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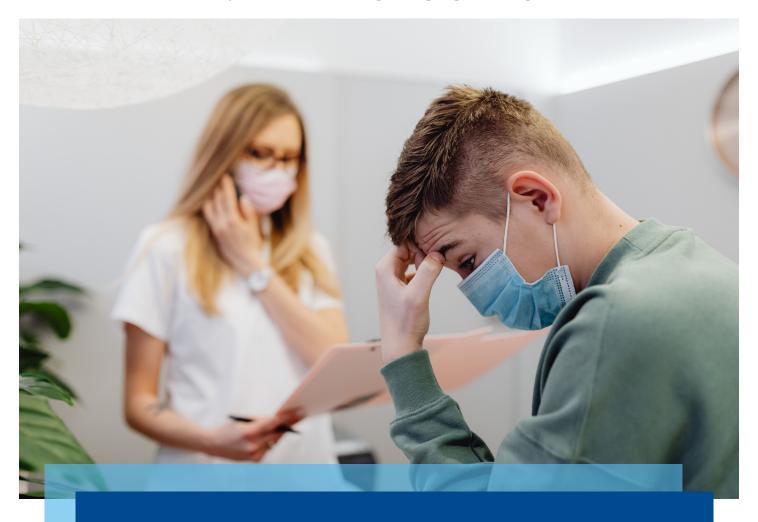
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### 1. INTRODUCTION



Welcome to *The Concussion Guidebook for Alaskan Patients and Caregivers*. You are likely reading this because you or your loved one recently experienced a concussion, also known as a mild Traumatic Brain Injury (mTBI), or have lingering concussion symptoms. You are no doubt concerned and are probably searching for information and resources.

This guidebook is intended to provide you with fundamental knowledge of concussions, information about symptoms, details about evidence-based treatments, best practices for being a caregiver, and resources in Alaska for support throughout your recovery or caregiving journey.

#### mTBI & TBI Statistics in Alaska

Understanding the prevalence and trends associated with concussion may provide valuable context to you or your loved one. If you need practical information to support recovery, see the next sections on injury management, basic facts, treatment options, and care providers.

A concussion, or mild Traumatic Brain Injury (mTBI), is caused by a bump, blow, or jolt to the head or body that causes the head and brain to move rapidly back and forth. The severity of injury and symptoms can vary widely between concussions, and the frequency of injury in the general public is difficult to establish. Past estimates from the Centers for Disease Control and Prevention (CDC) suggest as many as 1.6 to 3.8 million concussions occur in the U.S. each year from sports and recreation alone<sup>1</sup>.

While data focused specifically on concussions in Alaska is needed, broader data available for all Traumatic Brain Injury (TBI) in Alaska, including mild to severe injury, provide valuable insights. For example, the <u>State of Alaska Epidemiology Bulletin on Traumatic Brain Injury</u> released in May 2023 describes the patterns of TBIs, factors that increase the risk of death after a severe TBI, expenses covered by Medicaid due to TBI-related injuries, and services needed for TBI care in Alaska. The information and findings described below are informed by this bulletin.

Broadly, TBIs can range from mild to severe and may cause loss of consciousness, coma, or even death. They can also lead to various neurological problems like seizures or dementia, as well as issues like anxiety, depression, or post-traumatic stress disorder (PTSD). In children, TBIs can negatively affect their development, causing problems with learning, behavior, and social interactions. Although anyone can get a TBI, people living in rural areas are at a higher risk of TBI-related death compared to those in cities.

Alaska has one of the highest rates of TBI-related deaths in the country. In 2020, the death rate from TBIs in Alaska was twice the national average and the highest in the country<sup>2</sup>. With a population of about 734,000 people spread across vast distances, Alaska faces many of the challenges seen in rural areas, including difficulties in accessing healthcare due to travel distances, higher healthcare costs, scarcity of specialized TBI care, and a higher frequency of outdoor activities that may increase the risk of TBIs. Rural TBI survivors also face unique challenges in accessing specialized care and services for their recovery.

#### Noteworthy findings about TBIs in Alaska include:

- American Indian and Alaska Native (AI/AN) people are disproportionately affected. Although they make up 15-20% of the population, they account for a larger share of TBI-related emergency room visits, hospitalizations, and deaths<sup>2</sup>. AI/AN people had higher rates of TBIs from motor vehicle accidents, particularly involving ATVs and snowmachines<sup>2</sup>. Promoting helmet use and safety education is crucial, especially in rural areas.
- Males in Alaska experienced more TBIs than females, which is consistent with national trends<sup>2</sup>. This is because males are more often involved in activities that lead to TBIs, such as physical altercations, military service, and contact sports. However, TBIs in females, especially from intimate partner violence, are likely underreported.
- A significant number of TBI-related deaths in Alaska resulted from suicide using firearms<sup>2</sup>.
   Efforts are needed to prevent TBIs related to suicide, including primary prevention programs and monitoring changing trends.
- The economic impact of TBIs affects society in terms of healthcare costs and disability funding. Medicaid spent over \$11 million in Alaska between 2017 and 2021 to cover the costs of TBIs, with expenses increasing each year<sup>2</sup>. The highest costs were related to inpatient services and long-term care.



#### Who is at risk for Concussions?

While anyone can get a concussion, some people in Alaska are at greater risk:

- Babies and young children up to age 4
- Teenagers age 15-19
- Elders age 75+

Individuals working in certain occupations have a higher risk according to CDC data:

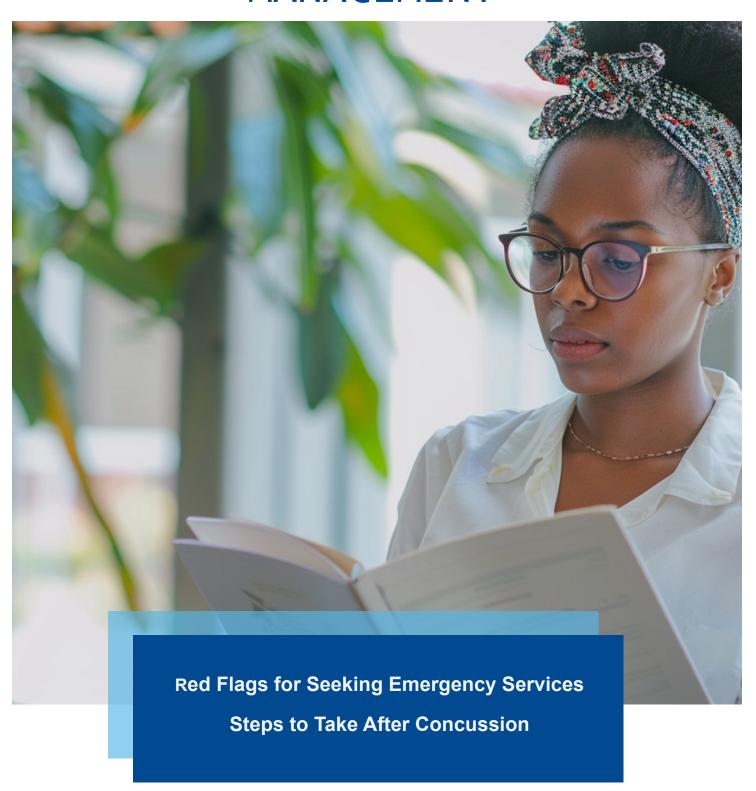
- Law enforcement, firefighters, and emergency medical personnel
- Military
- Construction and building trades
- Machinists
- Professional drivers
- Loggers
- Miners
- Professional athletes

Participating in certain sports and recreational activities also has an increased risk:

- Football (especially tackle)
- Rugby
- Ice hockey
- Soccer
- Downhill skiing
- Snowboarding
- Gymnastics
- Cheerleading
- Equestrian sports (horseback riding)
- Riding a snow machine
- Riding an ATV
- Riding a bicycle
- Riding a skateboard or scooter
- Riding a motorcycle



# 2. QUICK GUIDE TO CONCUSSION MANAGEMENT



This section focuses on information that may be helpful to address needs in the hours and days following a concussion.

#### Red Flags for Seeking Emergency Services

Individuals who have suffered a head injury should visit the Emergency Department immediately if any of the following warning signs are present:

- Seizures or convulsions
- Slurred speech
- Weakness, numbness, or decreased coordination
- Pupil changes
- Vision changes
- Increased confusion
- Agitation
- Discharge of fluid from nose and/or ears
- Loss of consciousness
- Repeated nausea and vomiting

Individuals should also visit the Emergency Department if any of the following complications arise in the hours and days after a head injury:

- A headache that won't go away
- Unusual behavior, mood swings or trouble concentrating
- Difficulty falling asleep or waking up
- Symptoms worsen or change in severity or character



#### **Steps to Take After Concussion**

- Seek Medical Care: Get evaluated by a medical professional. If there is any doubt, it's safer to
  assume you have a concussion until evaluation is possible. Sport concussion assessment tools
  are not always accurate and symptoms can appear days later.
- Pause Activity: Reduce the risk for further head impacts and avoid exertion. Continuing to exert oneself physically or cognitively can prolong the recovery process and increase the risk of potentially life-threatening injuries.
- **3. Prioritize Rest & Recovery:** Get adequate amounts of sleep, nutrition, and hydration. Take time off from school or work to allow for healing and recovery.
- **4. Track Changes:** Familiarize yourself with typical concussion symptoms and make note of unusual physical, emotional, or cognitive changes. Record symptoms, including severity and frequency.
- **5. Avoid Isolation:** When possible, share what you are going through with loved ones or trusted friends. Isolation in a dark room is not good for recovery. Physical and social isolation can lead to feelings of anxiety and depression and make recovery harder.
- 6. **Gradually Return to Activity:** With medical supervision, returning to moderate activity is advised. Take breaks as needed and do not push too hard. As symptoms subside, gradually return to preinjury levels of activity as tolerated. If symptoms worsen, decrease the level of physical and mental activity to allow more time for rest and healing to occur.
- 7. Remember: It's okay to take breaks and roll back activities if symptoms reappear. Recovery does not progress in a straight line, and does not look the same for everyone. While keeping a positive attitude can be difficult when symptoms get in the way of responsibilities and obligations, giving yourself space to heal and staying positive are crucial components of recovery.



