fee for service'. That means you have to look for funding services. See funding options below.

Funding Options

- **Automobile Insurance Benefits -** If you were injured in a motor vehicle collision, your auto insurer should cover some of the expenses, but funding has to be approved first. Each health professional who is going to work with you must submit a 'Treatment Plan', and this plan is either Approved, Partially Approved or Denied. Talk with your lawyer to help guide you through this confusing process. Also, you may find some of our ABISS materials on this subject helpful. To access the ABISS website, please click here.
- **Worker's Compensation** - If you were injured at work you can apply for worker's compensation for assistance. Contact WSIB and ask to speak to one of their intake personnel. Caution, you may need an advocate to help you negotiate this process.
- **Extended Health Benefits** - Many people have extended health insurance that helps them pay for their dentist or optometrist. There are usually other rehabilitation services on these plans. Look at your or your spouse's, if applicable, extended health policy to see what it covers or call the insurer and ask. Be advised that there is usually a maximum amount allowable each year and it is common for the insurer to not pay for the whole amount of a service.

The size of your team, funding for services, and the length of time you work with your team will vary greatly over the course of your recovery.

Advocating for Yourself

As you build your team it's important to advocate for yourself. This means being aware of your own challenges, goals, needs, and communicating about your preferences. It is okay to say, "this doesn't work for me". However, in order to progress, you do need to follow up with, "How can we make this work for me?".

While thinking about your needs, it also helps to have a list of things that help you. These are called 'Accommodations' or 'Strategies'. Keep a printed copy with you always. Make sure everyone who assists you is familiar with it. As your needs progress, update this sheet to reflect your new needs. To see an example, click here.

It is your right to ensure that team members are the right fit. If you feel you need a change on your team, speak with a trusted advocate or support person. You will be spending a lot of time with your team, and they will need to coordinate and collaborate, especially in the beginning. There are many reasons that you may need to change a team member including, "They aren't great at communicating" or even, "They're way too serious and just don't get my sense of humour". Advocating for yourself will help you:

- strengthen your recovery
- ensure your recovery is less stressful
- become more self-aware of your conditions and strategies to accommodate for any challenges you face
- hold your doctors, your therapists, and yourself more accountable for your rehab feel more in control of your own life

In the same way that your recovery is a process or journey, so is advocacy. It can be overwhelming in the initial stages. As people with lived experience of brain injury, we can assure you that you will become more comfortable as your journey progresses.

Managing your Health Records



For many appointments, you will need to be able to produce your current medications, medications you've tried in the past, treatments you've tried in the past, doctors/therapists you've seen in the past, referrals, scans doctors have ordered, scan reports, and actual scans. In addition, your health records will be integral to proving injury for insurance companies and law firms, to receive benefits and compensation. As such, **your health records will play a significant role in your recovery. tTherefore we cannot stress enough the importance of keeping track of your health information on your own**, rather than relying on the hospital or doctor's office to keep them for you.

It can be difficult to access your records from a health records keeper months to years later and not all information will be kept on file. It's easiest and best for you if you obtain a copy of every record and put it in a file for your future reference and for sharing with members of your health and support team.

Managing your records is about preserving the scans, reports, medications history. It is also about having that information at your fingertips for your day-to-day life.

Don't assume that one health office is automatically sending your health information to another place or service. Sometimes they do and sometimes they don't. It's best if you keep track of your information and have it on hand.

Why do you need your health records?

- You will be asked at every appointment to provide a list of medications, scans etc. Having all of this information in one place ensures you don't forget to relay important information and avoids you having to repeat yourself all of the time.
- Because they represent your health history and provide evidence that enables you to get better care and advocate more effectively for yourself with medical doctors, therapists, and insurance providers.
- Your health history is a part (not the whole part) of who you are now.
- To show that you want to be an active participant in your recovery.
- To show that you will hold service providers and yourself accountable for your recovery process.
- Keeping track of your health records is also important in case you decide to pursue legal action as they will be required to make your case.

What is included in health records?

- Scans (X-ray, CT, MRI, PET, etc.) or reports from scans
- Medications you are on (including dose and frequency)-
- Medications you are allergic to
- Medications you have taken in the past and reasons why you are not still on them (side effects, didn't work, found something that works better for you, or no longer need)
- Blood work/labs
- List of vaccinations
- List of special conditions: e.g. diseases, allergies, immunocompromised, etc.
- Assessment, progress, and discharge reports

Where do you access your health records?

- Ask for hospital discharge reports before you leave. Some may provide electronic copies. Some only send reports to the family doctor, and some will provide paper copies at a cost. Ask about your right to information.
- Ask for any scans or x-rays or at least find out how to get them.
- The hospital Health Records - a fee may be required, and they may have time limitations for keeping records.
- Whichever lab you go to for lab/blood work may provide online access which can be downloaded. Be aware that not all results are available. Life Labs provides online access to most test results. Click here for access to the Life labs website, then click on *see my results*.
- Many imaging labs also provide electronic options from which to access and download your records such as "PocketHealth" provided by True North Imaging. Some have fees and some do not. Check to see what apps are currently available.
- Doctor's Office (Secretary/Office Manager)
- For rehab therapists, you probably only need these records if you are changing therapists or gaining a new therapist altogether (there will be a fee for these records but keep in mind there is a time component on the therapist's behalf to provide these).

How do you keep track of health records?

- Right from the start your family/friend/advocate can begin the process for you in something as simple as a notebook.
- Ask for records of scans, lab work etc. when they are completed.
- Record findings and next steps at each doctor's appointment.
- Keep track of records or reports whenever there are new assessments or when there is any change in your team/health condition/therapies/specialists.
- Set up a folder for these materials immediately: in a file box and/or digitally and put anything related to your health in that folder.

Where do you keep your health records?

- Actual scans will be digital which means that you will have to keep them as digital records (online, disk, key fob/usb stick)
- Detailed records can be kept at your house in a digital copy or a paper copy (some place safe and organized, i.e.: banker's boxes/file boxes)
- You may want to summarize your health information using a template. See the examples in the Practical Resources section here.

Where do you take your health records?

- Pertinent records should be taken to all appropriate healthcare appointments (e.g. doctor, therapist).
- Insurer assessments.
- Lawyer's appointment (if you are working with a lawyer).

The most important thing is to just have your health records and maintain them or ask for help if you can't do it yourself.

Key Points

- Keep a digital record of your history and carry your current information on paper.
- Prepare to share your current health information. Doctors, specialists, and therapists will need access to at least some portion of your records.
- You have a right to maintain your privacy. Therefore, a health professional should only release your private information if you've provided consent.
- Choose a method to keep your health records that suits you. There are many apps or systems available, or you might choose to keep paper files. Talk with your family and team about what works for you.
- Take an active role in your recovery by having your health records available. Having copies of your medical information, notes from appointments, and test results equips you to take part in your recovery and to provide proof of what's working and not working for you. Remember you are your own best advocate.
- Don't worry if you can't understand all your health records. Hold onto them and ask others for help interpreting when needed. Your records are primarily for your doctors and therapists so that they have access to the information they need to better treat you.

