# **Traumatic Brain Injury:** Educational Materials For Family & Friends





#### **IMPORTANT:**

If your loved one that sustained the traumatic brain injury (TBI) is experiencing a medical emergency, please call 911 on their behalf or have them present to the nearest emergency room for evaluation and treatment.

It is important for them to go to the nearest emergency room if the following conditions are present:

- ANY period of loss of consciousness
- Unable to wake them up
- Experiencing double vision or loss of sight
- A weakness or burning in their arms or legs
- A severe headache or one that progressively gets worse

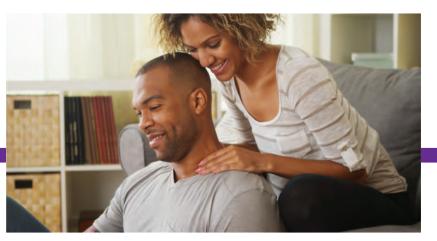
- Any kind of seizure or convulsion
- Bad nausea or excessive vomiting
- Unsteadiness while they are walking or standing
- Any bruising around their eyes or ears
- Slurred speech
- If they become confused or exhibit odd behavior



## **Caring For Your Loved One**

We realize that the traumatic brain injury doesn't affect just your loved one, but it impacts your entire family. It may cause you to question why your loved one is acting differently, exhibiting extreme emotional swings, or feeling depressed. It is important for you to understand that each person's brain is unique – just as each traumatic incident that causes the injury can be different. The effects of the TBI may be temporary for some, while others can be long-term or even permanent. We have created this educational guide to help you better understand your loved one's injuries and how you can be supportive of them through the recovery process.

Please understand that it may be difficult for the patient to clearly express or put into words what they are experiencing. This is not an injury like a broken bone that will show up on an X-ray. TBIs are different as we can't see the actual injury unless there was a brain bleed that was detected through imaging or some other diagnostic device. With a broken bone, we know we either reset the bone and cast it, or some surgical procedure is performed to repair and stabilize the fracture. The guidelines and treatment protocols are pretty clear for those types of injuries. But with a TBI, there is no real timeline or formula for recovery as each person is uniquely affected by the trauma. Also, with a fracture, the patient doesn't normally have emotional outbursts, mood swings, states of depression, memory challenges, or episodes of confusion or disorientation.





## Don't Go It Alone

Another word of advice about you trying to be the only caregiver to your loved one: please don't try to go it alone as is this a recipe for burnout. This state of utter exhaustion can be physical, mental and emotional. It can also affect the attitude you might have towards the patient. If you have already experienced this frustration, please know it happens. And it doesn't mean you are a bad person. This is only natural as you have a lot of worries:

- Will they recover?
- How long will it take for them to recover?
- What are the lasting physical effects from the TBI?
- What are the lasting financial effects?
- Will this be the "new normal?"





## Do Not Be Afraid To Ask For Help

We feel it is so important to enlist the help of family and friends. There is no shame in asking for help. This will allow you to take a break and recharge yourself so you can offer even better care to the patient. Make sure you are getting enough sleep. Watch what you are eating and take breaks. If you are struggling emotionally with all of this, find a therapist or support group to help support you through the process.

Do not take the behavior of the patient personally. Sometimes normal activities may cause an exaggerated reaction from them. For example, you click the remote to the television and it turns on with the sound blaring. You quickly try to turn down the volume but you fumble with the remote and it takes a few seconds to find the button and lower the sound. But they scream at you – not because you did something terrible, but the loud noise triggered something in their brain that was painful or made them panic which led to their exaggerated response towards you. These outbursts can and will happen. This lack of emotional control is difficult for them to understand and accept as well. If you have children that may be affected by these outbursts, it might help to have them sit down with you or a professional to help explain that their family member's brain is not like it was before and it needs to heal and have time to "calm down."







### IMPORTANT ADVICE ABOUT MEDICAL APPOINTMENTS AND YOUR CONVERSATIONS WITH THEIR TREATING DOCTORS

At the beginning, you can help play an integral part in keeping track of all medical appointments for testing, treatment, and therapy. Some people with TBIs can do more than others at the beginning, but it is best to err on the safe side and help coordinate the family calendar. It can be very helpful for you – and the patient – to write down ALL medical appointments as well as other family events on a shared desk or wall calendar so you AND the patient can see it. This better helps the family plan the schedule, and the patient is not "surprised" with appointments. Discuss the calendar events the night before, as well as in the morning to cover all activities.

