

Post-Concussion

Caregiver Guidebook



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What is a Concussion?

<u>A concussion</u> is a type of traumatic brain injury (TBI), caused by a bump, blow, or jolt to the head or by a hit to the body that causes the head and brain to move rapidly back and forth. Rapid movement causes brain tissue to change shape, which can stretch and damage brain cells. This damage also causes chemical and metabolic changes within the brain cells, making it more difficult for cells to function and communicate. Since the brain is the body's control center, the effects of a concussion can be far-reaching.

Concussions are usually not life-threatening, but the effects of a concussion can change a life and the injury should be treated seriously.

What is PPCS?

Persistent post-concussion symptoms (PPCS), also known as Post-Concussion Syndrome (PCS), occurs when concussion symptoms persist beyond the average course of recovery. Most concussion symptoms will resolve within about a month. In cases where symptoms last longer than one or two months, doctors may diagnose persistent post-concussion symptoms. Patients with PPCS can experience concussion-like symptoms at rest or in response to too much physical or cognitive activity, often forcing them to withdraw from their usual physical, professional, and social lives.

What Are the Symptoms of PPCS

Since PPCS (or PCS) is the persistence of concussion symptoms, it's important to understand typical patient experiences. Symptoms fall into four main categories:

| Cognitive | Mood/Behavior |
|--|--|
| Short-term memory loss Trouble concentrating Lack of focus | Anxiety Depression Irrational anger Increased sadness Irritability |
| Physical | Sleep |
| | |

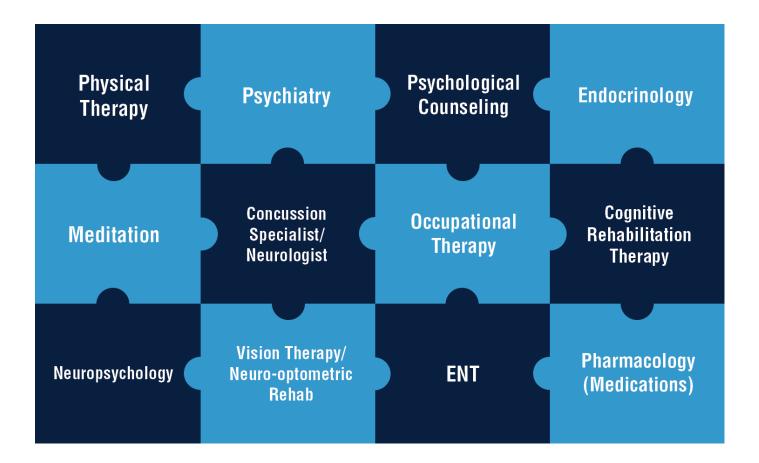


Building a Foundation of Medical Support

One of the most important steps toward recovery and stability for your loved one is establishing a foundation of medical and mental health providers and treatments. No two concussions or cases of PPCS (or PCS) are exactly alike. Similarly, no two recovery journeys look alike.

Here's the good news: persistent post-concussion symptoms will get better with time and the right therapies. But it's important to set appropriate expectations for recovery. First, persistent post-concussion symptoms can have many causes, so your doctor may recommend multiple treatments. In addition, some treatments and therapies can take weeks before you will notice improvement, so it is important to be patient. Finally, you may need to try multiple therapies before you find the one that works for you, so it is important to never give up!

The image below illustrates the many types of treatment providers you may work with along the way. It is designed as a puzzle to remind us that PPCS treatment can require an interdisciplinary team working together to solve your unique constellation of symptoms. You will want to work with your primary care physician or your concussion specialist to decide on what treatments you want to pursue.





Evidence-Based PPCS Treatment Practices

The treatments listed below are supported by peer-reviewed scientific studies. At this time, CLF is not listing experimental or off-label therapies that lack peer-reviewed evidence.

If you are thinking about trying therapies not listed below, it is important to consider if the potential benefits are worth both the risks, time, and costs. Be skeptical of treatments that are expensive and not covered by insurance, especially therapies that have existed for a long time and have still not produced enough peer-reviewed evidence of effectiveness to be reimbursed by insurance for treatment of concussion symptoms.