As much as possible, and especially within the first 24-48 hours, try to avoid:



Physical or cognitive exertion



**Environments with lots of sensory stimuli (lights, sounds, crowds)** 



Heavy use of screens or technology (TV, phone, computers)



Alcohol and illicit drugs

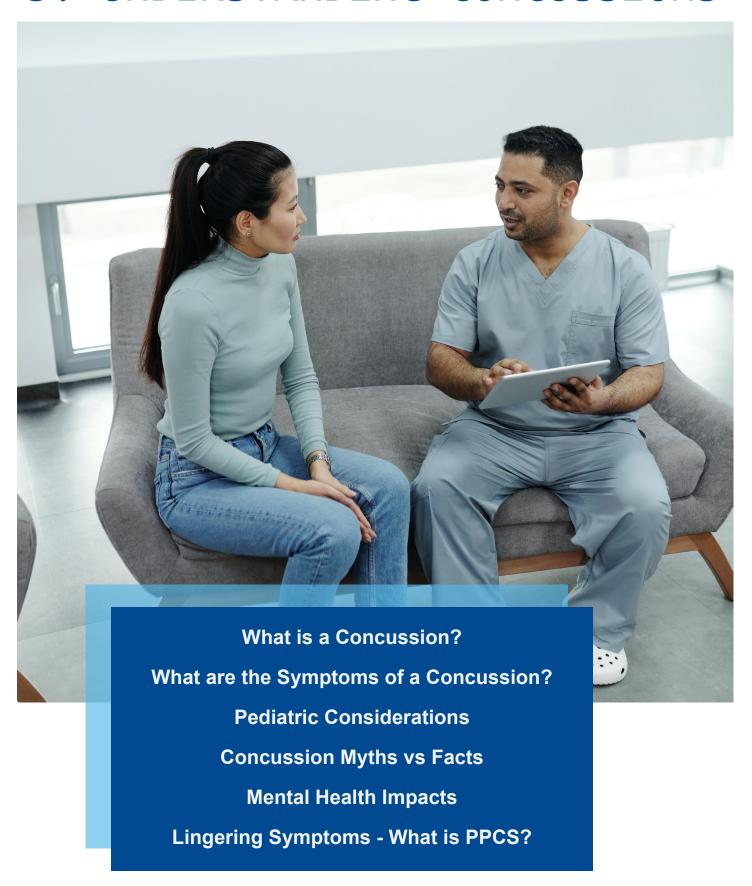


High-risk activity (collision sports, bad-weather travel, physical work)



Mental, physical or emotional stressors

## 3. UNDERSTANDING CONCUSSIONS



This section focuses on basic facts and important knowledge to support the decision making process during concussion recovery or caregiving for a loved one.

#### What is a Concussion?

A concussion is a type of traumatic brain injury (TBI), caused by a bump, blow, or jolt to the head or body that causes the head and brain to move rapidly back and forth. Rapid movement can cause brain tissue to change shape, which can stretch and damage brain cells. Chemical and metabolic changes within brain cells make it more difficult for cells to function and communicate. These changes in the brain can lead to symptoms that may affect how a person thinks, learns, acts, and sleeps<sup>3</sup>.

Concussions are categorized as "mild" Traumatic Brain Injuries (mTBI), a medical classification unrelated to symptom severity. While concussions are generally not life-threatening, their effects can alter a person's life. It is important to take these injuries seriously and seek medical attention.

Concussion symptoms appear during the normal healing process and generally improve over time. Most people with a concussion feel better within two to four weeks. Some symptoms may appear right away, while other symptoms may not appear for hours or days after the injury. Many people do not realize they have some symptoms until they try cognitively or physically demanding activities.

#### What are the Symptoms of a Concussion?

Symptoms fall into four main categories which can impact you or your loved one's thinking, emotional state, physical experiences, and sleep. Being familiar with these symptoms can aid communication with medical providers and help structure a recovery plan. Following a head injury, common symptoms that may arise include one or more of the following:

Cognitive	Mood/Behavior
Confusion Slowed Thinking Difficulty Focusing or Concentrating Forgetfulness Trouble Finding Words or Communicating Short-Term Memory Loss	Anxiety Depression Increased Sadness Irrational Anger Irritability Social Withdrawal
Physical	Sleep
Headache Dizziness Nausea Sensitivity to Light or Noise Blurry Vision or Double Vision Hearing Issues Balance Issues Fatigue or Extreme Tiredness Changes in Appetite Changes in Sex Drive	Sleeping More than Usual Sleeping Less than Usual Trouble Falling or Staying Asleep Inconsistent Sleep Patterns

Some of these symptoms can also be caused by other conditions, such as depression or Post Traumatic Stress Disorder (PTSD). Consult a medical provider to determine the best assessment and treatment for symptoms.

Monitoring and documenting symptoms to share with your healthcare provider is a valuable practice. A detailed record offers insights into the progression of symptoms, highlighting improvements or areas where you may be facing ongoing challenges. Sharing a record of symptoms can help your healthcare provider tailor treatments more effectively for you or your loved one. For your convenience, an example of a symptom tracker is included in the Appendix.

#### **Pediatric Considerations**

Like adults, a child's concussion symptoms will most often resolve within two to four weeks after injury. Some children are at increased risk for persistent symptoms and delayed recovery. Children with the characteristics or risk factors listed below should have regular monitoring by their healthcare provider to determine if additional services are needed to support recovery<sup>4</sup>.

- Prior history of mTBI
- Lower cognitive ability (for children with an intracranial lesion)
- Neurological or psychiatric disorder
- Learning difficulties
- High number or high severity of initial symptoms
- Significant family and social stressors

Making temporary changes to daily activities while a child is recovering from a concussion can help them get back to a regular routine more quickly. Until cleared by a medical provider, it is important for children to avoid activities that put them at risk for another injury to the head and brain.

Every child is different. During the recovery process, decisions about their participation in household and school activities should be guided by their symptoms. If a child's symptoms do not worsen during an activity, then that activity is generally okay for them. If symptoms worsen, activity should be cut back or modified<sup>5</sup>. If you do not feel like your child is getting better, talk with their healthcare provider. Keep track of your child's concussion symptoms and share them with the healthcare provider. This may help the healthcare provider identify the best treatment for your child's symptoms.

Infants, toddlers, and those with certain disabilities may lack communication or developmental skills to report the signs and symptoms of a brain injury. Clinicians and families should be aware of the following observable signs of a brain injury:

- Changes in the ability to pay attention
- Changes in eating or nursing habits
- Changes in play (e.g., loss of interest in favorite toys/activities)
- Changes in sleeping habits
- Irritability, persistent crying, and inability to be consoled
- Lethargy (i.e., deep and lasting drowsiness)
- Loss of acquired language
- Loss of new skills, such as toilet training
- Sensitivity to light and/or noise
- Unsteady walking, loss of balance

For infants and toddlers, acute deficits following a concussion tend to be in skill areas that are developing at the time of injury. Lack of obvious changes in these young children just after concussion does not mean that they will not require services later. For skills that are not fully developed at the

time of injury, later-onset symptoms can arise, including memory and attention deficits, language delay or deficits, or behavioral problems. These younger children are also more likely to have difficulties academically compared with children who were injured at later ages<sup>6</sup>. The full extent of deficits may become evident only as the child's brain matures, and expected skills fail to develop or emerge more slowly<sup>7</sup>.

#### **Concussion Myths vs Facts**

Myth	Fact
You have to lose consciousness to have a concussion	90% of concussions do not result in a loss of consciousness.
Signs and symptoms of a concussion are always apparent immediately after injury	Symptoms can appear up to a week after injury, although they usually appear within hours or days.
Resting after a concussion means sitting in a dark room with no stimulation	Rest is relative and can include activities at home such as social interactions and light walking that do not result in more than a mild and brief worsening of symptoms.
You should not sleep for 4 hours post- concussion	After concussion is diagnosed, getting adequate rest and maintaining a consistent sleep schedule is an important part of the recovery process <sup>8</sup> .
Helmets and equipment prevent concussions	Helmets do not completely prevent concussions. They are designed to prevent catastrophic traumatic brain injuries. No devices or equipment can completely prevent a concussion.
It's better to have a brain injury as a child because younger brains are more resilient	Children may be more susceptible to the chemical changes that occur in the brain after a concussion. The functional impact of concussions in children can differ from that in adults because the pediatric brain is still developing. Therefore, some children may not exhibit immediate effects of a concussion, but they may encounter challenges later in their development, especially as academic demands increase <sup>9</sup> .
I should not go to school, play, or work until all symptoms are resolved post concussion	Rest is important immediately after a concussion (first 48 hours). After that, activities should be gradually progressed as tolerated without severe exacerbation of symptoms.

