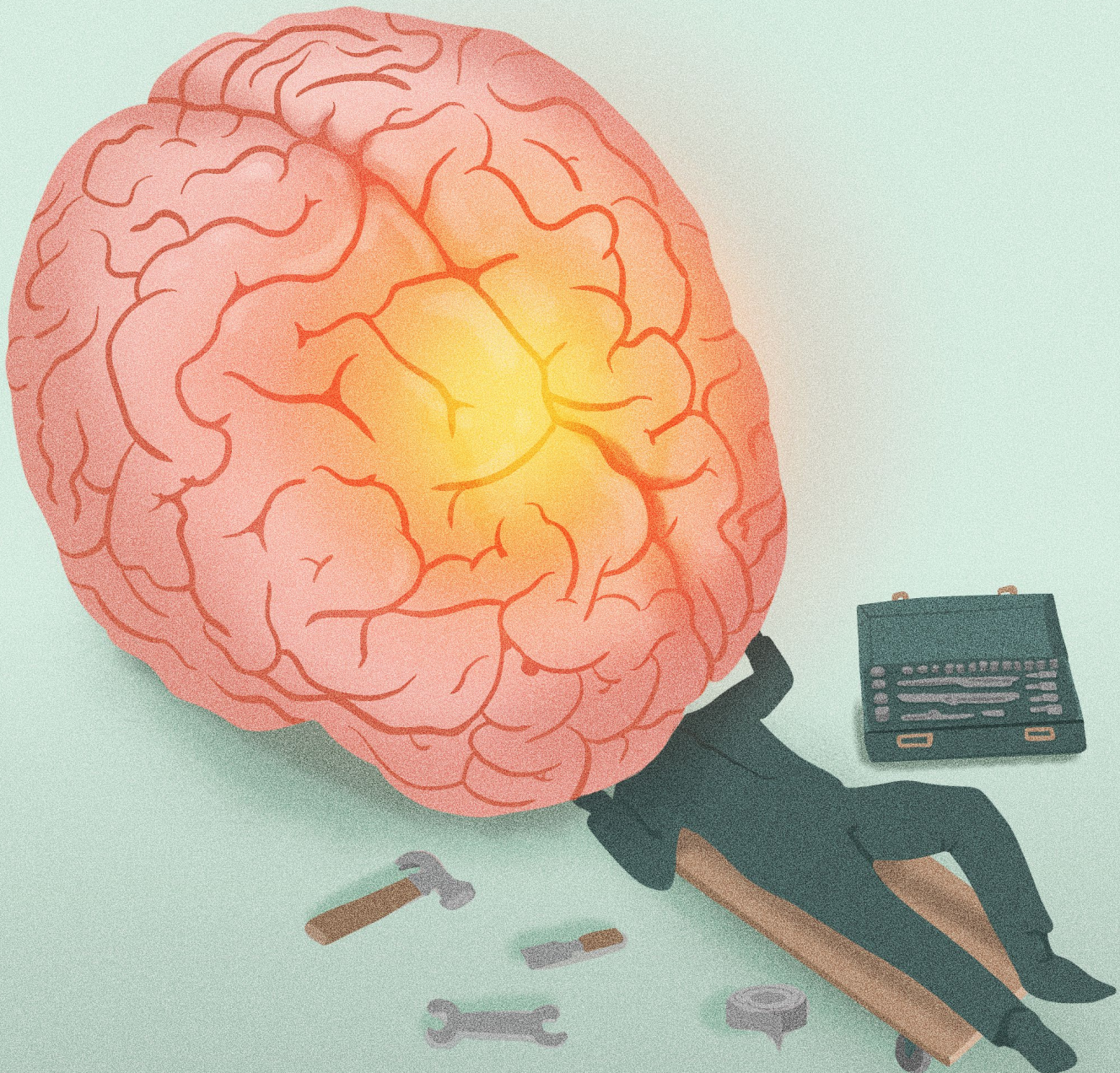


TOOLS AND STRATEGIES FOR DAILY LIVING WITH TRAUMATIC BRAIN INJURY

Traumatic brain injury resources for Veterans and Families



This resource was prepared by the Atlas Institute for Veterans and Families. Atlas would like to thank the following individuals for their contributions to the resource. Please note the names listed include only those who have explicitly consented to being acknowledged as a contributor.

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The purpose of this resource is to provide Veterans and Families with **practical strategies and tips to improve functioning and well-being while living with a traumatic brain injury (TBI)**. This resource includes communication strategies, information about how TBI impacts daily living, strategies and “tools for the toolbox” for daily living and information on self-care.