Section 6

Caregiver Tips and Tools

A brain injury can be devastating. The person who suffers one may behave, think, and see the world differently than they did prior to their injury. When someone suffers a brain injury family members and other support people may take on the role of caregiver or support person. This is a critical role and can be a tenuous balancing act as the support person balances the changing needs of the person with a brain injury with their own needs and others in their sphere. Providing this support is often a delicate, demanding task which can be exceptionally challenging. At the very least, it's a stressful time that can call on the caregiver's mental and physical resources and abilities.

Be mindful of taking care of your needs as you give to others.

This section provides some tools and guidance for those who are supporting the person with a brain injury. Specific supports for those with a brain injury can vary depending on the degree of injury and the timing of intervention post-injury.

Providing In-hospital support

Family and support team members will want to have several supplies on hand when tending to the person with a brain injury in hospital. Touch is important so things like ChapStick, lotion, oils, nail files or even dry hair shampoo, anything that gives a close caregiver reason for physical touch, is great.

Another important item to consider is music. Play recordings of music (or even play music yourself) which may have had significance to the person.

Providing structure

A person with a brain injury often needs a structured environment and a consistent routine. Consistency and predictability are very helpful. Others may take some time to learn their needs and develop a routine. Develop and maintain a consistent schedule as much as possible. Include as much activity as the person can handle without becoming overly fatigued. Build in time for rest. Also allow flexibility for changing symptoms, changing demands, and changing levels of energy. Never assume that all people with brain injuries are the same. If you've met one person with a brain injury, you've met one person with a brain injury. Let the person's symptoms, needs, preferences and tolerance levels be your guide.

Educating yourself

Read about brain injury or ask your doctor about the main elements of your loved one's condition and what to expect. The Ontario Brain Injury Association has a very helpful website www.obia.ca. Become involved in their recovery during the rehabilitation process. Doing so enables you to have a clear understanding of struggles the person will face and of strategies that you can implement at home to lessen the impact of these problems.

Engaging the person

Find the type of music, movies, art, or writing that interested them before the injury. But also look for the things they can enjoy now. Think of gradually returning to activities one step at a time. It may take a long time for the person to be able to go out to community events and locations. For example, even going out to a movie or to an arena could be overwhelming for some. Gatherings with family and friends might also feel daunting because of multiple people, stimuli, and background noise. As a caregiver providing support is often a delicate and demanding balancing act. Try to find activities that they can enjoy here and now. Then gradually build upon these successes. Introduce new locations, stimuli, people, and demands gradually, with their input, and according to their tolerance . It helps to plan each activity ahead of time. What are the physical, cognitive, communication, and emotional demands of the situation? What will be easy and what will be hard (painful, tiring, frustrating, unfamiliar etc.)? Adjust accordingly.

When possible, involve their friends with activities they might enjoy. Be prepared to adapt or change the activity. It may also be necessary to adapt everyone's expectations. Prepare favourite foods or help them do it. Help them with personal grooming if that was something they enjoyed before. Talk, read, listen.

Thinking of how to support

It is crucial for a person with a brain injury to receive support in their recovery process. Family support is particularly important as parents and siblings and other relatives probably know the person best. If family support is not available for any reason, close friends may be best at caregiving if available. There are also organizations and institutions that will provide caregiver support. Your health professionals will be able to assist with this.

There are of course many different types of support that can be offered, some of which are:

Helping with Communication

It is of the utmost importance to talk to the person with a brain injury and converse in a natural manner. The person may have difficulty speaking or understanding. Some will have difficulty thinking but others will have difficulty communicating while aspects of thinking are intact. Keep in mind that communication is central to a person's self-confidence and quality of life. A common misperception among the public is that if someone has difficulty expressing themselves, they also have trouble with thinking. It is possible to have communication problems without cognitive problems or to have cognitive problems without communication problems. Talk to your team to learn about your loved one's communication strengths and weaknesses.

Communication partners need to learn how and when to support and how to help the person participate and make decisions as much as they can/want. One person with lived experience of a brain injury noted the following reactions from communication partners when she attempted to communicate.

Communication partners might be embarrassed and uncomfortable making eye contact. They may be impatient or angry and finish the sentence for the person whether correctly or not. They might feel sorry for the person and use a patronizing tone. All reactions are equally harmful for the self-esteem of someone with a brain injury.

When a person has a brain injury, communication can be more difficult. Here are some general tips to help with communication.

1. Get their attention. Don't start talking until you are sure that they hear you.
2. Make sure they are comfortable.
3. Speak clearly and directly.
4. Slow things down. Pause often. Give them time to process.
5. Turn down background noise and remove distractions.
6. Stay on one topic at a time.
7. Give them time to respond.
8. Include them.
9. Write down key words from your discussions to help them remember ideas later.
10. Remember that a brain injured person is often keenly aware of and sensitive to being patronized. Avoid 'talking down' to the individual.

For more tips on how to help the person's communication, click here to review the handout by Sheila MacDonald, SLP, called Adaptive Communication.



Knowing What to Say

Knowing what not to say to a person with a brain injury is just as important as knowing what to say.

Understand the invisible signs - A person with a brain injury often suffers from hidden signs such as fatigue, depression or being emotionally flat. Statements such as "You look fine to me." are minimizing their injury and are not helpful.
Realize that if the person is slower at processing, speaking, or doing, it's a problem with efficiency not intelligence. Give them the time they need.
Validate the struggle by saying such things as: "That must be hard.", "I can't imagine.", or" How do you deal with that?" **rather than diminishing, discounting or devaluing statements such as:** "You look fine to me", "I have memory problems too.", or "I lose my keys all the time."
Help them get started on tasks. Lack of initiation or social engagement is common after brain injury. The person may need you to give them a nudge or help them initiate. A person may have trouble knowing where or how to start or summoning the energy to begin so try not to perceive a lack of activity as a lack of desire or suggest that they are not trying hard enough.
Recognize that brain injury fatigue is real It is not helpful to suggest that they try to "push on through" and statements such as "well I get tired too" or blaming it on aging minimizes the impact the fatigue has on the person
Remain patient when they're not. Irritability is a common sign of a brain injury, and it can come and go without reason. There is nothing to be gained by pointing out their grumpiness.

Rather than complaining about having to repeat yourself or becoming frustrated which only emphasizes the issue, try to understand the need for repetition. Almost everyone who suffers a brain injury will experience some memory and processing problems. Try to build in some repetition by saying things in different ways or writing it down. When you repeat, use a natural voice. We call it '**respectful repetition.'**
Emphasize positive behaviours rather than negative ones and avoid bringing up past errors or negative behaviours.
Talk about feelings openly. Provide them time and space to express feelings and accept the feelings they express without discounting them. Ask the person how they are feeling. If they express anger, ask how you might address their concerns. **Don't assume that everything is because of the brain injury.** People may have a valid reason to disagree or express something beyond the brain injury
Learn about how to provide feedback in a direct, constructive, respectful, and understanding way. Try not to engage in corrective feedback, testing questions or patronizing feedback. Therapists or the brain injury association may have helpful resources on this.

Offer specific ways you can help

For many reasons (e.g. fatigue, processing), it can be difficult for a person to make decisions or answer questions. For example, it might be difficult for them to come up with a list of ideas in response to a question such as, "How can I help?" Instead, think of a list of specific things that they might need help with and let them pick something. For example:

- Can I cut your grass for you?
- Can I make a meal for you?
- Can I bring your parents somewhere?
- I am going to take your dog for a walk in the morning because I pass right by your house. Is that OK?