While this list is not exhaustive, it does provide a comprehensive overview of the most frequently used strategies for managing concussion symptoms.

| Treatment | Symptoms Targeted | Typical Providers | |
|---|--|---|--|
| Cognitive Behavioral Therapy (CBT) | | | |
| A psychological therapy frequently used to treat mood and behavior. | Depression Anxiety Impulsivity | Clinical Psychologist Mental Health Counselor Social Worker Occupational Therapist | |
| Cognitive Rehabilitation Therapy (CRT) | | | |
| Also known as cognitive therapy. A goal-oriented rehabilitation approach to restoring and improving functional cognitive skills. | Attention Memory Executive functioning Word-finding skills Cognitive decline | Speech and Language Pathologist (trained in CRT for head trauma) Occupational Therapist (trained in CRT for head trauma) | |
| Endocrinology | | | |
| Specifically, neuroendocrine assessment of pituitary function to determine if an initial TBI has caused hormonal imbalance. | Treatment-resistant: Brain fog Fatigue Listlessness Depression | Endocrinologist | |
| Exertional Therapy | | | |
| Exertional Therapy involves a concussion patient performing light aerobic activity in a controlled and monitored environment. | Fatigue Balance Fear of activity/re-injury Sensory sensitivities | Physiatrist Physical Therapist | |

| Treatment | Symptoms Targeted | Typical Providers |
|--|---|--|
| Meditation | | |
| Meditation is a practice where an individual uses a technique such as mindfulness to train attention and awareness to achieve a mentally clear and emotionally calm and stable state. | Sleep disturbances Anxiety Attention deficits | Licensed counselor trained in mindfulness or meditation Apps: Calm, Headspace, Insight Timer to find a guided meditation practice |
| Neuropsychology | | |
| A branch of psychology focused on how the brain and nervous system influence a person's cognition and behavior. | Memory Word finding Concentration Motor function Multitasking Depression Anxiety Impulsivity | Neuropsychologist |
| Occupational Therapy (OT) | | |
| The therapeutic use of everyday activities to help patients develop, recover, improve, and maintain the skills needed for daily living and working. | Fatigue Headache Sensory sensitivities Dizziness Sleep Memory loss Concentration Processing speed Language Communication Executive function Vision impairment Return-to-Learn Return-to-Work Return-to-Play | ► Occupational Therapist |
| Otolaryngology (ENT) | | |
| Physicians trained to treat patients with diseases and disorders of the ear, nose, throat, and related structures of the head and neck. | Dizziness Tinnitus (ringing in the ears) Extreme noise sensitivity Vertigo or balance issues | ► ENT |
| Physical Therapy | T. T | |
| A wide discipline of medicine treating ailments through physical means. | Balance issues Motor function Fatigue Neck/shoulder pain for whiplash injury Headaches | Physiatrist Physical Therapist |

| Treatment | Symptoms Targeted | Typical Providers |
|---|---|---|
| Psychiatry | | |
| The medical specialty devoted to the diagnosis, prevention, and treatment of mental health disorders. Psychiatrists assess both the mental and physical aspects of psychological problems. | Personality changes Anger/Rage Depression Sustained hyperactivity (mania) Paranoia Detachment from reality (psychosis) | Psychiatrist |
| Vestibular Therapy | | |
| A wide range of techniques, including habituation exercises, gaze stability training, and balance training. | Persistent dizziness Vertigo Balance problems Headaches | Neurologist ENT Physiatrist Physical Therapist |
| Vision Therapy | | |
| Range of techniques designed to help train specific aspects of the visual system. | Sensitivity to motion Eye strain Headaches Nausea Dizziness/balance Sensitivity to light Blurry vision Double vision Peripheral vision Convergence | Neuro-Ophthalmologist Neuro-Optometrist Physiatrist Physical Therapist Occupational Therapist |

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Types of Providers

The providers listed below can be relied upon for evidence-based treatment practices to address persistent concussion symptoms or the challenges associated with recovery.