Just as the patient needs help in calendaring activities, they may also need extra assistance while attending medical appointments. It is important for you to let the patient talk to the doctor and answer the questions as best they can. Encourage them to be honest with their assessment of how they are doing, and to be as descriptive as possible when telling the doctor their symptoms. Here is a sample conversation you can have with them before the visits:

- If you feel you are getting better, be as specific as possible in letting your doctors know in what ways you are improving, but also let them know the areas where you still have residual symptoms.
- The same is true if you feel your condition is NOT improving. Don't sugar coat it.
- Don't consider it whining or complaining. When you tell the doctors with as much specificity as possible how you are feeling and in what ways you are still hurting, this will better help the doctor help you. Your doctor can decide what additional tests may need to be ordered. They may need to add/modify prescriptions. The doctor may need to cut back on the frequency or the intensity of your therapy or exercise program. In some situations, there may need to be referrals to specialists for more evaluations.
- Start from the top of your head and go to the tip of your toes and let them know about all of your injuries/symptoms. Don't be tough guy/tough girl. Help the doctors help you!

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## **Other Ways You Can Help**



If there are things you feel you need to discuss with the doctor outside of the presence of the patient, then as discreetly as possible, let one of the nurses or the doctor know before the appointment. Sometimes the patient does believe they are doing better than they actually are. They may not want to admit to forgetting things, or the fact that they are struggling with the injuries and have to take frequent naps.

It may also be helpful for you to attend therapy sessions. When they are prescribed home exercises, you can be there to record the specifics and frequency of the exercise so you can supervise/direct at home. You will also be able to keep track of the next scheduled appointments so you can put it on the shared calendar.

Please understand that there may be times when it is not in the best interests of the patient for you to be present. This is not an effort to exclude you, but there may be a need to conduct an assessment or complete an element of patient care without interruptions. Sometimes this is done to more effectively promote your family member's return to being as independent as possible. We have found that a lot of people actually make more progress in therapy when their family members or friends are not present and watching them.

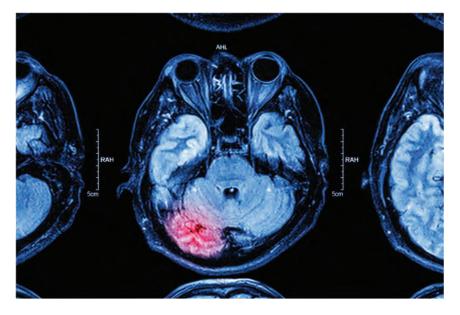


# What is a Concussion?

It is important for you to understand the nature and severity of the injury your loved one has sustained. And before discussing WHAT a concussion is, it is important to know WHAT the brain does so you can learn how an injury to it can be serious and life threatening. The brain barely weighs three pounds within our skull, but it is the control center for our bodies. It performs the following functions:

- it regulates and controls our physical movements;
- it is responsible for the regulation of blood pressure, our heart rate, our breathing, and even our body temperature;
- it interprets our senses and the appropriate responses;
- it is the computer that handles our ability to think, to act or react, to feel, and to communicate with others.

A <u>concussion</u> is a mild, traumatic brain injury (TBI). We know it is not "mild" when your loved one is the actual person that sustained the injury. It is usually caused by a bump, blow, or jolt to the head that disrupts the normal function of the brain. These TBIs can rage from "mild" (a brief change in mental status or consciousness) to "severe" (an extended period of unconsciousness or memory loss after the injury).



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## What are the symptoms of a concussion?