#### **Mental Health Impacts**

During the course of recovery from a concussion, seek medical attention for mental health challenges that are not normal for the affected individual, such as feeling very emotional, irritable, or sad; difficulty falling or staying asleep; or new or worse feelings of depression or anxiety.

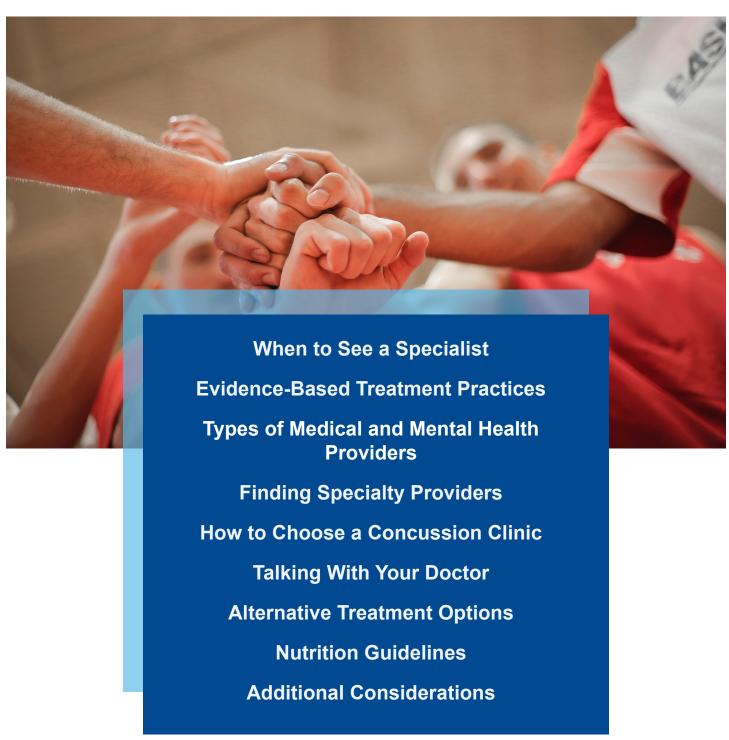
While most concussions resolve on their own, symptoms can be devastating and long-lasting. Recent research has shown troubling links between concussions, mental health problems, and suicide. A 2018 Harvard University systematic review and meta-analysis showed that study subjects with a history of concussion were twice as likely to die by suicide and were at much higher risk of suffering from suicidal ideation or attempted suicide<sup>10</sup>. A recent study from the Children's Hospital of Eastern Ontario (CHEO) found that in a large cohort of youth aged 5-18, those who had concussions were 40% more likely to have mental health problems, hospitalization, and self-harm, compared to those who had orthopedic injuries<sup>11</sup>. Improper recognition and treatment can increase these risks and exacerbate the worst outcomes of concussion. The days and weeks following injury are crucial to improve short- and long-term recovery, and access to proper care is imperative.

"Approximately 1 in 5 individuals may experience mental health symptoms up to six months after mild traumatic brain injury (mTBI), suggesting the importance of follow-up care for these patients. Scientists also identified factors that may increase the risk of developing post-traumatic stress disorder (PTSD) and/or major depressive disorder following mild mTBI or concussion through analysis of the Transforming Research and Clinical Knowledge in Traumatic Brain Injury (TRACK-TBI) study cohort." - National Institutes of Health

#### **Lingering Symptoms - What is PPCS?**

Persistent post-concussion symptoms (PPCS), also known as Post-Concussion Syndrome (PCS), is when concussion symptoms persist beyond the average course of recovery. Most concussion symptoms will resolve within a month. In cases where symptoms last longer than one or two months, doctors may diagnose PPCS. PPCS is a fairly common complication in concussion recovery and may affect up to one-third of patients who sustain a concussion. Patients with PPCS can experience concussion 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. PPCS can last months or years. While some changes may be permanent, symptoms most often can and do eventually improve with the right support and treatment.

# 4. BUILDING A FOUNDATION OF MEDICAL & MENTAL HEALTH SUPPORT



One of the most important steps toward recovery and stability following a concussion is establishing a foundation of medical and mental health providers and treatments. No two concussions are exactly alike. Similarly, no two recovery journeys are identical.

Setting appropriate expectations for recovery is important. Concussion symptoms can have many causes, so your doctor may recommend multiple treatments. Some treatments or therapies can take weeks before you notice improvement, making patience and observation crucial. You or your loved one may need to try multiple therapies before finding one that works, meaning persistence is key.

No two concussions are exactly alike. Similarly, no two recovery journeys are identical.

Here's the good news: concussions, even persistent post-concussion symptoms (PPCS), also known as Post-Concussion Syndrome (PCS), can and do improve over time with appropriate care and accommodations. It's essential to collaborate with various types of treatment providers along the way. Addressing PPCS often involves an interdisciplinary team working together to solve you or your loves one's unique symptoms. Consulting with a primary care physician or a concussion specialist is recommended to determine the most suitable treatments to pursue.

#### When to See a Specialist

It is important to seek medical attention from a medical provider such as a primary care doctor within 48 hours after any concussion. Normally, a concussion will self-resolve in 4 weeks. If there are continued symptoms, or difficulty with a normal return to play, learn, and work protocol, then a referral should be made to a concussion specialist and/or clinic.

#### **Evidence-Based Treatment Practices**

The treatments for concussion symptoms listed in this section are supported by peer-reviewed scientific studies. While this list is not exhaustive, it provides a broad overview of options frequently called upon for managing concussion symptoms.

If you or a loved one are thinking about trying therapies not listed below, it may be worthwhile to consider whether the potential benefits outweigh potential risk, time, and cost. Skepticism is generally warranted when considering treatments that are expensive or not covered by insurance, are relatively new, or have existed for a long time but have not demonstrated effectiveness for the treatment of concussion symptoms through repeated studies in reputable peer-reviewed academic journal publications.

Treatment	Symptoms Targeted	Typical Providers
Cognitive Behavioral Therapy (CBT)		
A psychological therapy frequently used to treat mood and behavior.	Anxiety Depression Impulsivity	Clinical Psychologist Mental Health Counselor Social Worker
Cognitive Rehabilitation T	herapy (CRT)	
Also known as cognitive therapy. A goal-oriented rehabilitation approach to address functional cognitive skills.	Attention Cognitive decline Communication Concentration Dizziness Executive functioning Fatigue Headache Information processing Language Memory Sensory sensitivities Sleep Vision impairment Word-finding skills	Neuropsychologist Occupational Therapist Speech-Language Pathologist
Endocrinology		
Specifically, neuroendocrine assessment of pituitary function to determine if an initial TBI has caused hormonal imbalance.	Treatment-resistant: Brain fog Depression Fatigue Listlessness	Endocrinologist Neuroendocrinologist
Exertional Therapy		
Performing light aerobic activity in a controlled and monitored environment.	Balance Fatigue Fear of activity/re-injury Sensory sensitivities	Athletic Trainer Physiatrist Physical Therapist

Treatment	Symptoms Targeted	Typical Providers
Low Vision Rehabilitation		
A wide range of strategies, concepts, and skills taught for those experiencing low vision, and/or vision changes who have not recovered.	Blurry Vision Contrast Sensitivity Depth perception challenges Dizziness/balance Double vision Glare control Headaches Nausea Nystagmus (repetitive uncontrolled movements of eyes) Sensitivity to light Sensitivity to motion Visual fatigue/strain Visual field loss or changes	Certified Assistive Technology Specialist (CATIS) Certified Orientation and Mobility Specialist (COMS) Certified Low Vision Rehabilitation Therapist (CVLT) Certified Vision Rehab Therapist (CVRT) Low Vision Optometrist Teacher of Students with a Visual Impairment (TSVI/TVI)
Mindfulness/Meditation		
A practice where an individual uses a technique, such as meditation, to train attention and awareness to achieve mental clarity and emotional stability. A primary goal of this practice is to achieve greater awareness of one's internal experience and accept one's internal emotional or physiological state.	Anxiety Attention deficits Sleep disturbances	Mental Health Counselor Occupational Therapist Speech Language Pathologist Apps: Calm, Headspace, Insight Timer, CBT-i Coach
Neuropsychology		
A branch of psychology focused on how the brain and nervous system influence a person's cognition and behavior.	Anxiety Concentration Depression Impulsivity Memory Motor function Multitasking Word finding	Neuropsychologist

Treatment	Symptoms Targeted	Typical Providers
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.	Communication Concentration Dizziness Executive function Fatigue Headache Language Memory loss Processing speed Sensory sensitivities Sleep Vision impairment	Occupational Therapist Occupational Therapy Assistant
Otolaryngology		
Physicians trained to treat patients with diseases and disorders of the ear, nose, throat and related structures of the head or neck.	Dizziness Extreme noise sensitivity Tinnitus (ringing in the ears) Vertigo or balance issues	Otolaryngologist / ENT
Physical Therapy		
Physical medicine and rehabilitation designed to promote recovery through means of exercise, manual therapy, and modalities.	Balance issues Fatigue Headaches Motor function Neck/shoulder pain for whiplash injury	Athletic Trainer Physiatrist Physical Therapist Physical Therapist Assistant
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.	Anger/Rage Depression Detachment from reality (psychosis) Paranoia Personality changes Sustained hyperactivity (mania)	Psychiatrist
Vestibular Therapy		
A wide range of techniques including habituation exercises, gaze stability training, and balance training.	Headaches Balance problems Persistent dizziness Vertigo	Audiologist ENT Neurologist Physiatrist Physical Therapist

Treatment	Symptoms Targeted	Typical Providers
Vision Therapy		
A range of techniques designed to help retrain specific aspects of the visual system including eye teaming, visual processing, and visual-vestibular coordination.	Blurry vision Convergence insufficiency Dizziness/balance Double vision Eye strain Headaches Nausea Peripheral vision Sensitivity to light Sensitivity to motion	Neuro-Ophthalmologist Neuro-Optometrist Occupational Therapist Physiatrist Physical Therapist

#### Types of Medical and Mental Health Providers

You or 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 the care team, seek doctoral-level clinicians such as MD, DO, ND, or a relevant PhD; advanced training level clinicians such as NP and PA; or certifications in concussion management such as Certified Brain Injury Specialist (CBIS), subject to availability.