In addition to being informed by research, this resource was co-developed with an advisory committee comprised of Canadian Armed Forces (CAF) and Royal Canadian Mounted Police (RCMP) Veterans and Veteran Family members. We thank these advisory members for sharing their time and expertise to co-create these resources.

RECOGNIZING THE **IMPACT** OF TBI ON DAY-TO-DAY LIVING

TBI can impact many areas of life and well-being. However, there is no one specific way to experience a TBI or its impact on your life. And while the person with the TBI experiences the symptoms of that injury, the Family can also be affected by the life changes TBI can bring. It's important to recognize the impact on both the Veteran and the Family so that everyone can find strategies to be well, both on their own and together.



Impact on the person with TBI

- Experiencing **exhaustion and fatigue** which can come after engaging in daily life or working on a task or activity for several hours in a row. Without breaks or naps, you can feel more exhausted.
 - **Cognitive difficulties** such as memory loss, brain fog, speech difficulties and confusion.
-
- Frequent/regular **emotional struggles** such as being triggered by events or situations that would not usually bother you or experiencing anxiety or depression.
 - **Forgetting** dates, appointments, tasks or personal items and **feeling frustrated** that it feels harder to remember than before the injury.
-
- **Memory struggles** might even mean having no recollection of what happened that caused a brain injury. This might make it harder to talk about the experience and to feel understood by others.
 - **Balance and mobility issues** in daily life that make it harder to move and use your body as you did in the past. You may feel that you can't participate in all the activities and hobbies that you want to.

- You may feel **disconnected from your partner** due to the injury. The disconnect can come from several things: the injury itself, the symptoms you experience, changes in your mental, emotional or physical state, difficulties talking about your experiences or exhaustion from the injury while navigating services and treatments.
- Feeling easily frustrated when **routines get off-track**.

- **Not feeling like yourself** after the injury. This can stem from the symptoms and the changes to life after a TBI.
- Noticing that **alcohol has more of an impact** on you. It may take more time to feel like yourself after consuming alcohol or you might find that alcohol makes your symptoms worse.



Impact on the Family

Family members can be impacted when a Veteran they care about has a TBI. The Family members that interact with the Veteran on a regular basis may feel that life and the way the Family functions together has changed. TBIs can affect the whole Family – although one person is injured, each member of the Family can be impacted by the life changes after a TBI.

The following are some of the ways Family can experience this impact:

- Family members might experience **burnout and exhaustion** from taking on more tasks to help the Veteran with the TBI. Burnout is often the result of regular exposure to stressful and emotionally challenging situations. People experiencing burnout may be unable to take time to look after their own needs and may gradually begin to feel worn out.



Impact on the Family (continued)

- You may feel that you need to take on a **caregiver or “fixer” role** instead of being an individual and loved one of a Veteran.
 - Many Family members feel **frustrated or fatigued** from providing care or support to their loved one.
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- **Compassion fatigue** can be experienced by Family members who spend time caring for or supporting a Veteran with a TBI. Compassion fatigue can be experienced by anyone who is a caregiver to a person with a chronic illness. It also impacts many people in helping professions (such as nurses, doctors and social workers) who are repeatedly exposed to traumatic situations¹. Symptoms of compassion fatigue can include emotional disconnect, numbness and irritability among others².
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- Family members might feel that they **have no time for the things they enjoy** in life and **miss out on social support** from loved ones, as it may be harder to attend social events in the same way after a TBI.
 - They may also feel **helpless or hopeless** at times if they do not have the tools, resources or support to care for themselves and their loved ones.

HOW TO COMMUNICATE WITH SOMEONE WITH A TBI

When communicating with others, most people want to feel heard and understood, but some aspects of life with a TBI can make this more difficult. Awareness and understanding of the challenges in communication is one part of improving communication. Another part is having strategies to navigate the challenges.

Keep in mind that the severity of a TBI (mild, moderate or severe) may impact the way a person experiences some of these challenges, if at all. For example, a person with a mild TBI may have trouble finding the right word to use while a person with a more severe injury may have slurred speech.



Potential communication challenges

Speech difficulties

A person with a TBI may have trouble saying certain words, finding the word that they want or may have slurred speech which can be affected by stress levels. This can make it hard for them to feel understood by others.

Barriers to being heard

Difficulties with speech can be frustrating for a person with a TBI. They may feel that they have to repeat themselves—, which can make them feel that they aren't being heard.

Forgetfulness

A person with a TBI may not remember what they wanted to talk about or what was said earlier in the conversation. They may have difficulties with recalling words and phrases.

Difficulties with being interrupted

It can be challenging for a person with a TBI to be interrupted. The interruption may cause them to lose their train of thought and they may then find it difficult to recall. Sudden interruptions can also be hard to process.