- Loss of consciousness
- Headache
- Confusion
- Irritability
- Dizziness
- Blurred vision
- Ringing in the ears
- Nausea
- Vomiting
- Slurred speech
- Fatigue
- Appearing dazed
- Fogginess
- Temporary loss of bowel or bladder control as their overall awareness may be diminished



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## **Delayed symptoms could include:**



- Memory problems
- Difficulty in concentration
- Sleep impairment
- Problem with the senses, such as difficulty tasting or smelling, or a sensitivity to light
- Balance issues
- Changes in moods
- Crying and emotional swings
- An inability to monitor their behavior or act/react in a socially acceptable manner
- Agitation
- Restlessness
- An inability to control their impulses
- Seizures

Some of these symptoms may appear right away. Others may not be noticed for days or months after the injury, or until the person resumes their everyday life. Sometimes, people do not recognize or admit that they are having problems. Others may not understand their problems and how the symptoms they are experiencing impact their daily activities. The signs and symptoms of a concussion can be difficult to sort out. Early on, problems may be overlooked by the person with the concussion, family members, or doctors. People may look fine even though they are acting or feeling differently.

It is important to note that a brain injury can be sustained without a penetration or fracturing of the skull. Also, a brain injury can occur WITHOUT loss of consciousness. The damage to the brain happens on a <u>cellular level</u>, so CT or MRI scans may not detect the injury. The injury may be to a specific area of the brain (FOCAL), or brain cells in multiple areas of the brain are affected (DIFFUSE). A patient might even have both a focal and a diffuse injury to the brain.



## There are reasons why you should be concerned about your loved one's concussion

Traumatic brain injuries can be serious – especially when they are undiagnosed and not treated in a timely fashion. In fact, evidence shows that a Traumatic Brain Injury (TBI) actually reduces life expectancy and results in an increase in long term mortality. Further, a study of over 350,000 veterans revealed that the risk of developing dementia after sustaining even a "mild" TBI without loss of consciousness, is more than double that of individuals who have never suffered a TBI.

According to the Center for Disease Control (CDC), traumatic brain injuries are a major cause of death and disability in the United States. For example, in 2014, an average of 155 people died each day from injuries that include a TBI. (Centers for Disease Control and Prevention (2019). Surveillance Report of Traumatic Brain Injury-related Emergency Department Visits, Hospitalizations, and Deaths—United States, 2014. Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.)

## **DEMENTIA RISK = 2x**



## "It Depends..."

When we are asked if your family member will get better, our only honest answer is "it depends." The long-term effects from a TBI can be difficult to predict, especially at the early stages after the injuries. We do know that the most rapid improvement your family member will experience normally occurs in the first few months after the injury (with the majority occurring within one year from the date of injury). Please know - there will be good days and there will be difficult ones. It can be frustrating for the patient and their family when progress is slow or appears not to be happening. There are a variety of factors that can slow or impede recovery, including:

- the patient's overall health BEFORE the injury
- their individual personality
- their emotional functioning BEFORE the injury
- their intellectual level
- the availability and involvement of family/friends

Our treatment plan is designed to help assess the severity of the TBI, as well as to offer a treatment plan which will support them in their recovery.





## Your loved one has been diagnosed with a traumatic brain injury. What next?



THINGS TO DO:

- **REST:** Get plenty of rest. They are to avoid any kind of strenuous activity and are to practice LOW ENERGY output.
- **SLEEP:** Make sure they get a good night's sleep. They can take naps throughout the day, if necessary. It is important for them to get at least 8 hours of sleep each night. The darker the room, the better sleep they should get.
- **DIET:** Proper diet and nutrition will play an important role in their recovery. We will provide you with more details on this.
- **HYDRATE:** Make sure they drink lots of water! Approximately 60% of our body is made up of water. The brain and heart are 73% water. If they are dehydrated, it can cause many problems including headaches, organ issues, joint problems, and much more. The better their hydration, the more their body can flush out the harmful toxins that have accumulated in their brain since the injury.
- **UNPLUG:** Help them fight the urge to go online and look at their smart phone, iPad, laptop, or computer screen. Also, make sure they put down the video games. It is best they take a break from looking at a computer screen or monitor or television.
- **FOLLOW:** Help them to follow the directions that they are given so they can be the compliant patient.

**DO NOT DO EVERYTHING FOR THEM!** This is tough, especially when you may see them struggles with small tasks. But sometimes this struggle may be the key to their actual recovery. They may need to do these things that can be difficult to help train their brain to work on problem solving. They may be slow to answer a question. Resist the urge to jump in and answer. They may have problems ordering something off of a menu. Don't order for them – just be there to support them.