| Provider Type | Function | Relevant Specializations | |
|--|---|--|--|
| Case Manager | | | |
| A plan developer and coordinator to connect clients to the services they need. Other titles: Care Coordinator Nurse Case Manager Transition Manager Patient Navigator Patient Care Facilitator | Reduce chaos and confusion to help you focus on recovery or caregiving. | Advocacy and mediation Appointment reminders Insurance coverage Connection to resources Medical record transfers | |
| Clinical Psychologist | | | |
| A PhD or PsyD educated, licensed mental health professional qualified to do counselling and psychotherapy, perform psychological testing, and provide treatment for mental disorders. | Evaluate, diagnose, and treat behavioral, emotional, and mental disorders through cognitive behavioral therapy (CBT), psychoanalytic therapy, etc. | Adjustment issues Emotional and psychological problems Interpersonal or social problems and dysfunction Behavioral problems Intellectual, cognitive, and neurological conditions | |
| Neurologist | | | |
| A medical doctor with specialized training in managing disorders of the brain and nervous system. | Treat disorders of the brain, spinal cord, nerves, and muscles. | Neurologic assessments Blood panel CT/MRI scans Behavioral dysregulation Headaches Seizures Sleep problems TBI – mTBI/concussion Neurodegenerative diseases | |
| Neuro-Ophthalmologist | | | |
| A medical doctor who sub- specializes in neurology and ophthalmology. | Diagnose and treat visual problems related to the nervous system (vision problems that do not necessarily come from the eyes themselves). | Neuro-Optometric Rehabilitation therapy Rehabilitation referrals Broad medical or surgical options Vision therapy Eye training | |

| Provider Type | Function | Relevant Specializations | |
|---|--|---|--|
| Neuro-Optometrist | | | |
| An optometrist with an additional year of training to specialize and work in vision therapy and neuro- optometry. | Comprehensive evaluations of sensory motor, visual field, accommodative, and oculomotor function. Stimulate parts of the brain not functioning to their highest potential following a brain injury. | Neuro-Optometric Rehabilitation therapy Vision therapy Eye training Corrective lenses | |
| Neuropsychologist | | | |
| A licensed clinical psychologist specializing in how the brain affects behavior | Administer certain types of cognitive and emotional tests. | Neuropsychological assessments of cognitive function Clinical psychotherapy | |
| Occupational Therapist | | | |
| A medical professional who specializes in activities of daily living. | Assess patients' needs and help patients develop, recover, improve, and maintain the skills needed for daily living and working by the adaptation of movement, improving motor skills, hand-eye coordination, or learning to do tasks in new ways. | Adaptive equipment recommendations for home Cognitive rehabilitation Vision therapy Return-to-Learn/Play/ Work | |
| Physical Therapist | | | |
| A wide discipline of medicine treating ailments through physical means. | Provides services that help restore body function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities from an injury. | Physical rehabilitation Vestibular rehabilitation Neck pain Headaches | |
| Primary Care Provider (PCP) | | | |
| A medical doctor who practices general healthcare and addresses a wide variety of health concerns. Other titles: Family Practice Physicians Internal Medicine Physicians Clinical Nurse Practitioners Physician Assistants | Coordinates the ongoing care of all your family member's general medical needs. | First-line care and guidance Referral to specialists Care coordination and centralization Medication | |

| Provider Type | Function | Relevant Specializations | |
|---|---|--|--|
| Psychiatrist | | | |
| A medical doctor specializing in preventing, diagnosing, and treating mental illness. | Assess the mental and physical aspects of psychological problems. | Psychotherapy Medication Medication management | |
| Social Worker | | | |
| A Licensed Clinical Social Worker (LCSW) is trained to evaluate and treat mental illnesses. | Trained in psychotherapy and help individuals deal with mental health and daily living problems. | Psychotherapy/ counseling Patient & family advocacy Case management Resource facilitation | |
| Speech Language Pathologist (SLP) | | | |
| A health professional who specializes in language and communication. Rehabilitation for cognition, communication, and swallowing disorders. | Evaluates, diagnoses underlying problems. Develops personal treatment plans. | Reestablishing communication Adaptive technologies for work or school Cognitive therapy Memory training | |

Finding Providers

Begin the discussion with established care providers, such as primary care physicians. From there, locate concussion/traumatic brain injury specialists for comprehensive care and targeted specialties.

Keep in mind, finding care for a recent concussion (<6 weeks) can differ from persistent concussion symptoms (6 weeks - 2 years or more). Some clinics set restrictions for intake, such as requiring referral or limiting intake to patients with an injury within the last 6 months. Clinic capabilities and limitations vary, so be sure to continue searching until you find a good fit for your loved one's needs. Reach out to the <u>CLF HelpLine</u> for recommendations in your area.



How to Choose a Concussion Clinic

A concussion clinic is a comprehensive, multidisciplinary care facility with the ability to target multiple symptoms. Concussion clinics are a great option for recent or persistent symptoms. It's important to do research before selecting a concussion clinic for potential treatment. Here are the five things CLF recommends considering when evaluating concussion clinics:

How many patients does the clinic see?