It can help to write out a list and have them check off a list of what would be helpful or who is doing what.

Helping to Manage Healthcare Appointments

When you meet with the person's health provider you will likely have many questions. Do not be afraid to ask. We recommend you take a list of questions with you and a notepad to write the answers. We have included some common questions people might ask below. You will want to shape these to your personal experience. In the Practical Resources section in the back of this book, there are helpful forms to use to keep track of each appointment including what was said and follow ups.

Questions for attending doctors

- Can you provide a list of the physical injuries?
- Will they have problems thinking or remembering?
- Will they develop headaches from this injury?
- Tell us which conditions are likely to be short term and which are long term.
- What community resources should they be connecting with?

Questions for family physicians

- They are experiencing these symptoms. Is there anything that can be done to mitigate symptoms?
- How often should they be seeing you to check in?
- They are connecting with these community resources. Are there any others that you know of?
    - e.g. Therapists (occupational therapy, speech-language therapy, counselling)
- How can you best help them in their rehabilitation?
- Are there other therapists who should be involved in their rehab?
- Please tell us about your experience with brain injury.
- Are there other health professionals we should consult with?

Documentation

Managing health records

As noted in Section 5, keeping track of medical records is important for many reasons, especially to receive medical care and benefits to which the individual is entitled (click here to access information on keeping track of your medical records). It is also very important for the person and/or their primary caregiver to have a notebook or other record keeping system to record and keep track of medical visits. This can include medical history to convey to the attending health care professional, any questions to ask of them, concerns you may have, and detailed notes of what was said to you.

Visitor's guestbook

It can be very helpful have a visitor's notebook on hand in the person's hospital room or home. The person's visitors can record in the notebook when they visited along with any messages or pertinent comments. This is not only a useful record but one the person may long appreciate. Says one person who experienced brain injury, "I still have my visitor's book from 40 years ago and it means a lot to me!"



Journal for self-reflection

Another notebook, or part of the same one you are using for records of medical care, could be for the person's self reflection about how they feel about what's happening to them, what they remember or can't remember and anything relevant to the challenges they are now facing. Occasionally, this might include even a rant or two to dissipate some of the anger they may be feeling.

Click here to access the templates we have included for these notebooks.

Interaction notes for visitors and/or new caregivers

Family and caregivers will become able to teach visitors and others how best to interact with the person with the brain injury. Having a notebook with guidance notes for this task would also be helpful. Therapists may help families to build the guidance notes.

Community resources and support groups

In many geographic areas there is a strong brain injury community with organizations providing brain injury services. Some of the services that may be provided include:



The Ontario Brain Injury Association (OBIA) offers information and support for any person in Ontario, Canada with a brain injury and their support network. They offer:

- Online concussion support group
- Online caregiver support group
- Peer support program
- Helpline

There are 21 local associations across the province that are part of the OBIA network that offer primarily support group type activities. Finding your local association is a good place to start, get to know other individuals with brain injury and how they are coping and what some of the successful community integrations have been. For a list of local Brain Injury Associations, click here. No one knows what you are going through like another person who has experienced a brain injury.

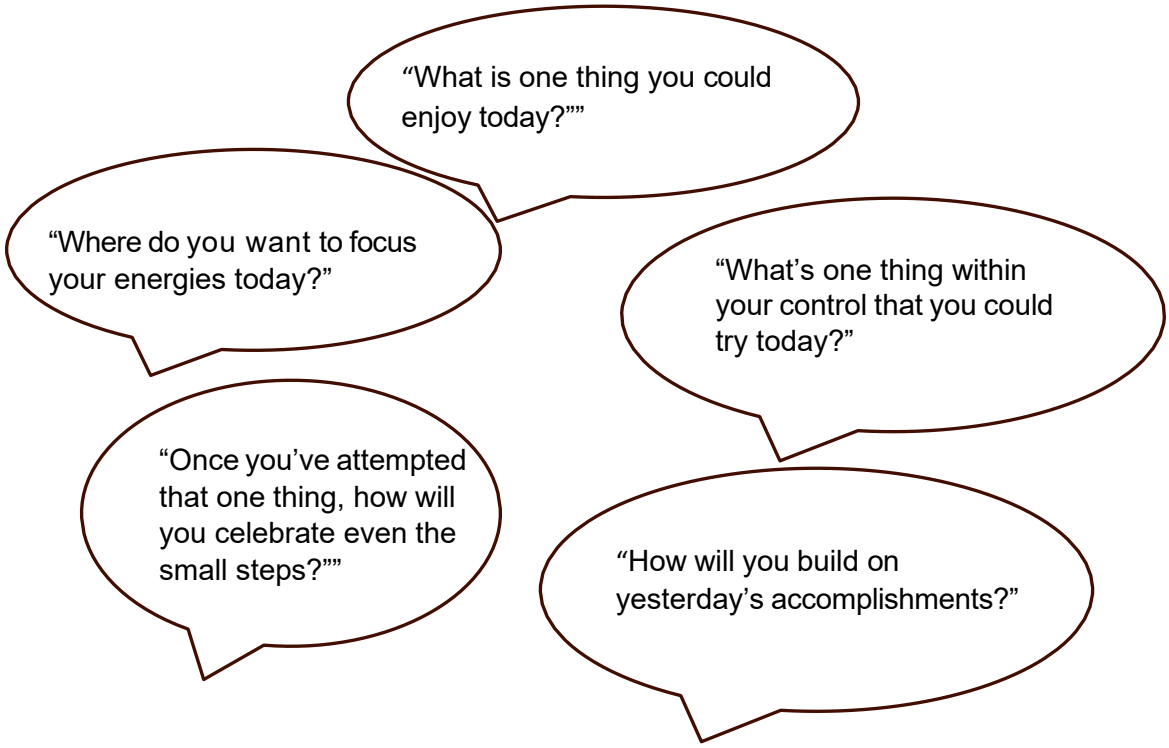
Right-sizing expectations

One of the most important aspects of coping with a brain injury is the adjustment of expectations from the person's, family's and caregivers' perspective. Life looks and feels different right now. It will take time to adjust to your new situation and plan next steps. Give yourself and your loved ones time.

The guidance of health professionals such as occupational therapists, speech language pathologists, rehabilitation specialists and physiotherapists, is extremely important. Their main role is to help the injured person with tools and direction to adapt their life structure and activities to cope with their brain injury and function the best they can. One person living with the effects of a brain injury says,

It may be hard for people with a brain injury to make adaptations because at times they feel completely normal. They may expect they can function as before. On the other hand, comparison with pre-injury self is understandable but can be discouraging. After a brain injury, the person will need more time. Support them through challenging, overwhelming or stressful situations that are hard to avoid.

A helpful practice to keep in mind is to plan for each day and identify the most important thing to do or consider. As the caregiver, you may ask your loved one (or they may ask themselves),



Everyone is learning as the person with a brain injury adapts to their new situation. The person is exploring their new abilities. Consider that the person with a brain injury has a different perception than the caregiver. They may be only recently "waking up" to their new reality. They are in a different place of acceptance than their loved ones. Please give them time to emotionally catch up. Family members are learning from the health care team and trying to teach others in the family as well as friends and visitors. Be kind to each other and be as patient with yourself as you would with anyone in a learning situation!