## Things to avoid:

- Avoid any kind of high risk activity that might result in another traumatic brain injury! This is so important as a second TBI on top of one that has not fully healed can be extremely dangerous!
  Second Impact Syndrome (SIS) occurs when two traumatic brain injuries (concussions) happen in a relatively short period of time AND the second concussion is inflicted <u>BEFORE</u> the first one has fully healed. This can cause rapid and severe swelling, and the brain may lose its ability to self-regulate pressure and blood volume. As the brain swells, it can press against the skull resulting in decreased blood flow. When the blood flow is disrupted, it can cause severe disability or even death.
- Avoid the use of alcohol.
- Avoid the use of caffeine. Sometimes patients will want to use caffeine to eliminate their cognitive fatigue or "brain fog" that often comes with a TBI. Caffeine in small amounts may be safe after a TBI, but excessive caffeine consumption could slow down their recovery process. It is important to understand that caffeine is a vaso-constrictor, which means it constricts the blood vessels in the brain reducing blood flow. Without enough cerebral blood flow, the brain cannot get the vital nutrients it needs to repair itself.
- Avoid the use of stimulants or energy drinks.
- Avoid junk food. Instead, consume healthy, energy rich foods. These include blueberries, bananas, broccoli, fatty fish, and nuts.
- Avoid stressful circumstances and over-stimulation of the mind.

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# Things to avoid:

- Avoid being on the computer or smart phone.
- Avoid prolonged conversations on the phone.
- Avoid being on social media sites.
- Avoid the use of sugar, carbohydrates and dairy products. At a minimum, help them reduce their intake.
- Avoid the use of Ibuprofen or Tylenol unless recommended by a doctor familiar with the patient's condition.
- DO NOT let them play sports before a full recovery, or exercise unless it has been approved by their treating physician.
- DO NOT let them drive unless it has been approved by their treating physician. This is especially important if they have been prescribed any medication.
- If possible, they should take some time off of work or study until they feel better.
- Some of their symptoms may come and go throughout their recovery. Unless they are in the DANGER category, they can expect to have some good days and bad days. Most people will take several weeks before they feel back to "normal." However, their return to "normal" activities may cause their symptoms to return. Please don't let them overdo it and they should notify their treating physician regarding their condition and any recurring symptoms.



## Dietary Recommendations:



Diet can play an important role in the healing process for their TBI. What the patient puts into their body will not only affect their health, but it can be an integral party of minimizing their symptoms and facilitating a quicker recovery. We have created these post-TBI recommendations to help you understand more about what their body needs, and what they should avoid. Please understand: healthy eating will not make their TBI symptoms go away, but it will give the injured brain a better shot at recovery and will provide it with the fuel it needs to function as best it can.

Their brain has some important nutritional requirements that must be met:

- Water
- Protein
- Lipids (fats)
- · Carbohydrates
- Vitamins and minerals
- · And sodium.

Their body will benefit from proper nutrition as they should experience an increase in their energy levels, their mood should improve, and they should reap short and long term health gains.



# The following will provide you more information on each of these nutritional requirements.





#### Water:

This is the MOST important recommendation. It is easy to get dehydrated, especially in warm temperatures. Water helps the body digest foods and absorb other nutrients. Consuming water will also help the body to regulate its temperature better and increase circulation.

How do you calculate the amount of water their body needs?

Take their body weight. Divide by 2.

That is the approximate total of how much water they need to drink each day. But keep in mind, if your family lives in warmer temperatures and in an environment where it is natural to sweat more, you will need to increase their water consumption.

For example:	Body Weight:	160 pounds	
	Divide by 2		
	Their goal:	80 ounces of water	
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Now if the patient has pre-existing medical conditions, you should check with their health care provider and ask what they would recommend the daily water intake should be. Some of our patients may need to drink less water throughout the day.

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#### **Protein:**

Protein will help them maintain their muscle mass, their strength, and it will help them have a "fuller" feeling in their stomach. Some of the best sources of protein are meat, fish, eggs, beans, nuts and seeds. These protein sources will provide the brain with the essential amino acids it needs for proper functioning.

Meats could include:

Chicken Turkey Lean beef Fish

Other beneficial proteins include:

Eggs Greek Yogurt Cottage Cheese Almonds Oats Lentils Chickpeas



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If they are a vegan, it is so important to make sure they get enough protein from nuts and legumes. If you are cooking and serving them meat, be careful with your preparation. Avoid fried foods.