The providers listed below most often offer evidence-based treatment practices to address concussions including persistent symptoms or the challenges associated with recovery.

Provider Type	Function	Relevant Specializations
Athletic Trainer		
A certified and licensed health care professional who practices in the field of sports medicine.	Recognize and evaluate injuries. Provide first aid or emergency care. Develop and carry out rehabilitation programs for injured athletes. Plan and implement comprehensive programs to prevent injury and illness among athletes.	Injury prevention Safe return to play

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 Connection to resources Insurance coverage Medical record transfers
Clinical Psychologist		
A PhD or PsyD educated, licensed mental health professional qualified to do counseling 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 Behavioral problems Emotional and psychological problems Intellectual, cognitive,and neurological conditions Interpersonal or social
		problems and dysfunction
Low Vision/Blind Rehabilit	tation Specialist	
Rehabilitation Specialists in various disciplines associated with blind/low vision patients.	Perform functional vision evaluations and learning media assessments to evaluate how a person uses their vision in a practical setting.  Provide training on other sensory integration strategies, lighting adaptations, assistive devices, optical devices, mobility aids, and/or combination devices.	Progressive vision impairment and/or vision impairment which cannot be corrected with glasses.
Low Vision Optometrist		
An Optometrist specializing in comprehensive clinic low vision evaluation to determine appropriate prescriptions, such as optical magnification and electronic devices as well as other recommendations.	Perform Clinical Low Vision Evaluations. Diagnose progressive conditions. Identify secondary conditions. Provide recommendations for:  Visual efficiency strategies Specialist lenses Handheld & low vision specific electronic optical devices	Maximum visual functioning, field of view, or refractive correction. Some similar duties as Neuro-Optometrist.

Provider Type	Function	Relevant Specializations
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.	Behavioral dysregulation Blood panels CT/MRI scans Headaches Neurologic assessment Seizures Sleep problems
Neuro-Ophthalmologist		
A medical doctor who subspecializes 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).	Broad medical or surgical options Eye training Neuro-Optometric Rehabilitation referrals Rehabilitation therapy Vision therapy
Neuro-Optometrist		
An optometrist with an additional year of training to specialize and work in vision therapy and neuro-optometry.	Evaluate visual strength, eye movements, double vision, sensory motor integration, field of view, accommodation, and binocular function. Stimulate parts of the brain not functioning to their highest potential following a brain injury.	Corrective lenses Eye training Neuro-Optometric Rehabilitation therapy Vision therapy
Neuropsychologist		
A licensed clinical psychologist specializing in how the brain affects behavior.	Administer cognitive and emotional tests. Provide treatment plans based on assessment.	Clinical psychotherapy Neuropsychological assessments of cognitive function
Occupational Therapist		
A medical professional who specializes in activities of daily living.	Assess patient 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 Safe return-to-learn/play/work Vision therapy

Provider Type	Function	Relevant Specializations
Peer Support Specialist		
Someone with lived experience and some training who can provide social and emotional support throughout the recovery process.	Provide support and help navigate throughout the caregiver or recovery process.	Community Emotional support Problem solving
Physical Therapist		
A medical professional who specializes in movement disorders and graded exercise exposure.	Provides services that help restore body function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities from an injury.	Headaches  Neck pain  Physical rehabilitation  Vestibular rehabilitation
Primary Care Provider (PC	SP)	
A medical doctor who practices general healthcare and addresses a wide variety of health concerns.  Other titles: Family Practice Physicians Internal Medicine Physicians Naturopathic Doctors Clinical Nurse Practitioners Physician Assistants	Coordinates ongoing care and general medical needs.	Care coordination and centralization First-line care and guidance Medication Referral to specialists
Psychiatrist		
A medical doctor specializing in preventing, diagnosing, and treating mental illness	Assess the mental and physical aspects of psychological problems.	Medication Medication management Psychotherapy
Social Worker / Licensed Professional Counselor		
Licensed Clinical Social Workers (LCSW) and Licensed Professional Counselors (LPCs) are trained to evaluate and treat certain mental illnesses.	Trained in psychotherapy and help individuals deal with mental health and daily living problems.	Case management Patient & family advocacy Psychotherapy/counseling Resource facilitation

Provider Type	Function	Relevant Specializations
Speech Language Patholo	gist (SLP)	
A health professional who specializes in language and communication who may further specialize in addressing the communication and cognitive challenges that can arise after a TBI.	Provides assessment and targeted interventions for attention, processing, memory, problem-solving, and executive functions, word-finding, language comprehension, and challenges in expressing thoughts clearly.	Adaptive technologies for work or school Cognitive therapy Memory training Patient and Family education Reestablishing communication

#### **Finding Specialty 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. Certifications such as Certified Brain Injury Specialists (CBIS) can help identify these providers.

Finding care for a recent concussion (<6 weeks) can differ from persistent concussion symptoms (6 weeks to 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. Clinical capabilities and limitations vary, so be sure to continue searching until you find a good fit for you or your loved one's needs.

#### **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. Alaska currently does not have dedicated concussion clinics. If you or your loved one are considering seeking care out of state, it's crucial to conduct thorough research before selecting a concussion clinic for potential treatment. Here are five things to consider when evaluating concussion clinics:

#### How many concussion patients does the clinic see?

A healthcare provider 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?

You or 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 the care team, seek doctoral-level clinicians such as MD, DO, or a relevant PhD; advanced training level clinicians such as NP and PA; or certifications in concussion management such as Certified Brain Injury Specialist (CBIS), subject to availability.

#### Are multiple disciplines represented on staff?

Concussions are complex injuries, 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 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?

Many top-tier clinics are affiliated with hospitals or universities, and affiliated clinics tend to have more treatment or referral resources available. There are many 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 healthcare provider will ask for is a concussion history summary. Coming prepared to the first appointment will help get the individual on the road to recovery as soon as possible. It can be a challenge, especially if an experienced symptom is memory loss. Here are a few tips:

#### Start with diagnosed concussions

If the individual has been diagnosed with a concussion before, have as much information about the injury ready as possible.

- When did it happen?
- What caused the injury?
- What symptoms were experienced?
- How severe were those symptoms?
- Did symptoms change as you or they recovered?

Noting 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 equal and the severity of past concussions may be more important than the total number. How long symptoms last is a strong indicator: the longer the duration, the greater the severity. Level of disruption to daily life resulting from a symptom compared to pre-injury function is another strong indicator.

#### When they happened matters, too

The interval between injuries is important when looking at the full concussion history picture. Sustaining two concussions one-week apart is different than two concussions a year apart, even if they are of similar severity. Organizing a timeline with all past concussions can help provide background for a doctor to reference when developing appropriate return to activity or long-term concussion management plans. Be sure to have it ready for the first appointment.

#### Consider undiagnosed concussions

Just because a healthcare provider never made a diagnosis doesn't mean a concussion didn't happen. After recounting the diagnosed concussions, look at the symptoms of a concussion and try to remember instances where you or they felt any symptoms after a hit to the head. Think about past injuries in sports, recreational activities, the military, or at work. It's common for estimates to increase after reading the definition of a concussion. Remember: dings and bell ringers count.

#### <u>Alternative Treatment Options</u>

Careful thought is warranted when considering treatments that are expensive or not covered by insurance, are relatively new, or have existed for a long time but have not demonstrated effectiveness for the treatment of concussion symptoms through repeated studies in reputable peer-reviewed academic journal publications. Consider whether the potential benefits outweigh potential risk, time, and cost. The following is a list of frequently debated practices with varying levels of consensus or disagreement from medical researchers regarding effectiveness for mitigation of concussion symptoms. The extent of insurance coverage for these treatments varies among providers and insurance companies. We advise consulting with your provider to determine any potential out-of-pocket costs before proceeding with the treatment.