Specific Communications for Supporting the Three Broad Levels of Brain Injury Cognitive Functioning

1. Minimal consciousness

A person at this stage may have limited awareness of their surroundings or of what has happened. Here are some helpful communication tips for individuals in this state:

- It is very important to communicate with them in your usual conversational manner.
- Assume they are understanding you even if it does not appear so or if they are not able yet to respond or communicate.
- Provide and advocate for intervention for your loved one at this point
- Provide continual orientation constantly by telling them what has happened, where they are, when it is, and what help is being provided.
- Speak in slow, short phrases, with repetition, and with one person speaking at a time.
- Avoid speaking in a young child-like manner or speaking more loudly as this could seem to be patronizing or startling.

2. Fully conscious, but confused

An individual in this state may be confused about their surroundings and may show signs of agitation. They may also be overwhelmed by stimuli (noise, sights, touch) resulting in the brain being "overloaded" and the individual not being able to handle it. In this state, they are not "acting out" or "being rude." Agitation is a common brain injury symptom that involves saying or doing things before thinking. The person has cognitive or thinking problems due to the brain injury. It is a cognitive problem not a behaviour problem.

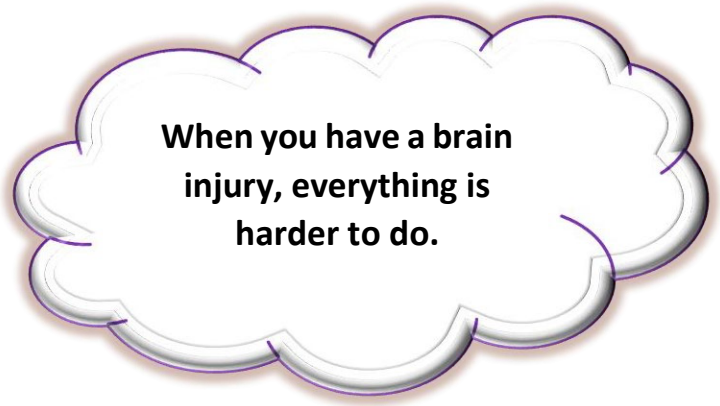
When the person is in a confused state, accept what they say and gently redirect or orient them.
Communicate in a calm and respectful manner so as not to aggravate the condition.
During confusion, provide structure and direction.
Give advanced cues of what is happening and what will happen next.
Reduce your messages to short direct statements and avoid complex sentences.
Provide a lot of reassurance.
Observe and **take some notes** so you can notice small improvements over time. Talk to your healthcare team about what you might include in your notes.
Questions that you will typically hear the doctor ask such as "Where are you? What month is it? etc. are called orientation questions. The health team needs to ask them to measure progress but do not ask them yourself. Your role is to provide comfort and conversation. We call these "testing questions". No one likes to be tested all the time.
Instead of asking testing questions, try to tell the information in conversational ways throughout your visits without correcting or belittling the individual. Eg. "Well, here we are at XX hospital. It's cold outside for May."



There are many things you can do as a conversation partner to help your loved one's cognitive or thinking skills. Your speech-language pathologist can give you some ideas. There are also many ways you can add structure and routine to support thinking skills, and your occupational therapist can give you some ideas. Talk to your team. They will be an excellent resource.

3. Not Confused but Managing Limitations

At this stage the person may exhibit cognitive, communication, emotional or physical difficulties. They may have difficulties with concentration, memory, or expression. Each person will have their own pattern of strengths and weaknesses. The symptoms may be more apparent when the person is overwhelmed, tired or when the situation is complex or new.



Communication is often affected by cognitive challenges making it difficult to understand, discuss, read, write, or socialize. Breaks or frequent rest periods may be required. Encourage your loved one to pace themselves throughout the day. There is more information on pacing above in the general brain injury tips section.

There is a great deal that friends and family need to learn to be the most helpful to a loved one with a brain injury. As a caregiver you will be called on to provide support, structure, pacing, encouragement and hope. Your loved one may pick up on your exhaustion and may feel some guilt about this. Therefore, it's important for everyone that you seek support for yourself also.

Take Time for Yourself

Caregiving is a huge responsibility and those attending must be sure to take care of themselves as well. It can be easy to ignore your own fatigue and frustration while you're caring for someone with a brain injury. Taking time for yourself, calling on the help of others, joining a caregiver support group – are all ways that can help you to not become physically and emotionally exhausted. Above all, be kind to yourself and give yourself credit for all that you do.



Close family members may experience high levels of stress or even anxiety or depression during the years following a brain injury. As time elapses, there may be reduced capacity for coping, particularly with emotional and behavioural problems. Seek professional help from a counselor such as a psychologist, social worker or psychotherapist when needed. Family members need to be prepared for these changes and have a strategy to help all involved, including themselves when challenges happen. This can be a huge load both on everyone in the family and the support team and you may need professional help in forming a strategy to successfully manage these challenges.

The Mayo Clinic Foundation for Medical Education and Research has many helpful tips for caregivers. Please click here for this information caregiver tips .

Section 7

Managing Transitions and Life Changes

It's important to be aware that transitions can be a challenge. For example, communications among your team members or service providers may be dropped at times of transition. One service or provider may not be aware of what another service or provider is doing. Also, you may find that one service ends with a gap before another begins or services may be dropped altogether. You may find that your services are accidentally duplicated. Planning ahead at times of transition can really help. We will summarize some examples of transitions and provide 10 steps to help.

Types of transitions

Medical Transitions - discharge planning, discharge home from hospital or rehabilitation center, move to a new treatment centre, new doctor or therapist, re-injury, medication changes

School and Work Transitions - planning for return to school and work, planning for new school or new job

Social Transitions - move to new home or community, moving from supported living to independent living, travel, events that change routines

Aging - aging, retirement, and situations requiring more support

Challenges with transitions

- Difficulties with returning to work after a brain injury can cause considerable emotional and financial stress.

- You might find that while you are unable to return to

- paid work, you want to engage in other meaningful activities.

- Some people find it helpful to get involved in community activities. Volunteering might provide an opportunity to work at your own pace and get used to a structure or routine that works for you. Click here for information about reconnection with the community in the section on Building Your Team.

- You may have to make changes in your daily routines, work, hobbies, recreation, or social pursuits. All of this change can lead to stress and frustration. To help with this stress you may want to communicate with a counselor or someone else on your team. Some people find it helpful to make a list of coping or resilience strategies that work for them (e.g. humour, physical activity, helping others, meditation, walks in nature etc.).

Ten steps to help manage transitions

1. Ask a close person to be present in all discussions.

2. Take notes or have someone take notes.

3. Provide everyone with the same information.

4. Always leave a discussion with a summary of next steps or action plan.

5. Convey to your team “nothing about me without me - involve me in all discussions and decisions.”

6. Plan ahead for changes in your team or support system.

7. Prepare summaries of your history, current services, and current needs that you can give to any new service provider (click here to access this section)

8. Take up to date health documentation with you to an appointment.

9. Recognize that transitions can be tiring. Plan for more rest.

10. New things and non-routine things such as transitions can present cognitive and emotional stressors. Talk it over with your support person(s) and have a plan in place. Plans and routines reduce stress.