### Lipids:

These are HEALTHY fats that the body needs. Olive oil is high in mono-unsaturated fats and is a healthy way for you to prepare grilled foods for the patient.

Here are ten foods that are high in fat that you should consider incorporating into the patient's diet:

Greek Yogurt Fatty fish, like salmon or mackerel Avocados Cheese Dark Chocolate Whole eggs Nuts, like almonds, walnuts and macadamia Chia seeds Extra Virgin Olive Oil (EVOO) Coconuts (and Coconut Oil)



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#### Vegetables:

Vegetables are a great source of vitamins, fiber, and potassium. They are naturally low in calories, fat, and cholesterol, and the natural fiber can help reduce blood cholesterol and promotes better, regular bowel function.

Here is a list of recommended vegetables:

ArtichokeArugulaAsparaBeetsBroccoliBrusseCabbageCarrotsCaulifiCeleryCollardsEggplaLettuce (such as Romaine and Iceberg)OnionsPeasSweet PotatoesTurnips

### Asparagus Brussel sprouts Cauliflower Eggplant eberg) Spinach

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#### For example:

You could put together a salad with a mix of Romaine Lettuce, Iceberg Lettuce, and Arugula for the patient. Cut up some Avocado, add some chopped almonds or walnuts, maybe some dried cranberries, and drizzle with Olive Oil. You can add a protein to the salad like some grilled chicken, steak or fish.





### Fruits:

Fruits are also a great source of vitamins and anti-oxidants. It is recommended that the patient avoid fruit juices because of their high sugar content. A better choice would be raw fruit as these are naturally low in fat and calories.

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Here is a list of recommended fruits:

Banana Berries Grapes Grapefruit Melons, like cantaloupe, honeydew or watermelon Oranges Pears Pineapple Tomato





### Dairy:

Dairy products can be a great source of calcium and vitamin D, but make sure you select one that is low fat for the patient.

#### Whole Grains vs. Refined Grains:

Whole grains should be chosen over refined grains. Whole grains are high in fiber and help promote cardio-vascular health. Refined grains are milled, a process which removes part of the grain. Also removed in the process are some of the fiber, iron and vitamins.

Here is a list of whole grains:

Barley Buckwheat Corn Oats Quinoa Rice, including wild rice Sorghum Wheat



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## Here are some foods/items to AVOID:

- Table sugar
- Artificial sweetener
- Caffeine including coffee, tea, and soft drinks
- Alcohol
- Fried foods
- NO smoking!!!
- Donuts and high calorie pastries



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And consult with the patient's physician before allowing them to take any vitamins or supplements!



## The Importance of Exercise In The Patient's Recovery



Another important element to the healing process is getting a good night's sleep. It is important for the patient to have at least 8 hours of restful sleep each night. Studies have shown that the darker the room and/or the cooler the temperature, the better the quality of sleep you will get.

However, it is not a good idea for the patient to lay in bed all day as this can do more harm than good. At some point, we will direct the patient to gradually start increasing their daily activities as their body and brain can tolerate it. Regular exercise can improve their metabolism which will make it easier for their body to receive and absorb the nutrients it needs from meals. Exercise will also help proper blood flow to the brain and can alleviate some of the symptoms they are experiencing.

PLEASE NOTE: we must be cautious when trying to incorporate exercise into the patient's routine. Before the patient attempts any exercise or moderately strenuous activity, please FIRST consult with their treating physician to see if this is appropriate at this time.



# Why is exercise AFTER a Concussion so important to the recovery process?

In the past, most doctors would recommend that their patients who sustained a TBI should not exercise and should refrain from all mental and physical activities until the concussion symptoms disappeared completely. However, it was discovered that this period of inactivity could last from several days to several months as the concussion symptoms still lingered. The "cocooning" or to use a phrase from the Covid pandemic – the "sheltering in place" – actually led to an increase in depression and anxiety for the patients and it slowed their overall recovery time. The most recent studies have shown that when a patient rests for more than 2 days, this period of inactivity can actually lead to worse outcomes. Sadly, a lot of health care practitioners are not aware of the newest research and they continue to tell their patients that the only treatment they need is rest. This is just not supported by science.