Having trouble with loud or overstimulating environments

A person with a TBI may find it challenging to process information in loud or noisy environments, which can make it difficult to have conversations in public.



Tips to improve communication

For everyone

- **Being present and listening** can be a powerful source of comfort. Paying attention and listening to others can be especially helpful if they are struggling and find it difficult to communicate.
- **Regular communication** can be helpful for “staying on the same page.” You can also try repeating what you heard to ensure you are understanding the other person.
- **Try taking a step back from a conversation** and revisit it at another time if you are feeling overwhelmed. Sometimes a problem can’t be solved in the moment and stepping away can give you the time and space to self-regulate and breathe.
- **It is important to hear the other person’s perspective** to gain insight into their experience and the impact of what they are feeling. Don’t assume you know how they feel or what they might be struggling with.

For Veterans

- It may be good to **talk openly with Family members** about any difficulties you may have with speech and forgetfulness so they can provide support and understanding. Both the person with the TBI and the Family members need support to communicate well with each other.
- Creating a **safe and supportive space** for your Family to express their emotions and fears is important. If you aren’t sure what that means, try asking your Family members what makes them feel heard and cared for.

For Families

- **Family members may need their own support system** in order to be and feel well. This can mean getting support from a friend, a counsellor or a peer supporter or getting involved with community.
- **Focus on one topic at a time** when communicating with others.— Be concise and clear and try not overwhelm the listener with unnecessary details. Take your time and speak slowly — receiving information too quickly can make it difficult for a person with a TBI to process and can be overwhelming. Pauses are helpful for processing information.
- Hold your thought until there is an **appropriate opportunity for you to speak**, instead of interrupting the person with the TBI.
- Find ways to accept that a **person with a TBI may need to say what's on their mind** right when they are thinking it, otherwise they may not be able to recall their thought later.

I want us to feel comfortable expressing our thoughts and feelings to each other.

What do you need from me to feel supported?





How to talk about the impacts of TBI

You may find that at times you need to speak with your loved one about how a TBI is impacting your life as a Veteran or Family member. You may want to talk about how TBI symptoms affect your day-to-day life, explore solutions together or discuss some other aspect of your experience.

Here are a few tips for sharing those experiences and asking for what you need:

1 Explain how you are affected.

What is happening in your life that you want to discuss? You might start by sharing that you've noticed a symptom come up in daily life, such as difficulties completing day-to-day tasks or remembering appointments or that you're feeling overwhelmed or fatigued. It can be helpful to share how you are affected by this: Does it impact you physically, mentally, emotionally? For example:



"I noticed that when I'm feeling tired, it's harder to remember the next task I need to do. It makes me feel frustrated and angry with myself."

2 Ask for what you need.

What do you think might help reduce the negative impact of this experience? Do you need your partner or Family to listen and support you or are you looking for solutions or outside help? If you know what you need, ask for it. If you are unsure, it's okay to ask for help from a loved one to figure out what you need. For example:



"I'm not sure what I can do to remember my tasks. Can you help me find a solution?"

3 Look for solutions together.

Working as a team can help you determine which strategies are most helpful for everyone involved as you try to solve a problem. It can make it more effective for everyone to be mindful of their own and others' capacity. For example:



"Sure, I can help with that. Let's try writing down the tasks for the day on a whiteboard beside your desk."



"I'm not in a good place to help you with that today. I do want to help, but I need some time to care for myself first. Can we schedule some time later this week to discuss and work on a strategy together?"

STRATEGIES FOR DAY-TO-DAY LIVING

TBI symptoms can impact many areas of functioning and can affect your daily life. The following are some practical tips to help you manage the day-to-day.

Not all of these strategies will apply to you — pick the ones that you can use. If something is missing, see if you can join forces with your loved ones or health care providers to come up with something that works for you.



Things to keep in mind

- **There is no perfect strategy** — you may need to try different things to see what works. A strategy that is good for someone else may not work the same for you.
- **Strategies may not all be useful right now, but they could help later or in specific situation.** They can be "tools for the toolbox" that you take out as needed.
- **Think about the problems you encounter the most.** What strategies would help you with the most challenging parts of your life or your daily frustrations?
- **Recognize your own capacity and when to ask for outside help,** which is important for both the Veteran and the Family. Remember that it's okay to ask for help.

Strategies for Veterans



Routine

Having a consistent routine can be helpful for the day-to-day as it can provide a sense of control and stability.



Get help with appointments

It may help to have someone assist you with creating memory aids or calendars to keep track of appointments. A Family member may be willing to help you create a system for scheduling appointments if they have the capacity to do so.