A doctor who sees primarily concussion patients will be more familiar with the complexities of concussion recovery than a more general practitioner. If it's an option, choosing a concussion

specialist can help avoid missteps through the recovery process that can potentially prolong symptom duration.

What level of medical training did the clinicians receive?

Your loved one's care team may eventually involve multiple specialties and include doctors, clinicians, therapists, and more. However, for an initial evaluation, and to lead their care team, we suggest doctoral level clinicians such as MD, DO, or a relevant PhD.

Are multiple disciplines represented on staff?

Concussions are a complex injury, and treatment could require multiple specialists. Look for a multidisciplinary team that may include neurologists, psychiatrists, neuropsychologists, psychologists, physical and occupational therapists, athletic trainers, and more. A clinic with a diverse staff of specialists is best.

How long has the clinic been open and seeing patients?

Resources for concussed patients continue to expand. Existing clinics are beginning to tailor their practices to the needs of concussion

patients, and new clinics are opening faster than ever before. There is a steep learning curve, however, and practitioners at new clinics may be less experienced than specialists at established clinics.

Is the clinic affiliated with an accredited medical institution?

Most top tier clinics are affiliated with hospitals or universities, and affiliated clinics tend to have more treatment resources available. There are notable exceptions of top tier clinics operating independently, but in general, affiliations can be helpful when trying to distinguish between several clinic options.







Talking with Your Doctor

One of the first things a doctor will ask for is a summary your loved one's concussion history. Coming prepared to their first appointment will help get them on the road to recovery as soon as possible. It can be a challenge, especially if they're experiencing memory loss. Here are a few tips:

Start with diagnosed concussions

If they've been diagnosed with a concussion before, have as much information about the injury ready as possible.

- 1. When did it happen?
- 2. What caused the impact?
- 3. What symptoms were experienced?
- 4. How severe were those symptoms?
- 5. Did symptoms change as they recovered?

Patterns from previous injuries can be helpful in predicting what recovery might look like.

Severity matters

Some people get worried when they start counting their concussions and realize they have had more than they thought. It's important to remember not all concussions are created equal: the severity of past concussions may be more important than the total number. How long symptoms lasted is the best indicator: the longer the duration, the greater the severity.

When they happened matters, too

The interval between injuries is important when looking at the full concussion history picture. Two concussions one week apart is a different story than two concussions a year apart, even if they are of similar severity. Organizing a timeline with all their concussions is a helpful way to easily see how they cluster and can help provide background for their doctor to reference when developing an appropriate return to activity and long-term concussion management plan. Be sure to have it ready for their first appointment.

Consider undiagnosed concussions

Just because a doctor never made a diagnosis doesn't mean a concussion didn't happen. After recounting their diagnosed concussions, look at the symptoms of a concussion and have them try to remember instances where they felt any symptoms after a hit to the head. It's common for estimates to increase after reading the definition of a concussion. Remember: dings and bell ringers count.



How Can I Support Someone with PPCS?

Offering validation is a great place to start. This means believing what your loved one tells you about their symptoms and experience. Living with a complex, invisible injury is difficult enough, but when you doubt your loved one's symptoms or imply that they are making them up, it can be devastating. Don't be one of those doubters. Giving your loved one unconditional validation and support can be more meaningful and beneficial to their recovery than you realize.

Here are some additional ways to support your loved one:

- Help them talk through the emotional challenges of the injury and validate the challenges of recovery
- Be an advocate for them at school, in sports, and with doctors
- Prepare for the impact the injury can have on the whole family
- Build a support team, and realize you can't do it alone as a caregiver

Prepare for Setbacks

Concussion recovery is not always linear, and no two concussions are the same. Without a set timeline for recovery, it can be hard to know if your loved one is making progress. It can be even more difficult when they seem to improve one day and then are worse the next. Try to be patient and know setbacks are normal.

Here are some strategies to keep in mind:



- Setting and sticking to a routine
- Providing support for fluctuating emotions and personality
- Tracking and exploring additional treatment options

Communication

Many patients have trouble with interpersonal communication after concussion or brain injury. It's important to keep this in mind as you work with your loved one to continue building momentum.

These tip sheets from <u>Brainline</u> and <u>MIT</u> offer helpful strategies for maintaining clear and effective communication.

Self-Care

It's easy to feel helpless watching a loved one suffer from persistent post-concussion symptoms. An invisible injury is especially hard to care for because it is not as obvious when and how someone is in pain. We understand the struggle and want you to know you are not alone.