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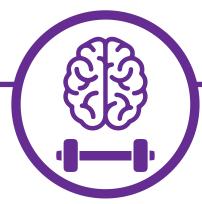


# So what is the right exercise after a TBI?

Again, the starting point for the answer to this question begins with the patient and their treating physician. There are so many factors, including pre-existing disease processes or other injuries which might make exercise risky or even dangerous in some situations. We do not want the patient engaging in any physical activity which could increase their risk of re-injury. These activities could include contact sports like karate, jiu-jitsu, or boxing. Also, any activity which could cause their head or body to be jolted or impacted should be avoided, such as running or jumping rope. The best approach is to start slow and see what they are capable of doing that can elevate their heart rate without increasing their symptoms.

#### What can you do to "exercise" your brain?

One consequence from a TBI is swelling/inflamation of the brain. Because of this inflammation, their brain may not be able to use certain communication pathways like it normally would. For most patients, these pathways will begin to work after a couple of weeks. But for some, there are delays and the brain may need to generate "new" pathways for this communication to flow. This innate healing ability in the brain is known as "neuroplasticity." Cognitive exercises can help retrain the patient's brain "muscles" to re-establish connections or re-route connections that may have stopped working because of the TBI. At some point, we will provide the patient with a list of "brain games" they can play to help exercise the brain.





# Some final, helpful hints for interacting with your loved one:

- As best you can, be calm and controlled when talking with your loved one. This may be easier said than done if you feel you are being wrongfully attacked or on the receiving end of an emotional outburst. Don't take their bad behavior personally. Just understand that this confusion and agitation can be expected.
- As best you can, provide a calm, quiet environment around the home. Make sure the noise level from televisions or radios are reduced. The same rules apply when in the car. Turn down the radio volume.
- Talk in shorter sentences. Engage in eye contact when possible to visually confirm if they heard you and understand what you are saying.
- Help them break down tasks into simple, easy to complete stages.
- Safety proof your home! This is a time to get items off of the floor that can be trip hazards like children's toys or slippery rugs.
- At first, limit the number of visitors to see your loved one. Allow them time to rest in between those visits.
- Rely on written notes to help you keep things together. Keep track of all of the medical appointments, including names, addresses, phone numbers and dates of visits.
- Don't be afraid to ask questions at doctor's appointments/PT appointments when you don't understand something. You can be the patient's best advocate when you are fully informed.
- Try and keep life as normal as possible for your children.
- Celebrate achievements. Enjoy the good days and learn to bounce back from the difficult ones. Take one day at a time, and remember that progress is measured in small steps and achievements.
- Be slow and deliberate when contemplating major life/financial decisions.
- Seek help if you need it. This applies to tasks around the home or errands to the grocery store or pharmacy. There is NO shame in asking for help from a family member, friend, counselor or pastor. We know you feel a sense of "loss" because the person you know and love is now somehow "changed" or "different." Professionals that work in the mental health field all agree that it is completely normal for you to experience a wide range of emotions yourself as you go through this process, and it may take a significant period of time for you to adjust to the injury. We just encourage you to seek the help and support of family, friends, and others who are in your same situation.



## **Some Final Notes**

There are many resources and groups that are available to patients and their families to help them deal with TBIs. These include:

• Academy of Cognitive Therapy.

#### www.Academyofct.org

• American Academy of Physical Medicine and Rehabilitation.

#### www.aapmr.org

• Brain Injury Association of America.

#### www.biausa.org

• Brain Trauma Foundation

#### www.braintrauma.org

• Family Caregiver Alliance

www.caregiver.org/resource/traumatic-brain-injury

• National Institute of Neurological Disorders and Stroke.

#### www.ninds.nih.gov

• TBI National Resource Center

#### www.neuro.pmr.vcu.edu

#### BOTTOM LINE:

Please don't give up. It is okay to question what the future may hold and you may grieve about the past that is no longer the present. You are allowed to have these feelings. Just know that the brain is an amazing organ that can regain some or most of its function through the process known as neuro-plasticity (forming NEW connections within the brain to allow regrowth/ repair). This may be an emotional roller coaster for some time so buckle up - but hang in there!



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