Section 8

Insurance, Legal, and Financial Issues

Overview

- An acquired brain injury can be a life altering event.
- The changes in your life are often extremely difficult to process and will likely affect everyone close to you. Some changes might be long term. You may have needs that you only recognize over time. It's important to plan for the long term.
- The costs associated with managing such an injury can be staggering.
- At this time, you may not be able to work or earn an income and that creates financial stress for you and your family.
- It's very difficult to understand how to access funding for rehabilitation and income.
- It is difficult to imagine how much money rehabilitation and support services cost throughout your recovery.
- Beware of funding sources that want to minimize the amount of funding required.
- **NEVER** sign for a cash settlement without having a lawyer and support people to advocate for you.
- It's important for you to learn your rights and learn about this system over time.
- No matter which funding system you need it will be complicated and time consuming.
- Find your support systems to help you through it.
- This guide will provide you with an overview, but we strongly recommend you seek legal and financial support.

What does Rehabilitation Cost?

Publicly funded: Some rehabilitation is paid for by the government. This is called publicly funded and usually includes services like physiotherapy at a hospital. The services that are publicly funded vary from hospital to hospital and region to region. These services are offered for people who meet very specific criteria and for a finite period of time.

Privately funded: Once the publicly funded services run out, you need to be able to access privately funded services that cost money each time you use them. Most services you need after an acquired brain injury are privately funded. Usually, you access these privately funded services once you leave the hospital. The good news is clinicians who work in private practice are often specialized and may be knowledgeable about brain injury. The bad news is you will have to find money to pay for them. You may also need to pay for transportation or travel costs for them to come to you. What are the sources of funding for these private rehabilitation services?

Sources of Funding for Rehabilitation and Income

- **Auto Insurance** - If you were injured in or by a motor vehicle collision, you will likely be eligible to receive rehabilitation funding and/or income replacement benefits from the auto insurer. There's a complex process for this. It begins with one of your health practitioners filling out a form to say that you have an injury and needs for rehabilitation. Next you meet with an insurance adjuster and sign more forms to allow them access to all your records. Then the practitioner you want to go to has to submit a treatment plan or an estimate of the services you need and the amount of money it will cost. Speak to your health practitioner about whether they are set up to bill directly to auto insurers. Ask them for help with this process. You should also ask a lawyer for help in advocating for funding from your auto insurer. Meet with a personal injury lawyer. This is covered in more detail further in this section.

- **Extended Health Insurers** - Some people have insurance policies, usually through their work, or their spouse's work, that will pay for some health services like dental, hearing (audiology), vision (optometry), physiotherapy etc. Check with your employer and/or your family member to find out if you have any coverage and what the limitations are. This is a good time to pull out the insurance policies to read which services are covered and what the maximum coverage is for each. Note that for some insurers, you need a doctor's note to activate this funding. Some services may not be covered by your policy (e.g. speech-language therapy; occupational therapy). Sometimes policies require the health practitioner to have certain qualifications or training. It's common for policies to cover a small amount of each service (e.g. physiotherapy, speech therapy) that may run out after 1-2 sessions. The insurer may only cover a certain percent (e.g. 80%) of the cost up until a maximum value. Many health practitioners are not able to bill the extended health insurer directly. So, you may be required to pay up front and then submit receipts for reimbursement. This can be a time-consuming administrative task. Start a folder and save all your receipts. Ask someone to help you with this task.

Income replacement benefit - If you have an LTD (Long Term Disability) policy, be sure to check and see what percentage of your salary it covers, whether or not there are cost of living increases or if the amount will be fixed for the duration of your coverage. An important thing to ask your lawyer, is whether or not you qualify for coverage under CPP Disability. If you do, this means your private insurer will deduct this amount from their payment to you, and you will receive income from two sources, but it is important if you are unable to return to work. Because if you qualify for CPP Disability your pension will not be affected due to the fact that you stopped contributing prior to age 65.

~ Jackie Cribb, ABISS Member

Disability Insurers - Some employers pay for insurance policies for their staff to cover them if they acquire a disability. These policies may provide short term or long-term disability benefits while you are unable to work. The amount of benefit and the length of time they assist you depends on your policy. The criteria for you to qualify for these benefits will also vary. Usually if you are injured and have a disability, you contact the insurer, and they assign you to one of their staff. This person will ask you many questions about your condition and all the recommendations of your health practitioners. It's crucial to save all the reports and recommendations in one place. For more information on this, click here.

Workplace Safety Insurance Board (WSIB) - Employers and the Government in Canada provide a system of supporting workers who are injured on the job. In Ontario this is called WSIB. The employer pays to be part of the WSIB system to ensure coverage for their workers. Also, the employer and workers must meet safety standards. In return the employer is guaranteed not to be sued if an injury happens on the job. This means if you were injured on the job, you need to contact your employer (supervisor, human resources department, union) to ask how to start a WSIB claim. Do this as soon as possible. WSIB sends out their own team to assess you and decide which rehabilitation and support services will be paid for. Some will have expertise with brain injury, and some won't. If you were injured in an automobile while working, it would be helpful to talk to a personal injury lawyer to determine whether you fall within the WSIB or auto insurance system.

Why do you need a lawyer?

- Most funding systems today are complicated and become adversarial.
- A lawyer is there to support you and advocate for you and your needs.
- There may be complexities you aren't aware of. For example, there are multiple forms. There are firm deadlines by which to file a claim, and you don't want to miss them. Also, sometimes one insured person must sue another person's insurance to get the funds needed for rehabilitation.
- Even though, initially, interactions with your insurance company may be going smoothly, you may encounter problems down the road.

Factors to consider when looking for a lawyer

- The type of law they practice, for example, you will likely want a personal injury lawyer as they often deal with motor vehicle accident claims.
- Location – someone practicing in your province will be most beneficial as they'll know the pertinent and relevant laws.
- Knowledge of brain injury.
- No up-front fees until settlement.
- Dedicated staff who can assist with auto insurance claims or WSIB.
- Some personal injury law firms provide accident benefits support processing services in addition to personal injury law. This can be very helpful and take the burden of having to submit all the expenses etc. yourself, so you may want to consider this.
- Experienced team with track record of winning cases.
- Involvement in local brain injury association.
- Willing to give you accommodations based on your brain injury (write things down, staff who explain things, allow you to have a support person in meetings, provide you with extra time, limit meetings to a length you can tolerate, aid comprehension, consider your time, availability, and provide you with notice ahead of time).
- Transportation considerations - if you can't drive, will they come to you, meet with you virtually or provide a taxi etc.).
- Fee structure – on retainer, or by-hour, or by service.

Timelines for Legal and Insurance Claims

- This can take a long time (often several years) and you have to pace yourself for the long haul.
- Taking a long time might be a good thing (to be thorough, evaluate your future needs, etc.).
- Find ways to keep on living meaningfully as you await legal/insurance/funding decisions. You may need to temper expectations and recognize it may take a while. Keep your routines. Plan some fun times or times with less pressure with friends and family members. Laughter will be needed!! If necessary, see a financial advisor to bridge you over the waiting period which will likely be longer than you might expect.
- You may find it helpful to watch our ABISS movie *Adding Insult to Injury* to hear the experiences of our members who've gone through this process.

The costs associated with managing such a life-altering event can be immense. Choosing an experienced, knowledgeable, and trusted personal injury lawyer to help you access the benefits and recover the damages that you deserve, will be on of the most important decisions that you make.