Look After Yourself First

Setting aside time for self-care is an essential part of being an effective and supportive caregiver. Put your own healthcare needs first and reach out if you need help. Prioritize activities that build your physical, emotional, mental, and spiritual energy, such as:

- Regular exercise
- Mental health counseling
- Meditation
- Mindfulness
- Reading

- Listening to music
 Cooking
 Proper rest
- Healthy diet
- Socialization

Create a Support Network for YOU

It is important to build a strong and empathetic network of people who can support you. Ongoing conversations with a trusted sibling, friend, parent, counselor, or doctor is a great way to support yourself. Be open about your experiences with those who may not see your loved one at their worst.





Create a Resource Toolbox

A resource toolbox is your "just in case" list of supportive organizations and services. Think of it as a form of contingency planning. Since you can't predict when or how a situation may take a turn for the worse, it's good to know who you can reach out to for additional information, resources, and guidance.

If you or your loved one needs help, do not hesitate to reach out. The table below demonstrates an example list.

| Organization | Contact |
|---|------------------------|
| Suicide & Crisis Lifeline | Dial 988 |
| Veterans Crisis Line | Dial 988, then press 1 |
| Substance Abuse and Mental Health Services Administration (SAMHSA) Helpline | 1-800-662-4357 |
| National Domestic Violence Hotline | 1-800-799-7233 |
| National Alliance on Mental Illness | 1-800-950-6264 |
| CLF HelpLine | CLFHelpLine.org |

Peer Support Groups

Joining a support forum or support group is another great way to connect with people who understand what you are going through. The goal of the Concussion Legacy Foundation's <u>PCS</u>. <u>Resources Facebook Group</u>, for instance, is to build a community focused on providing resources, support, and hope to those affected by ongoing concussion symptoms and persistent post-concussion symptoms.

Peer Support Connections

The <u>CLF Mentorship Program</u> is an opportunity to connect with someone who understands the unique challenges of being a caregiver for someone with PPCS (or PCS) or suspected CTE.

Our Peer Support Volunteers are former patients and caregivers who have navigated similar challenges and want to give back to the brain injured community by sharing what their own journey taught them. Reach out to the <u>CLF</u><u>HelpLine</u> to be connected.

Get involved with CLF's Mentorship Program



Concussions are more common among schoolaged children than any other group, and their symptoms can be debilitating. A student with concussion symptoms may not be able to take a full course-load or learn as easily in class because of difficulty concentrating, headaches, memory issues, irritability, fatigue, and other symptoms. That's why a return-to-learn protocol is essential; read below for our tips on returning to school after concussion.



Go to School but Don't Rush It

Following immediate rest after a concussion, best practice suggests returning to school with the understanding that the patient may need academic adjustments and other modifications. This might mean students need part-time schedules or regular breaks, especially when reading or looking at a computer screen. It is important for students to be honest about their symptoms and know their limits to avoid increasing their symptoms and delaying their recovery.

Get Their School Involved

Teachers and school staff need to know if a student is suffering from a concussion. After a physician clears a student to return to school, the student and his or her family should work with the doctor to communicate his or her symptoms and necessary accommodations to teachers and faculty. Teachers can help monitor a student's symptoms and work with the student to gradually increase their workload while keeping track of missed assignments and assessments.

Coordinating with school nurses and medical staff is also recommended. The school nurse is often the quarterback of a school's return-to-learn program and can coordinate communications and execute physician-prescribed return-to-learn plans. Many school nurses also encourage students recovering from concussions to utilize their office for a quiet, dark place if a student needs to rest during the school day.

Find an Advocate at Their School



Emotional support is critical during concussion recovery, especially among teenagers. A student with a concussion would benefit from finding an advocate, whether it's a friend, teammate, coach, teacher, nurse, or school support staff member. An advocate who understands concussion symptoms are invisible but very real can speak up when the student may not feel comfortable. A student having someone in their corner while they are at school will lower the likelihood that they try to push through symptoms and help ensure they receive the care they need at school.