Treatment	Considerations			
Acupuncture				
Insertion of very thin needles through the skin at particular points on the body.	Some demonstrated evidence for pain management and reduction in inflammation in the body. Lacking reliable evidence for concussion symptom management.			
Craniosacral Therapy (CST)				
A massage technique that uses light touch to release tension around your body's connective tissue.	Lacking reliable evidence for concussion symptom management. Research needed to demonstrate efficacy for whiplash or other musculoskeletal injuries.			
Eye Movement Desensitization and Reprocessing (EMDR) / Brain Spotting (BSP)				
A psychotherapy that treats psychological symptoms following trauma.	Some emerging evidence for treatment of PTSD. Lacking reliable evidence for concussion symptom management.			
Hyperbaric Oxygen Therapy (HBOT)				
Breathing oxygen within a pressurized chamber.	No reliable evidence demonstrating effectiveness in treating concussion symptoms compared with placebo. Some demonstrated effectiveness for treatment of vascular issues.			

Treatment	Considerations		
Neurofeedback / EEG (electroencephalogram) Biofeedback			
Use of a computer program to record brainwave activity in response to auditory or visual stimuli with the intent to help patients recognize and modify thought patterns.	Some evidence for treatment of tinnitus, headache, and anxiety. Lacking reliable evidence for concussion symptom management.		
Transcranial Magnetic Stimulation (TMS)			
A procedure that uses magnetic fields to stimulate nerve cells in the brain.	Demonstrated evidence for treatment of intractable depression. Research needed for concussion symptom management.		

#### **Nutrition Guidelines**

Diet can be a helpful consideration during concussion recovery because nutrition can impact brain function. Consult a qualified medical professional, dietician, or nutritionist for individualized guidance to support recovery.

Outlined below are general guidelines based on the current understanding of how diet may positively or negatively impact recovery. Additional in-depth explorations of nutrition and concussion recovery can be found through organizations such as <u>UCLA Health</u> and <u>Brain Injury Canada</u>.

#### Consider a Mediterranean Diet

Evidence suggests that the Mediterranean Diet positively impacts overall brain health and may aid concussion recovery. This diet emphasizes whole, minimally processed foods. In particular, consuming fish, nuts, seeds, whole grains, and leafy green vegetables while avoiding large quantities of red meats.

#### Maintain general awareness of blood sugar levels

Evidence suggests maintaining stable blood sugar levels supports recovery<sup>12</sup>. For most individuals, eating regular meals every 3-4 hours helps prevent hypoglycemia (low blood sugar) and ensures a consistent supply of glucose (a simple sugar which is an important energy source for the body). During the healing process, there is an increased demand for glucose. Stable blood sugar helps support the healing process of the brain after a concussion.

#### **Monitor hydration**

Adequate water intake supports overall well-being and contributes to an effective recovery process.

#### Avoid substances that could exacerbate concussion symptoms:

- Alcohol
- Sweetened beverages (artificial or natural)
- Large quantities of sugar
- Large quantities of caffeine

#### **Additional Considerations**

#### Inflammation

While there's no direct evidence that reducing inflammation enhances concussion recovery, minimizing the consumption of inflammatory foods, such as red meat, may support the healing process by contributing to overall health.

#### **Gut Microbiome Composition**

The "gut microbiome" is a term used to describe the millions of bacteria in the intestinal tract which can impact many bodily functions. The gut microbiome can be influenced by food choices and meal consumption patterns such as timing. Taking steps to ensure a healthy gut microbiome can support overall health. While research is needed regarding potential connections between the gut microbiome and concussion recovery, studies exploring disturbances in the microbiome and their influence on neurotransmitter production are ongoing<sup>13</sup>.

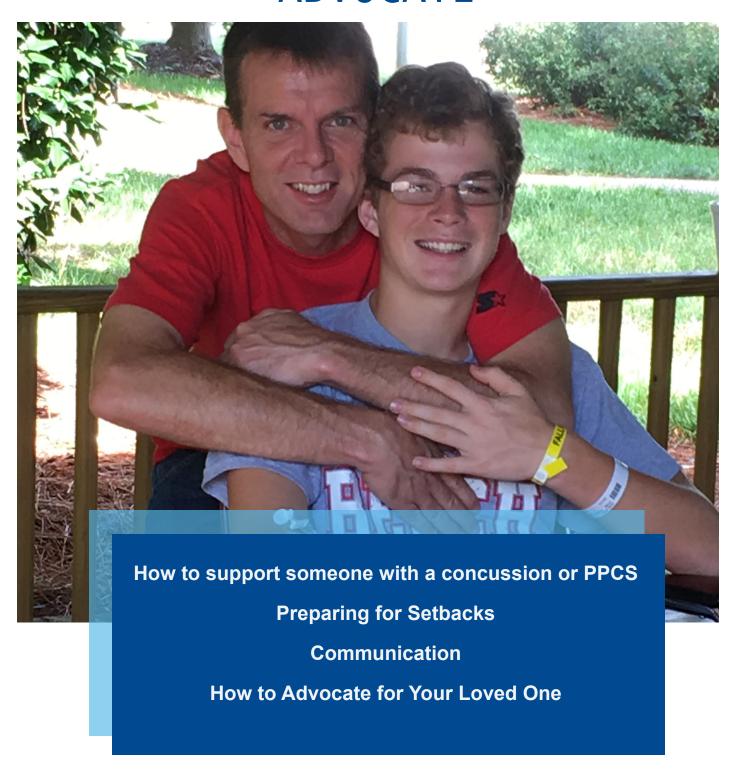
#### **Vitamins and Supplements**

The most suitable application of vitamins and supplements is to address specific nutrient deficiencies. A medical provider can conduct simple blood tests to assess levels of essential nutrients such as vitamin D, vitamin B-6, vitamin B-12, iron, magnesium, zinc, copper, and omega-3 fats. If deficiencies are identified, healthcare professionals can offer guidance on appropriate dosages and recommend any necessary nutritional or lifestyle adjustments.

Research is ongoing regarding the potential benefits of certain vitamins and supplements in concussion recovery. Vitamin D, for instance, may help in reducing inflammation and improving post-injury outcomes<sup>14-15-16</sup>. Magnesium may contribute to symptom reduction, expedite recovery, and enhance sleep quality while alleviating anxiety<sup>17-18</sup>. Omega-3 fats and DHA are also noteworthy, as they may play a role in repairing the brain and building new neural pathways<sup>19-20</sup>. However, it's important to note that current research is insufficient to establish direct links between these supplements and concussion recovery.



# 5. BEING A CAREGIVER AND ADVOCATE



#### **How to Support Someone with a Concussion or PPCS**

If you are supporting a child, spouse, family member, or close friend through concussion recovery, offering validation is a great place to start. This means believing what your loved one tells you about their symptoms and experiences. 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. Giving your loved one genuine validation and support can be more meaningful and beneficial to their recovery than you realize.

Here are additional ways to support your loved one:

- Help talk through the emotional challenges of the injury and let them know you see how challenging recovery can be.
- Be an advocate for them at school, in sports, and with healthcare providers.
- 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.

#### **Preparing for Setbacks**

Concussion recovery is not always a direct path, and no two concussions are the same. Setbacks from symptom resurgence can be disheartening. 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
- Track symptoms and explore additional treatment options

#### Communication

Many patients have trouble with interpersonal communication after a 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.

#### **How to Advocate for Your Loved One**

#### **Ensure Appropriate Screening**

Confirm that your loved one undergoes screening by medical professionals. For student athletes, the SCAT6 or most current screening tool should be utilized to gauge their injury accurately.

#### Seek Referral to Specialists

Obtaining a referral to a concussion or brain injury specialist for expert care tailored to their needs may require patience and persistence.

#### **Discuss Recommended Guidelines**

Initiate conversations with medical providers about adhering to recommended return to school, learn, play, and work guidelines. More information on these considerations are provided later in this guidebook.

#### **Engage with a Case Manager**

Work alongside a Case Manager who can guide you through the intricate advocacy process, offering valuable support and insights.

#### Secure Medical Records

Obtain a release of information or copies of medical records to bring to provider visits. Consider establishing power of attorney or a medical proxy for streamlined decision-making if your loved one is having difficulties with memory or decision-making."

#### **Ask Questions and Document Answers**

If your loved one is struggling with energy levels or cognitive function, it can help to actively participate in discussions by posing relevant questions and diligently recording responses to maintain a clear overview of your loved one's medical journey.

#### **Respect Communication Efforts**

To foster an atmosphere of respect and inclusivity in medical conversation, avoid discussing your loved one as if they are not present.

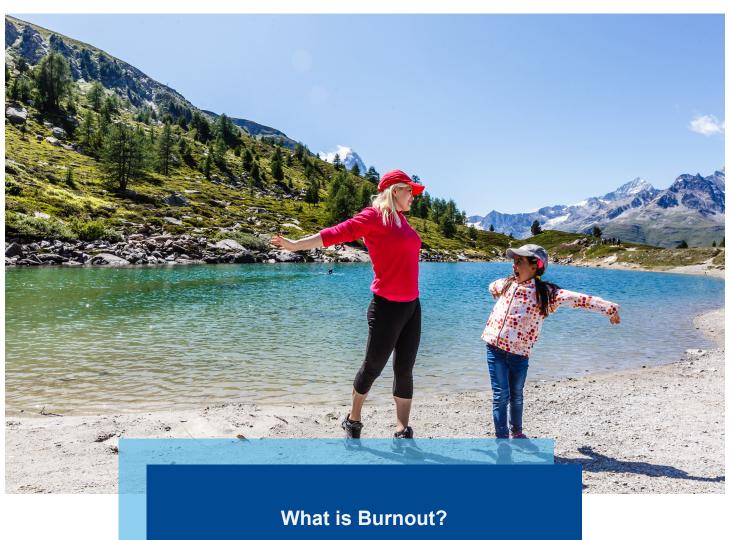
#### Collaborate with Athletic Trainers

If available and relevant, collaborate with athletic trainers on comprehensive return-to-play, return-to-learn, or return-to-work protocols for a safe return to activities.