Section 9

Resources and Interactive Materials

INTERACTIVE MATERIAL #1: MEDICAL INFORMATION SUMMARY SHEET

Name:	
Date of Birth:	Health Card Number:

Emergency Contact:

Name: _____

Relationship: _____

Contact Information:

_____

_____

_____

_____

INTERACTIVE MATERIALS #1

Summary of Medical Information (e.g. medical diagnoses, assessments, treatments, etc.)

INTERACTIVE MATERIALS #1

Doctors to be contacted/consulted in an emergency

Doctor's Name:
Specialty:
Contact Information:

Doctor's Name:
Specialty:
Contact Information:

Doctor's Name:
Specialty:
Contact Information:

INTERACTIVE MATERIAL #2: ACCOMMODATIONS LIST AND PREFERRED METHOD OF COMMUNICATION SHEET

ACCOMODATIONS LIST (This is what I need to succeed)

- ☐ A Quiet/Silent Space
- ☐ Extra Time
- ☐ Printed Instructions
- ☐ Verbal Instructions
- ☐ Fragrance Free Environment
- ☐ Physically Accessible _____
- ☐ Large Print
- ☐ **Bold Print**
- ☐ Specific Font
- ☐ Better Lighting
- ☐ Low Lighting
- ☐ Preferably NO Fluorescent Lighting
- ☐ Lack of Visual Distractions
- ☐ Having an Advocate/Support Person
- ☐ White Noise
- ☐ Timing of Appointment to Mitigate Fatigue
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

PREFERRED METHOD OF COMMUNICATION

- ☐ Handwritten on a card or piece of paper
- ☐ Email
- ☐ Text
- ☐ Phone
- ☐ Phone Message
- ☐ Through Another Person: _____
- ☐ Reminder of Appointments and Preferred Method of Reminder

  _____

INTERACTIVE MATERIAL #3: MY HEALTHCARE TEAM INFORMATION

(Doctors, Nurses, Rehab Specialists, Rehab Therapists…)

Name:
Specialty:
Address:
Phone:
Fax:
Email:
Reason for seeing them:

Name:
Specialty:
Address:
Phone:
Fax:
Email:
Reason for seeing them:

Name:
Specialty:
Address:
Phone:
Fax:
Email:
Reason for seeing them:

INTERACTIVE MATERIAL #3

Name:
Specialty:
Address:
Phone:
Fax:
Email:
Reason for seeing them:

Name:
Specialty:
Address:
Phone:
Fax:
Email:
Reason for seeing them:

Name:
Specialty:
Address:
Phone:
Fax:
Email:
Reason for seeing them:

INTERACTIVE MATERIAL #4: MEDICATIONS AND SURGERIES

MEDICATIONS:

MEDICATION	DOSE/FREQUENCY	REASON FOR MEDICATION

SURGERY SUMMARY:
Date:
Doctor:
Location:
Phone:
Procedure/What was surgery for:
Other Notes:

INTERACTIVE MATERIAL #4

SURGERY SUMMARY:
Date:
Doctor:
Location:
Phone:
Procedure/What was surgery for:
Other Notes:

SURGERY SUMMARY:
Date:
Doctor:
Location:
Phone:
Procedure/What was surgery for:
Other Notes:

SURGERY SUMMARY:
Date:
Doctor:
Location:
Phone:
Procedure/What was surgery for:
Other Notes:

INTERACTIVE MATERIAL #5: DOCTOR'S APPOINTMENT PLANNING SHEETS

Doctor's Name:	Date of appointment:
Doctor's Specialty:	Time of appointment:
Doctor's Address:	
Doctor's Phone:	Email:
Fax:	
Preferred Method of Communication:	

What do I need to bring to the appointment?

- ☐ Homework/Accountability chart from last appointment
- ☐ Images
- ☐ Reports
- ☐ Change of clothes
- ☐ Running shoes
- ☐ Water
- ☐ Another person (advocate, note taker)
- ☐ Other: _____

What am I seeing this doctor for?

_____

_____

Questions I would like to ask/discuss with doctor:

_____

_____

_____

_____

_____

What would I like to discuss/work on today?

_____

_____

_____

INTERACTIVE MATERIALS #5

What did we discuss?

_____
_____
_____
_____
_____
_____
_____

What is the plan moving forward? (Referrals, Tests, Homework for me)

_____
_____
_____
_____
_____
_____
_____

What follow up work/homework/to do list do I need to complete before the next appointment?

_____
_____
_____
_____
_____
_____
_____

How did I feel physically/mentally (cognitive fatigue)/emotionally after the appointment?

_____
_____
_____
_____
_____

INTERACTIVE MATERIALS #5

Did I feel heard during this appointment? Do I feel satisfied with the plan moving forward?

DATE AND TIME OF NEXT APPOINTMENT

INTERACTIVE MATERIALS #6: THERAPIST APPOINTMENT PLANNING SHEETS

Therapist's Name:	Date of appointment:
Therapist's Specialty:	Time of appointment:
Therapist's Address:	
Therapist's Phone:	Email:
Fax:	
Preferred Method of Communication:	

What do I need to bring to the appointment?

- ☐ Identification (e.g. **health card**, driver's license, photo ID)
- ☐ Another person (advocate, note taker)
- ☐ Homework/Accountability chart from last appointment
- ☐ Images
- ☐ Reports or Referral letters
- ☐ Change of clothes
- ☐ Running shoes
- ☐ Water
- ☐ Other:

_____

What am I seeing this therapist for?

_____

_____

_____

Questions I would like to ask/discuss with therapist:

_____

_____

_____

_____

_____

_____

INTERACTIVE MATERIALS #6

What would I like to discuss/work on today?

What did we discuss?

INTERACTIVE MATERIALS #6

What is the plan moving forward? (Referrals, Tests, Homework for me, ….)

What follow up work/homework/to do list do I need to complete before the next appointment?

How did I feel physically/mentally (cognitive fatigue)/emotionally after the appointment?

INTERACTIVE MATERIALS #6

Did I feel heard during this appointment? Do I feel satisfied with the plan moving forward?

DATE AND TIME OF NEXT APPOINTMENT

INTERACTIVE MATERIALS #7: ACTIVITY/FEEDBACK CHART

Plan For: _____(Doctor or Therapists Name)

What is the plan? What do I have to do each day?

	MON	TUES	WED	THURS	FRI	SAT	SUN
Activity							
Completed?							
Pain Level 1 - 10							
Fatigue 1 – 10							
Success 1 - 10							
Something Positive							

INTERACTIVE MATERIALS #8: MY OWN THOUGHTS ABOUT WHAT IS HAPPENING TO ME

Below are a few prompts to get you started. Feel free to add your own. After all, this page is called "My Thoughts"!

How am I feeling about my workload for rehab?

Is my rehab exhilarating me/frustrating me/exhausting me/other?

What are my feelings about my rehab plan(s)?

Do I feel listened to/heard by the members of my team (this can be about specific or more general)

Do I feel completely/somewhat/not at all overwhelmed?

Do I have someone that I feel I can talk to about my concerns/feelings? Do I want to have someone to talk to about my concerns/feelings?

Do I feel like something is still missing?

Is there another goal that I have that I would like to talk about?