Return-To-Learn & Return-to-Play Resources



<u>Return to Learn After Concussion</u> – Concussion Game Plan Podcast Episode 6



<u>Get Schooled On Concussions</u> – Resources for educators and parents



<u>REAP</u> – A community-based concussion management approach that stands for Remove/ Reduce, Educate, Adjust/Accommodate, Pace



Returning to School After Concussion – CDC Heads Up resource



Additional Support and Resources

CLF HelpLine

The <u>CLF HelpLine</u> provides personalized help to those struggling with the outcomes of brain injury. Patients and caregivers navigating concussion, persistent post-concussion symptoms (PPCS), and possible Chronic Traumatic Encephalopathy (CTE) can reach out for help finding the right doctor, understanding treatment options, or to have their questions answered.

If you or a loved one are seeking guidance on how to choose the right doctor, struggling with lingering concussion symptoms, or have any other specific questions, we want to hear from you. I am very pleased that I found this resource. Truly, I think it was a lifesaver.

Cognitive Symptoms w/ Dr. Dan Dane

Concussion Game Plan Podcast

<u>Concussion Game Plan</u>, an official podcast from the Concussion Legacy Foundation, is designed to help patients and caregivers navigate acute concussion recovery. The top experts in the field lend their expertise to help guide you through the concussion symptoms you can expect, how long they may last, and how to best manage them.

Each episode also features advice from someone who has suffered a concussion and handled the ups and downs of recovery. Concussion can be an isolating, confusing injury. Concussion Game Plan is here to help, and remind you, you are not alone.



PCS Recovery Corner

We launched this IGTV series, <u>PCS</u> <u>Recovery Corner</u>, featuring CLF Senior Director of Programs and Communications Julia Manning to help those who are currently coping with persistent post-concussion symptoms (or PCS). Julia shares tips and strategies she's learned throughout her three-year recovery journey.



PCS Recovery Corner with Julia

Videos & Webinars

- Helping Your Child Cope with Post-Concussion Syndrome Pt. 1 Learn strategies from parents on how to help your child cope with PCS.
- <u>Helping Your Child Cope with Post-Concussion Syndrome Pt. 2</u> Learn strategies from parents on how to help your child cope with PCS.

Helping Concussion and Suspected CTE Patients in Crisis

How caregivers can support those struggling with severe symptoms.

How Physical Therapy Can Treat Post-Concussion Syndrome

How PT can help treat PCS, with patient accounts.

Dr. Robert Cantu on Management and Treatment of Post-Concussion Syndrome How to medically manage and treat PCS, and advice for those who are recovering from PCS.

Impact of Concussion on Vision with Dr. Len Messner How brain injuries can disrupt the visual system.

Neuroendocrine Dysfunction after Concussion: What Patients & Families Should Know

If your loved one is experiencing persistent concussion symptoms (PCS) and isn't responding to active therapies, this webinar will be key to helping you understand how a pituitary gland injury may be involved.

Inspiring Stories

Looking for some inspiration? <u>Here</u> you'll find a gallery of stories of loss, recovery, community and hope to help patients and families who are struggling.



Ally Crich

Navigating PCS, the impacts it has on personal relationships and employability, and the importance of speaking up about PCS.



Brent Sullivan

Brent was forced to retire from hockey at age 22, following his 14th diagnosed concussion in a 10-year period.



Caty Hastings

A decade of concussions, lead to a series of emotional, mental, and physical challenges, and struggle to find doctors who understood concussions and the mental health symptoms they cause.



Erin Payne

A young gymnast's 2-year battle with PCS including providers and treatments.



Jamie Martin

A string of concussions turned her life upside down, with physical symptoms testing her limits and mental health deteriorating to the point of crisis.



Noah Abrams

A life-altering concussion and a yearlong recovery from a knee to the head while tending goal.



Noelle Foley

An amusement park concussion and the ups-and-downs of concussion recovery and battling PCS.



Final Note

The caregiver journey is incredibly challenging. From advocating for your loved one to preparing for the impact persistent symptoms can have on the whole family, the role demands compassion, organization, patience, and resourcefulness. The support you provide is invaluable, even if it sometimes goes unrecognized.

Perhaps the most valuable resource caregivers provide to their loved one is hope. Hope helps us keep going through our toughest challenges. Hope is the belief that there can be a better future, and it inspires us to take action. Hope helps reduce depression and improve mental health. Hope is a crucial component of recovery for people struggling with symptoms of concussion, and hope can be contagious. Simply "being there" for your loved one can be enough to cultivate and maintain the hope they need.

CLF is grateful for your commitment to helping your loved one navigate the effects of brain trauma. Remember that you're not alone – reach out to us through the CLF HelpLine if you need recommendations, support, or guidance.