#### Stay Organized

Keep a binder, folder, or digital record to facilitate streamlined access to essential documents and information.

# 6. SELF-CARE



What is Burnout?

Look After Yourself First

Create a Support Network for YOU

Navigating the challenges of dealing with a concussion or persistent post-concussion symptoms (PPCS), aka Post-Concussion Syndrome (PCS), can be an emotionally taxing journey whether you are the patient or a caregiver. The invisible nature of this injury adds an extra layer of complexity that can make it difficult for others to fully grasp the extent of the pain and challenges faced by a patient and their support system.

It's essential to recognize that, as someone managing the effects of a concussion or PPCS in yourself or a loved one, you may be susceptible to burnout. Prioritizing self-care becomes crucial, and seeking support from others who may be going through similar situations can make a significant difference.

Remember that you are not alone in this journey, and there are resources available to help you cope with the challenges of dealing with PPCS. Whether you're a patient or a caregiver, taking the time to care for yourself and accessing the support you need is vital in navigating the complexities of an injury that may not always be visible to others.

#### What is Burnout?

Burnout is a state of physical, emotional or mental exhaustion, accompanied by decreased motivation, lowered performance and negative attitudes towards oneself and others.

#### **Physical Signs & Symptoms**

Feeling tired and drained most of the time

Lowered immunity, frequent illnesses

Frequent headaches or muscle pain

Change in appetite or sleep habits

#### **Emotional Signs & Symptoms**

Sense of failure and self-doubt

Feeling helpless, trapped, and defeated

Detachment, feeling alone in the world

Loss of motivation

Increasingly cynical and negative outlook

Decreased satisfaction and sense of accomplishment

#### **Behavioral Signs & Symptoms**

Withdrawing from responsibilities

Isolating from others

Procrastinating, taking longer to get things done

Using food, drugs, or alcohol to cope

Taking frustrations out on others

Skipping work or coming in late and leaving early

#### **Look After Yourself First**

Setting aside time for self-care is an essential part of navigating the challenges of managing a concussion or persistent post-concussion symptoms (PPCS), whether you're a patient or a caregiver. Taking care of yourself is not only crucial for your well-being but also enables you to be more effective and supportive in your caregiving role.

As a patient, recognizing the importance of self-care is key to your overall recovery and well-being. For caregivers, dedicating time for self-care is equally vital. The demands of providing support and understanding can be emotionally taxing, making it essential for caregivers to recharge. 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
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Reading	Listening to music	Cooking	Proper rest
		5555	禁
Healthy diet	Socialization	Getting good sleep	Engaging in hobbies
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Journaling	Seeking support and help	Establishing and maintaining boundaries	Nature

# **Create a Support Network for YOU**

It is crucial to create a caring and supportive network of individuals to lean on. Engage in regular discussions with those you can trust and find reliable people who can provide support such as a friend, parent, sibling, counselor, or healthcare provider. Transparency about your experiences is key. Additionally, consider expanding your support network to include community groups or online forums where you can connect with others facing similar challenges.

#### **Create a Resource Toolbox**

A resource toolbox is your go-to list of supportive services and organizations that you can quickly access. It is always helpful to know who you can reach out to for additional support, guidance, information, and resources when times get tough.

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

Organization	Contact
Suicide & Crisis Lifeline	Dial 988
Veterans Crisis Line	Dial 988, then press 1
CopLine	1-800-267-5463
Substance Abuse & Mental Health Services Administration (SAMHSA) HelpLine	1-800-662-4357 FindSupport.gov
Mental Health First Aid	Text MHFA to 741741
National Domestic Violence Hotline	1-800-799-7233
National Alliance on Mental Illness	1-800-950-6264
Concussion Legacy Foundation (CLF) HelpLine	CLFHelpLine.org
Brain Injury Association of America (BIAA)	<u>biausa.org</u>

#### **Peer Support**

Peer support is a great way to connect with other patients and caregivers who can relate to what you are going through. The following is a list of groups and organizations offering in-person peer support options to Alaskans:

Group	Contact
Access Alaska	Anchorage: 907-248-4777 Fairbanks: 907-479-7940 Mat-Su: 907-357-2588 Kenai: 907-262-4955 Rural office (Anchorage): 907-545-0365 Email: info@accessalaska.org Website: www.accessalaska.org
Daybreak Inc.	Anchorage: 907-677-5988 Mat-Su: 907-746-6019 Email: contact@daybreakmhsc.com
Independent Living Center	Kodiak: 907-486-0493 Seward: 907-224-8711 Homer: 907-235-7911 Soldotna: 907-262-6333 Website: www.peninsulailc.org
Maniilaq Association	Phone: 907-442-7640 Website: www.maniilaq.org
Southeast Alaska Independent Living	Juneau: 1-800-478-7245 Ketchikan: 907-617-5704 or 206-491-9440 Website: www.sailinc.org

#### Online Peer Support

Organizations like the <u>Concussion Legacy Foundation</u> (CLF) and the <u>Brain Injury Association of America</u> offer virtual peer support programs throughout the country.

Patients and caregivers dealing with a recent concussion or Persistent Post-Concussion Symptoms (PPCS) can reach out to <a href="mailto:support@concussionfoundation.org">support@concussionfoundation.org</a> or through the <a href="mailto:CLF">CLF</a> HelpLine to join:

<u>CLF Zoom Support Groups:</u> Post-Concussion Patients, Post-Concussion Caregiver, and Concussed Moms Support Groups allow you to connect with other patients or caregivers across the country via Zoom.

<u>CLF PCS Resources Facebook Group</u>: An online community focused on providing resources, support, and hope to those affected by ongoing concussion symptoms and persistent post-concussion (PPCS) symptoms.

<u>CLF 1:1 Peer Support Connection</u>: CLF's Peer Support Connection program offers 1-on-1 partnerships with trained volunteers who understand the unique challenges of experiencing a concussion and having persistent symptoms or being a caregiver for someone with PPCS. 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.

# **Self Advocacy for Patients**

As a **patient**, effective self-advocacy is crucial. Here are recommendations to empower you in advocating for yourself:

**Learn the basics of brain injury:** Understanding your injury, symptoms, and treatment options equips you to advocate effectively by being well-informed about your own healthcare journey.

**Find the right providers:** Optimal care comes from providers with specialized knowledge in brain injuries. Refuse to compromise; seek professionals experienced in concussions and those you trust. For recommendations, visit <a href="https://www.CLFHelpLineAK.org">www.CLFHelpLineAK.org</a> which offers guidance on medical and mental health providers in your vicinity.

**Know your rights:** Being aware of your rights ensures that you receive fair and appropriate treatment. Familiarize yourself with your rights as a patient to advocate confidently for the care you deserve. For more information, visit <a href="https://www.dlcak.org/">https://www.dlcak.org/</a>.

**Set boundaries:** Establishing clear boundaries in your school, work, or healthcare interactions helps maintain your comfort and ensures your needs are prioritized. Communicate your limits effectively to contribute to respectful and effective relationships.

**Ask for support:** Don't hesitate to seek support from friends, family, or support groups. Asking for assistance when needed is a sign of strength, and a supportive network can play a crucial role in your recovery journey.

By incorporating these practices into your self-advocacy toolkit, you can navigate your brain injury journey with confidence and ensure you receive the best possible care.

# **Self Advocacy for Caregivers**

As a **caregiver**, advocating for both your loved one and yourself is crucial. Here are recommendations on how to effectively advocate for yourself:

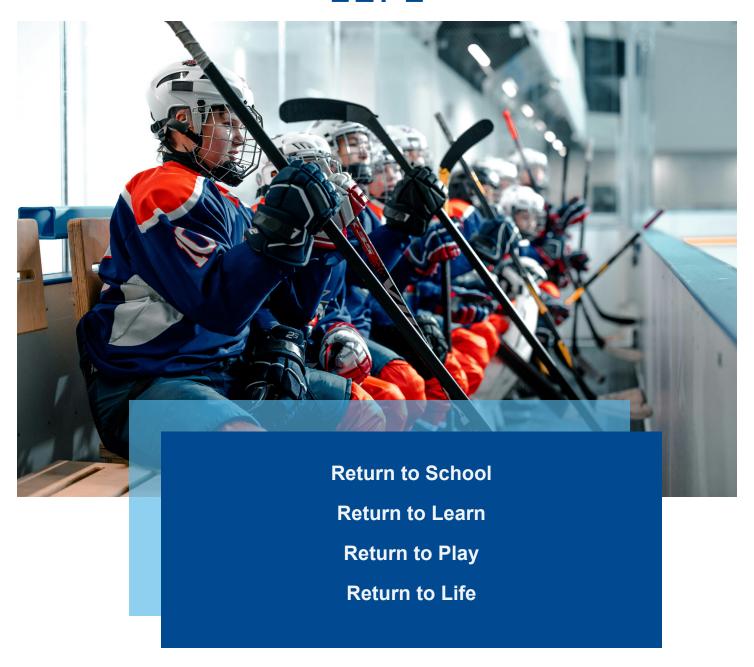
**Learn the basics of brain injury:** Understanding your loved one's injury and symptoms enables you to empathize with their experience and comprehend how their symptoms might impact you or your family. This knowledge forms a foundation for providing better support.