INTERACTIVE MATERIALS #8

INTERACTIVE MATERIALS #9: AFFIRMATIONS

Some people find it helpful to think about the positives or positive changes they've noted. Read the ideas below and choose one if it's applicable to you. This is different for everyone! You might prefer to find your own positive affirmation.

I'm really doing a great job with…

_____

Something I remembered that surprised me.

_____

I'm proud of myself for..

I'm grateful for…

I've seen progress in…

_____

I'm trying hard with…

I talked to someone who was friendly today

_____

I saw this beautiful…

_____

ABISS Personal Guide to Navigating Brain Injury

A Survivor-Centred Resource for Recovery, Support, and Advocacy

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Section 1: About Us – Acquired Brain Injury Survivor Solutions (ABISS)

About ABISS

Acquired Brain Injury Survivor Solutions (ABISS) started as a supportive community for individuals living with brain injuries. It offered a space to develop social and communication skills within a group setting. Despite differences in age, background, or type of injury, members found common ground in their experiences post-injury. This sense of community became a foundation for advocacy, with ABISS dedicating years to addressing injustices, particularly in the insurance industry. Learn more about our initiatives at www.abiss.ca.

About this Guide and Who it's For

We continue to support fellow survivors and have created this guide for those newly facing brain injury, as well as their caregivers. Written by people WITH brain injuries FOR people with brain injuries, this guide shares perspectives based on lived experience. It is not a substitute for professional guidance.

The recovery process can feel overwhelming for survivors and loved ones alike. This guide offers strategies for coping, tools to manage health information, and resources to help you advocate for a coordinated rehabilitation approach. Our aim is to provide clarity and organization during what can feel like a chaotic time.

This resource is intended for both survivors and their care teams, covering diverse topics and practical advice. It is a supplement to, not a replacement for, professional medical care.

About the Authors

The authors are primarily traumatic brain injury survivors, including those injured in car accidents, falls, or other incidents. However, the guide is relevant for anyone with an acquired brain injury (ABI)—that is, any brain injury acquired after birth.

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Click here to read our stories

Section 2: How to Use this Guide

This guide provides information and resources to help you advocate for your recovery. It is not therapy or a basis for healthcare decisions, but a starting point for your journey. If you have questions or concerns, consult your healthcare or support team. We hope the content offers reassurance and clarity. You are not alone.

We designed this book for survivors and caregivers—make it your own. Everyone's experience is unique. Adapt the guide to suit your needs. Some people are early in their injury, while others have been living with it for years. Challenges may be physical, cognitive, communication-based, emotional, or any combination. The impact of brain injury varies widely.

If you do not recognize your own difficulties, your family or support people may find the guide useful. Personalize your use of this resource. Read the sections most relevant to you, in any order. The guide is for general support; if any information raises concerns, please speak with your healthcare providers or a counsellor.

Section 3: About Brain Injury

Understanding Brain Injury

The term "head injury" is now replaced by "brain injury" to better describe changes in brain function. A brain injury can occur without a direct blow to the head, loss of consciousness, or visible symptoms. Brain function can be disrupted by visible damage (bleeding, fractures) or invisible changes (chemistry, blood flow, or neural connections).

What is a Brain Injury?

A brain injury is any disruption in brain function due to injury inside the skull. Causes, onset, and severity vary. Brain difficulties can occur before birth, during birth, or after birth. This guide focuses on "Acquired Brain Injuries" (ABIs): injuries that happen after birth and are non-progressive (improvements are possible over time).

Causes of Acquired Brain Injury (ABI)

- Traumatic Brain Injury (TBI): Caused by force to the head or body, not always from a direct hit. Examples include sports injuries, vehicle collisions, falls, assaults.
- Stroke: Occurs when blood flow to the brain is blocked or a vessel bursts.
- Infection: Brain infections such as Lyme disease, encephalitis, or meningitis can disrupt function.
- Lack of Oxygen: Causes include heart attack, blood loss, near drowning, or poisoning.
- Electrocution: Rare but possible through electrical injuries or lightning.
- Seizures: Severe seizures or epilepsy can lead to brain injury.
- Brain Tumour: Both benign and malignant tumours can affect brain function.

Severity of Brain Injury

Brain injuries are classified as mild, moderate, or severe. The Glasgow Coma Scale (GCS) is often used initially, but it is not a predictor of long-term outcome.

- Mild (GCS 13–15): Includes concussions; most recover but some experience lasting difficulties.
- Moderate (GCS 9–12): An initial measure, not a predictor of long-term recovery. Ongoing assessment is key.
- Severe (GCS 8 or below): May result in coma or minimally responsive states.

Three Broad Levels of Brain Injury Cognitive Functioning

- Minimally conscious: Limited awareness, possible “disorders of consciousness.”
- Fully conscious but confused: May be disoriented, agitated, or have memory issues.
- Not confused but managing limitations: May have subtle or prolonged difficulties with concentration, memory, or complex tasks.

Initial severity may differ from long-term experience—“mild” may not feel mild.

Stages of Recovery

Recovery involves physical, cognitive, communication, and emotional aspects, which may progress at different rates. The Rancho Levels of Cognitive Recovery describe common stages, but each journey is unique.

Recovery can continue for years. Neuroplasticity—the brain’s ability to reorganize itself—means improvements are possible long after injury. Maintaining hope is important.

How It Might Feel to Be the Person with a Brain Injury

Early on, survivors may not realize the extent of their difficulties. Awareness grows during the return to daily activities. Becoming aware can lead to feelings of discouragement, fear, or overwhelm. Support from counsellors and family is helpful. Brain injury impacts families and support networks too.

Tips from Survivors

- Recognize that things have changed—be patient with yourself.
- Take one day at a time; focus on one priority.
- Improvements may be gradual; notice small steps forward.
- Pacing is key—alternate activity and rest to manage fatigue.
- Remember: every reaction is normal. Advocate, adapt, and seek support as needed.

Section 4: About You – Your Recovery and Your Support

Every person and every brain injury is unique. Your needs will depend on factors like time since injury and severity. This section addresses common issues and ways you might handle them during recovery.

Family members and therapists may help with self-care, household tasks, driving, social activities, mobility, communication, community involvement, work or school planning, and management of information.

Key truths about you and your brain injury:

- Adapting to life after brain injury is difficult; seek help from professionals and loved ones.
- Your brain injury may affect your relationships.
- Brain injury impacts families, not just individuals.
- Family members have their own challenges too.
- Some challenges may be long-term; pace yourself and get support.
- Overcoming brain injury challenges can bring unexpected rewards.

Pacing and Adjusting for Fatigue

Fatigue—physical, cognitive, or emotional—is common after brain injury. “Pacing” means balancing activity with regular rest breaks, even if you feel okay. Use reminders or technology to structure your day. Pacing helps prevent cognitive problems and emotional outbursts.

Allow yourself space to rest, especially during gatherings or events. Communicate your needs with loved ones. A list of pacing strategies can help others support you.

Section 5: Building Your Team, Advocating for Your Needs, and Managing Your Health Records

Building Your Team

A brain injury team includes medical, rehabilitation, and legal professionals. You are at the centre of your team—family, friends, and advocates are important members. The team should collaborate and coordinate care.

You may need to advocate for yourself as you assemble your team. Choose team members who fit your needs, as you’ll spend significant time with them during your recovery.