Bubble packs

Bubble or blister packs for medications can help you keep track of when you've taken your medication. Ask your health care provider or prescriber to recommend that your medication be dispensed or provided in blister packs.



Calming activities

You can help reduce your stress and anxiety by engaging in calming, relaxing activities such as using a meditation app, reading a book or magazine, breathing exercises, practising yoga or getting a massage. Reducing stress is important for people with a TBI as stress can exacerbate symptoms.



Accommodations

Make use of the accommodations that are available to you – if you don't know what accommodations you can access, ask. You might benefit from accommodations at work, school, at appointments or while accessing treatment or health care. There are also many informational resources available to help Veterans with TBIs, such as this one.



Whiteboards

Whiteboards are another tool to manage appointments and tasks. Try putting all the appointments for the week on a large whiteboard in a central location in the home. Whiteboards can be especially helpful for Veterans to organize thoughts, information or to-do lists. They are a great alternative to technology and apps.



Balance activities

To have a productive day, some individuals with TBI may need to balance their activities for the day. You may need to limit the amount of physical exertion each day and use services to help with tiring tasks. For example, if you often feel fatigued after getting groceries, you could try ordering home delivery for groceries.



Take breaks

Taking breaks may actually help you be more productive. Instead of powering through activities, try to do things one at a time with frequent breaks to rest and take care of yourself. Pacing yourself and monitoring your energy levels can help you enjoy more of your daily activities because you won't feel as exhausted.



Exercise

Exercise can aid recovery and improve overall well-being. It can be as simple as going for a walk, practising yoga or any activity that gets the heart rate up. Make sure that you are doing physical activity in line with your health care provider's treatment plan.



Write it down

Try writing your thoughts down if you are feeling overwhelmed. You could also use lists – this might mean to-do lists, grocery lists, a list of upcoming appointments, a list of symptoms that you want to speak with your doctor about or a list of activities that help you feel well. It can be easier to make sense of your thoughts if you see them written down.



Reminders

Reminders on your phone or calendar can be useful tools in organizing and managing your life. You might use reminders for appointments, setting a timer for the laundry or to help maintain a routine.



Calendars

Many Veterans with TBI find it helpful to have calendars in visible areas, like a fridge or desk – some even have multiple calendars. You can use calendars to keep track of important events and appointments.



Peer support

If you're triggered, fatigued or overwhelmed, sometimes expressing that to a peer and getting their perspective can be helpful. Hearing a peer's perspective can help with understanding an experience or finding a solution. It's beneficial to have support during difficult times – "Don't go for a walk in your own mind by yourself."



Strategies for Families



Practise regulating your emotions

Frustrating situations can come up at any time, so it can be helpful to regularly practise emotion regulation strategies like pausing, deep breathing and positive self-talk to help you navigate difficult moments. Positive self-talk can mean speaking to yourself with the kindness, consideration and compassion you'd give loved one or friend.



Set boundaries

Get to know your limits so that you can set and enforce boundaries. What can you help with and when is it too much? A boundary is about your own limits – it's up to you to recognize when you have reached them.



Talk about your role

Determine what level of support you can offer, if at all. Family members are often assumed to be caregivers but you may not have the capacity or comfort to take on that role. Would you prefer to be a supporter or to connect your loved one with services?



Don't forget yourself

Your experience matters too and so does your life. What can you do for yourself today? How can you make yourself a priority in your schedule and routine?



Self-care

Make time for yourself and your wellness; you can't pour from an empty cup, and your own health is dependent on having enough time to rest and care for yourself. Experiment with taking care of yourself first before taking care of the needs of others – you matter.



Peer support

Get support for yourself, especially from other Families who understand what it's like to care for and support a loved one with TBI. You are not alone in your experiences and it can help to share similar stories with others. Learn more about peer support and browse the directory of services on the Atlas Institute website: atlasveterans.ca/peer-support



Maintain a life beyond the injury

Make time for your hobbies, activities and your own friends and support system. At times it may feel that the TBI is all-consuming. To maintain your wellness, it's important to have other things to focus on, especially ones that bring you joy. **It's not selfish** – it's necessary for you to be well and to have the energy to support your loved one.





Strategies for working with health care providers

- The health care provider likely has not walked in your shoes, so they may not understand everything about your experience.
- **Self-advocacy** may be a part of your journey. You may have to ask your health care provider to look into your TBI symptoms more or seek a second opinion. “No” is not necessarily the last answer — keep going and don’t be afraid to ask for support.
- It can be helpful to **write down the questions you want to ask** and the information you want to share.
- It’s okay to **ask for written information and handouts**, as well as appointment reminders. Ask your health care provider to summarize key points of your discussion at the end of your appointment.



WHAT STRATEGIES WORK FOR YOU?

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