**Explore family resources:** Inquire with medical and mental health providers about available resources for your family. This may involve seeking family counseling, exploring respite care options, and accessing additional support services. Understanding and utilizing these resources can contribute to the well-being of both you and your loved one.

**Understand financial resources:** Brain injuries often bring additional financial challenges, from medical expenses to necessary home accommodations. Collaborating with a case manager can assist you in identifying available financial resources that can alleviate some of the economic burdens associated with the care your loved one requires.

By incorporating these strategies into your caregiving approach, you not only enhance your ability to support your loved one but also prioritize your own well-being as an essential part of the caregiving equation.

# 7. RETURN-TO-SCHOOL | PLAY | LIFE



Every concussion is unique, and recovery is different for each individual. Making short-term changes to daily activities and avoiding activities that involve a risk of reinjury is important during the healing process. Like any medical diagnosis, a concussion requires direct involvement from a doctor, nurse practitioner, athletic trainer or licensed healthcare professional with relevant training to guide a safe return to school, work, play, and life<sup>21</sup>.

When facing decisions about returning to school, learning, play, life, or work it's helpful to remember the big picture. Consider the progressive steps outlined in the Recovery from Concussion Protocol from CDC Heads Up:

## 1. Rest

You or your loved one should take it easy the first 24-48 hours after the injury when the symptoms are more severe.

- Early on, limit physical and thinking/remembering activities to avoid symptoms getting worse.
- Avoid activities that put you or your loved one at risk for another injury to the head and brain.
- Get a good night's sleep and take naps during the day as needed.

## 2. Light Activity

As you or your loved one starts to feel better, gradually return to regular (non-strenuous) activities.

- Find relaxing activities at home. Avoid activities that put you or your loved one at risk for another injury to the head and brain.
- Return to school or work gradually. If symptoms do not worsen during an activity, then this
  activity is OK. If symptoms worsen, cut back on that activity until it is tolerated.
- Get maximum nighttime sleep. (Avoid screen time and loud music before bed, sleep in a dark room, and keep to a fixed bedtime and wake-up schedule.)
- Reduce or eliminate daytime naps.

# 3. Moderate Activity

When symptoms are mild and nearly gone, you or your loved one can return to most regular activities.

- Take breaks, or help your loved one do so, only if concussion symptoms worsen.
- Return to a regular school or work schedule.

## 4. Back to Regular Activity

Recovery from a concussion is when you or your loved one are able to do all regular activities without experiencing any symptoms.

## **Return to School**

Each year hundreds of thousands of K-12 students sustain a concussion as a result of a fall, motor-vehicle crash, collision on the playground or sports field, or other activity. A student with a concussion should be seen by a healthcare provider experienced in evaluating for concussion. Teachers and school staff need to know if a student is suffering from a concussion. Coordinating with school nurses or 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. The provider should work with the family and school team to determine readiness to return to school and the types of supports or accommodations that are needed based on the number, type, and severity of symptoms experienced by the student<sup>22</sup>.

Note: Some areas within Alaska might not have a medical provider readily available to evaluate or diagnose the concussion. Community Health Aides may only indicate minor or major head injury during a clinic appointment or there could be a delay in access to medical care. In these cases, the parent/caregiver should notify the school to ensure proper monitoring and supervision for academic concerns and support occurs.

All students should be monitored at school and follow a gradual support protocol while recovering from a concussion. The full effect of the injury may not be noticeable at first and some symptoms might not show up for hours or days.

For most students, only temporary or informal academic adjustments are needed as they recover from their concussion symptoms. However, some students might experience persistent symptoms that can last for months or longer and may affect their ability to participate, learn, and perform well in school. If this is the case, a more formal educational plan may be best to consider. For more details, see the 504 Plan or Special Education/IEP Process information in the Appendix under Academic Accommodations.

Following immediate rest after a concussion, best practice suggests returning to school with the understanding that the student 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. Many school nurses also encourage students recovering from concussions to utilize their office as a quiet, dark place if a student needs to rest during the school day. It is important for students to be honest about their symptoms and know their limits to avoid increasing their symptoms and delaying their recovery. Work with your primary care provider, school, and any specialists involved to decide on a return-to-learn schedule that works best for your loved one.

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 that concussion symptoms are invisible but very real and can speak up when the student might 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.

#### **Recommended Return to School Protocol**

A comprehensive return to school plan is advised following concussion and includes steps for academic, social, physical, and life activity. Alaska has legislation that mandates schools follow a Return to Play protocol (see Return to Play section) for student-athletes following a suspected concussion, but does not specifically address the other aspects of a student's school involvement. In

Alaska, SERRC's <u>Youth Brain Injury Program</u> is a free resource for families and schools looking for additional support implementing return to school plans for students returning to school following a concussion.

A return to school protocol to support recovery within the school environment should include:

- Procedures to support students in a gradual progression from relative rest through an increasing cognitive load and return to pre-injury school participation.
- Conversations initiated by parents or guardians with their child's school to ensure procedures are in place.
- Implementation of procedures by a principal, nurse, or guidance counselor who takes the lead on temporary accommodations to avoid significantly increasing symptoms during the school day.
- Monitoring of symptoms by school officials, such as teachers, to help work with the student to gradually increase their workload while keeping track of missed assignments and assessments.



For more detailed recommendations on progressive return to school protocols, consider the steps outlined by <u>Concussion Awareness Training Tool</u> (CATT) adapted from <u>PedsConcussion</u>, partially replicated below and shown in full in the Appendix:

# 1. Return to activities of daily living and relative rest, as tolerated

Maximum of 24-48 hours

- Activities at home such as social interactions and light walking that do not result in more than mild and brief exacerbation (worsening) of concussion symptoms, such as:
  - Preparing meals
  - Housework
  - Light walking
- Minimize screen time for the first 24-48 hours following concussion.
- Avoid driving during the first 24-48 hours after a concussion.
- Contact school to create a Return to School plan.
- After a maximum of 24-48 hours after injury, BEGIN STEP 2.

## 2. Return to school activities as soon as possible, as tolerated

Returning to school as soon as possible (as tolerated) is encouraged.

- Reading or other cognitive activities at school or at home. Goal: Increase tolerance to cognitive work, and connect socially with peers.
- Take breaks and adapt activities if concussion symptom exacerbation (worsening) is more than mild and brief.
- Use of devices with screens may be gradually resumed, as tolerated.
- Clearance from your doctor is not required to return to low-risk in-person or at-home school activities.
- A complete absence from the school environment for more than one week is not generally recommended.
- Communicate with school on student's progression.
- If school activities are tolerated, BEGIN STEP 3.

# 3. Part-time or full-time days at school with accommodations, if needed

- Gradually reintroduce schoolwork.
- May require accommodations, such as:
  - Partial school days with access to breaks throughout the day
  - Academic accommodations (extra time to complete work, reduced workload) to tolerate the classroom or school environment.
- Communicate with school on student's progression.
- Gradually reduce accommodations and increase workload.
- If full days without concussion related accommodations are tolerated, BEGIN STEP 4.

#### 4. Return to school full-time

- Return to full days at school and academic activities without requiring accommodations related to the concussion.
- Note: Medical clearance is NOT required to return to school.
- Return to school and return to physical education (PE) or sports should follow return to play or return to sport.
- Full academic load with no academic accommodations related to the concussion.

## **Return to Learn**

#### **Academic Accommodations**

Among children, concussions are most common in ages 0-4 and 15-19, and their symptoms can be debilitating. A student with concussion symptoms might not be able to take a full course load or learn as easily in class because of difficulty concentrating, headaches, memory issues, irritability, fatigue, environmental sensitivity (noise/light), and other symptoms.

As students gradually increase their cognitive stimulation and attend school with temporary or informal support, some symptoms might not resolve within the first month post-concussion. If symptoms persist and continue to impact a student's learning and success at school, it may be best to consider a 504 Plan or start the IEP process, depending on severity and impact.

#### 504 Plans

Students with persistent symptoms and who require assistance to be able to participate fully in school may be candidates for a 504 plan. A 504 plan will describe accommodations to assist a student in returning to pre-concussion performance levels, given their current symptoms. For example, a student recovering from a concussion might receive environmental adaptations, temporary curriculum modifications, and behavioral strategies.

If you are interested in learning more about 504 plans and processes, please see the Appendix, contact your local school 504 coordinator, school administrator (including homeschool, private or charter school), or Youth Brain Injury Program with SERRC Alaska Educational Resource Center.

## Special Education/Individualized Education Plan (IEP) Plans

The <u>Alaska State Special Education Handbook</u> describes students who may be eligible for special education services by various eligibility categories following an evaluation to determine if their education is adversely affected. Traumatic Brain injury is one of these categories:

"To be eligible for special education and related services as a child with traumatic brain injury, a child must

- (1) exhibit an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment or both, that adversely affects educational performance;
- (2) exhibit impairments in one or more areas, including cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech caused by open or closed head injuries;
- (3) not have brain injuries that are congenital or degenerative, or induced by birth trauma;
- (4) require special facilities, equipment, or methods to make the child's educational program effective;
- (5) be diagnosed by a physician as having a traumatic brain injury; and
- (6) be certified by the group established under 4 AAC 52.125(a) (2) as qualifying for and needing special education services."