Choosing a Team

- Consider physical, cognitive, communication, and emotional needs.
- Listen to your healthcare team and yourself as you progress.
- If available, a case manager with brain injury expertise is helpful.

Potential Team Members and Their Roles

Team Member	What They Do
Occupational Therapy	Helps with daily life activities and independence.
Physical Therapy (Physiotherapy)	Improves movement, balance, and physical activity.
Speech Language Pathology	Addresses communication and thinking skills.
Vision Therapy/Optometry	Assesses and treats vision and brain coordination.
Social Worker	Provides counselling and discharge planning.
Psychology/Neuropsychology	Assesses and supports emotional and cognitive needs.
Physiatrist	Medical doctor specializing in rehabilitation.
Neurologist	Medical doctor diagnosing brain and nervous system issues.
Psychiatrist	Diagnoses and treats mental health conditions.
Audiologist	Manages hearing and balance disorders.
Rehabilitation Support Worker	Implements recommendations from health professionals.

Choosing the Best Fit

- Being Heard: Your concerns should be listened to and addressed.
- Rapport: Positive relationships with your team support recovery.
- Ask Questions: You have a right to ask about qualifications, coverage, and approach.

Communication, Collaboration, and Coordination

Effective communication is essential for team success. Each member brings unique skills to address challenges. Over time, your needs and team will change as you move from hospital to home to community.

Advocacy is important—communicate your needs and make changes when necessary. Use accommodations and strategies to support yourself and share them with your team.

Managing Your Health Records

Keep copies of all health documents: medication lists, scans, reports, referrals, and assessments. Don't rely solely on healthcare providers to store your information. Organize your records in a file or digitally for easy access, especially for appointments, insurance, or legal actions.

- Ask for records at the time of service (hospital, labs, imaging, doctor's office).
- Store records safely at home (paper or digital copies).
- Take relevant records to appointments and assessments.

Section 6: Caregiver Tips and Tools

Supporting someone with a brain injury is demanding and can affect caregivers' well-being. This section provides guidance and tools for caregivers, recognizing the balance between supporting the injured person and caring for oneself.

Providing In-Hospital Support

Have comforting items available, such as lotion or music. Touch and familiar sounds can be soothing.

Providing Structure

Consistency and routine help the person with a brain injury. Develop a flexible schedule with activity and rest, adjusting as needs change.

Educating Yourself

Learn about your loved one's condition and the recovery process. Involvement during rehabilitation helps you support successful strategies at home.

Engaging the Person

Involve the person in activities they enjoyed before, adapting as needed. Introduce new activities gradually, considering their tolerance and preferences. Plan ahead for the demands of each activity.

Communication Support

- Get their attention before speaking.
- Speak clearly and directly; pause often and allow time to process.
- Limit distractions and background noise.
- Stay on one topic at a time; write key words as reminders.
- Avoid patronizing language.

Know what to say and what not to say—validate their struggles and avoid minimizing comments. Offer specific help rather than general offers, and provide written lists when possible.

Managing Healthcare Appointments

Prepare questions for appointments and take notes. Keep a notebook for medical visits, questions, and follow-ups. A visitor's guestbook can help track visits and provide encouragement.

A journal for self-reflection can help the person process their feelings. Caregivers may also create notes to guide other visitors' interactions.

Community Resources and Support Groups

Many regions have brain injury associations and support groups. Connecting with others who have similar experiences can be invaluable.

Right-Sizing Expectations

Adjust expectations as life changes. Give yourself and your loved one time to adapt. Health professionals can provide tools to help with these adjustments. Plan each day around one main priority.

Recognize that the survivor and caregiver may be at different stages of acceptance. Be patient and kind to yourself and your family.

Supporting Different Levels of Cognitive Functioning

- Minimal consciousness: Communicate respectfully, provide orientation, and avoid patronizing language.
- Fully conscious but confused: Accept statements, redirect gently, provide structure, avoid testing questions, and offer reassurance.
- Not confused but managing limitations: Encourage pacing, support communication, and seek support for yourself as a caregiver.

Self-Care for Caregivers

Take time for yourself and seek support when needed. Caregiving can be stressful and may impact your own health. Don’t hesitate to ask for help or join a support group.

Section 7: Managing Transitions and Life Changes
Understanding Transitions

Transitions—such as moving between care settings, returning to work or school, or changes in social routines—can be challenging. Communication among team members may be disrupted, and services may be duplicated or dropped.

Plan ahead for transitions. Types of transitions include medical (hospital discharge, new therapies), school or work changes, social moves, and aging.

Challenges with Transitions

Returning to work can be stressful. Some may find meaning in community activities or volunteering. Change may require new routines and support from counsellors or team members.

Ten Steps to Manage Transitions

1. Have a close person present for all discussions.
2. Take notes during meetings.
3. Share information with all involved.
4. Summarize next steps after each discussion.
5. Insist on involvement in all decisions—“nothing about me without me.”
6. Plan ahead for changes in your team or support system.
7. Prepare summaries of your history and current services for new providers.
8. Bring up-to-date health documentation to appointments.
9. Build in extra rest during transitions.
10. Recognize that change can be stressful; create routines to reduce stress.

Section 8: Insurance, Legal, and Financial Issues Overview

An acquired brain injury can bring life-altering changes, affecting survivors and their families. The costs of recovery can be significant, and it may be hard to access funding. Always seek legal advice before signing any settlement. Learning about your rights and support systems is important.

Rehabilitation Costs

- Publicly funded: Some services are covered by government funding, usually for a limited time and for those who meet specific criteria.
- Privately funded: Most services needed after hospital discharge require private payment. Specialized clinicians may be available, but costs vary, and you may need to pay for transportation.

Sources of Funding

- Auto Insurance: Funding may be available for those injured in vehicle accidents. The process involves numerous forms and approvals. A lawyer can help you navigate this system.
- Extended Health Insurers: Employer or family health plans may cover some services. Read your policy for details and keep all receipts for reimbursement.
- Disability Insurers: Some employers provide short- or long-term disability coverage for injured employees. Save all documentation for your claim.
- Workplace Safety Insurance Board (WSIB): If injured at work, contact your employer to start a claim. WSIB will assess your needs and recommend or pay for services.

Why You Need a Lawyer

- Legal and insurance systems are complex and can become adversarial.
- Deadlines and forms are important—do not miss them.
- A lawyer advocates for your needs and helps coordinate claims.
- Choose a lawyer with relevant experience, knowledge of brain injury, and the ability to accommodate your needs.

Timelines for Legal and Insurance Claims

Claims often take years to resolve. Find ways to maintain quality of life during the process. Keep routines and plan enjoyable activities to manage stress.

Section 9: Practical Resources – Interactive Materials

Medical Information Summary Sheet

A template to help you organize your diagnoses, assessments, treatments, and contacts for emergency situations.

Doctor's Name:
Specialty:
Contact Information:

(Repeat as needed for all emergency contacts.)

Accommodations List and Preferred Method of Communication

A checklist for communicating your needs and preferences, such as quiet spaces, extra time, accessible formats, and preferred communication methods (e.g., email, text, through another person).

My Healthcare Team Information

A template for recording names, specialties, contact details, and reasons for seeing each member of your healthcare team.

Medications and Surgeries

Medication	Dose/Frequency	Reason for Medication