If you feel your child should be considered for the IEP Process, it is best to contact your local school administrator (homeschool, charter, and private school included), or seek assistance with the Youth Brain Injury Program with SERRC Alaska Education Resource Center. More information about the IEP Process can be found in the Appendix.

# Return to Play

If a student is suspected of having a concussion, they must be immediately removed from play, be it a game or practice. Alaska Statute requires that

- A student who is suspected of having sustained a concussion during a practice or game shall be immediately removed from the practice or game.
- A student who has been removed from participation in a practice or game for a suspicion of a
  concussion may not return to participation in practice or game play until the student has been
  evaluated and cleared for participation in writing by a qualified person who verifies they are
  trained in the evaluation and management of concussions<sup>23</sup>.

Continuing to participate in physical activity after a concussion can lead to worsening concussion symptoms, increased risk for further injury, and even death. The CDC explains, "second impact syndrome (SIS) has been reported when a second concussion occurs within hours, days, or weeks following a prior concussion. SIS causes rapid brain swelling resulting in coma or death<sup>24</sup>." Parents, coaches, and officials are not expected to be able to "diagnose" a concussion, as that is the job of a medical professional. However, they must be aware of the signs and symptoms of a concussion and if they suspect a concussion, then the student must stop playing.

All students who sustain a concussion need to be evaluated and cleared for participation by an athletic trainer or qualified person who verifies that they are currently trained in the evaluation and management of concussions. Contact the student's healthcare provider, explain what has happened, and follow their instructions. If the student is vomiting, has a severe headache, or is having difficulty staying awake or answering simple questions they should be taken to the emergency department.

#### **Return to Play Protocol**

After it is determined that a student has suffered a concussion, they may not return to play or participate until they have completed the Alaska School Activities Association (ASAA) Return to Play Protocol. Concerns over students returning to play too quickly have led state lawmakers in Alaska to pass laws stating that no player in a school-sponsored sport shall return to play following a suspicion of concussion until they are cleared by an appropriate healthcare professional. The law also mandates that coaches receive education on recognizing the signs and symptoms of concussion.

There is a minimum of 24 hours between steps in the Protocol. Some athletes complete one step each day. An individual athlete may be guided through the Protocol more slowly if they are at risk for prolonged concussion or additional brain injury. If symptoms worsen during exercise, then exercise is ended and begins the next day at the preceding day's level.

For the latest Return to Play guidelines in Alaska, please refer to: www.asaa.org.

## Alaska School Activities Association (ASAA) Return to Play Protocol

Symptomatic Stage: Physical and Cognitive Rest, then Incremental cognitive work, without provoking symptoms. If no symptoms, for 24 hours then:

- **Day 1** 15 min light aerobic activity no resistance training.
- Day 2 30 min light-moderate aerobic activity, no resistance training. Start PE Class
- **Day 3** 30 min moderate-heavy aerobic activity, no resistance training.
- Day 4 30 min heavy aerobic activity, 15 min resistance training
- Day 5 Return to Practice, non-contact limited participation
- Day 6 Return to full-contact practice
- **Day 7** Medically eligible for competition when completes RTP protocol and is cleared by qualified person

Note: If symptoms worsen at any step, the athlete should cease activity and be re-evaluated by their health care provider

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When the Return to Play Protocol has been successfully completed, the student will be examined by the responsible healthcare provider. Additional tests may be appropriate. The provider will sign a medical clearance to resume competition. Completing the Return to Play Protocol and medical examination does not mean that the brain has fully recovered from a concussion or that there is no risk in returning to competition. Participation in athletics is accompanied by risk of injury, permanent disability, and death. Having recently sustained a concussion, a student is at increased risk for another head injury.

#### Return to Learn & Return to Play Resources

- SERRC Alaska Educational Resource Center Youth Brain Injury Program
- Alaska Return To School Resources
- Alaska School Activities Association
- CDC Heads Up Returning to School After Concussion
- CDC Heads Up Returning to Sports and Activities After Concussion
- <u>CLF Concussion Game Plan Podcast Return to Learn After Concussion</u>
- REAP Concussion
- Get Schooled On Concussions

# **Return to Life**

#### **Return to Work**

When planning your return to work after a concussion, it's important to have a medical professional assess your symptoms and cognitive abilities carefully. To support a faster recovery, you might need to initially limit both physical and mental efforts. It may be advisable to restrict your work activities in the early stages of recovery to aid the healing process. Regular assessment of both your symptoms and cognitive status is suggested to guide decisions about your management and ensure a smoother recovery<sup>25</sup>.

#### **Return to Exercise**

Returning to exercise should be a gradual process after a concussion. This should be guided by your medical care team. The general guidelines given by the CDC is a four-stage progression.

#### 1. Rest

The first few days after a concussion you should rest. Limit physical and thinking/remembering activities to avoid symptoms getting worse.

## 2. Light Activity

After the first few days and as symptoms improve. Begin increasing your activity to return to non-strenuous activity. Avoid any activities that put you at risk for another head injury.

Examples include walking, non-strenous housework, relaxing activities at home, or return to work.

## 3. Moderate Activity

When symptoms are mild and nearly gone, you can return to most regular activities.

## 4. Back to Exercise

When you can do all regular activities without symptoms, you can return to exercising and continue to progress your intensity of exercise as tolerated.

# 8. ADDITIONAL SUPPORT & RESOURCES



Alaska Traumatic and Acquired Brain Injury (TABI) Program
Relevant State, Local, and Non-Profit Organizations
Military Resources

Domestic Violence/Intimate Partner Violence Resources

Legal Resources

**Concussion Legacy Foundation (CLF) HelpLine** 

# Alaska Traumatic and Acquired Brain Injury (TABI) Program

The Traumatic and Acquired Brain Injury (TABI) Program provides independent living support to Alaskans experiencing traumatic and acquired brain injuries. Services include resource facilitation, information and referral, peer support, supplemental services (mini-grants), outreach and community awareness. Please reach out to your local TABI coordinator for more assistance:

- Access Alaska: Anchorage, Eagle River, Girdwood, Fairbanks
  - o 907-248-4777 (Anchorage)
  - o 907-357-2588 (Mat-Su)
  - 907-479-7940 (Fairbanks)
- <u>Daybreak</u>: Anchorage, Eagle River, Matsu Valley
  - 0 907-390-0981
- Independent Living Center (ILC): Gulf Coast Region
  - 0 907-235-7911
- Maniilag: Kotzebue, Nome and surrounding villages.
  - 0 907-442-7887
- Southeast Alaska Independent Living (SAIL): Southeast Alaska
  - 0 800-478-7245

# Relevant State, Local, and Non-Profit Organizations

- Alaska Brain Bus
- Alaska TBI Resource Locator
- Brain Injury Council of Alaska
- Traumatic Brain Injury Center of Excellence (TBICoE)
- ASAA Sports Medicine Committee
- Alaska Native Tribal Health Consortium
- Community Health Aide Program
- Alaska Military Healthcare System
- Alaska School Nurses Association
- Alaska Disability Law Center
- Alaska Department of Health Division of Public Health Injury prevention Unit
- Alaska 211

## **Military Resources**

The views expressed in this guidebook are those of the authors and do not necessarily represent the official policy or position of the Defense Health Agency, Department of Defense, Department of Veterans Affairs, or any other U.S. government agency. For specific information, please contact the applicable agency.

## Resources for Active Duty Military, Guard, & Reserves

For **service members**, your first resource is your Primary Care Manager (PCM) at your home military base medical facility. Alternatively, you might have an off-base PCM through the Tri-Care network. Schedule an appointment with your PCM to discuss your history of head injury, and any symptoms you think might be related. Your PCM will do a medical screening. They might then prescribe one or

more treatments to address your symptoms. In some cases, they might refer you for further testing or treatment to the TBI Clinic on Joint Base Elmendorf-Richardson (JBER), the TBI Provider at Bassett Army Community Hospital on Ft. Wainwright, or to a community specialist such as a Physical Therapist or Occupational Therapist.

The Traumatic Brain Injury Center of Excellence (TBICoE) is a part of the military health care system. Its mission is to unify a system of TBI health care, reliably advancing the science for the warfighter and ready to meet future brain health challenges. The <u>TBICoE website</u> has helpful information and resources for service members, veterans, families, caregivers, and medical providers.

#### **Resources for Military Veterans**

For **veterans** enrolled in VA healthcare, your first resource is your Primary Care Provider (PCP). Your PCP could be located at the Anchorage VA Medical Center, a VA Clinic, or a private Tri-Care contracted provider office. Schedule an appointment with your PCP to discuss your history of head injury and any symptoms you think might be related. Your PCP will do a medical screening. They might then prescribe one or more treatments to address your symptoms. In some cases, they might refer you for further testing or treatment to a specialty provider either within or outside the VA.

#### **VA Clinics**

VA Clinic	Contact		
Elmendorf-Richardson	5955 Zeamer Avenue, 673rd Medical Group, Building 673 Joint Base Elmendorf-Richardson, AK 99506-3702 907-257-4700		
Mat-Su	865 North Seward Meridian Parkway, Suite 105 Wasilla, AK 99654-7241 888-353-7574		
Fairbanks	2555 Phillips Field Road Fairbanks, AK 99709-3933 907-328-1750		
Soldotna	237 West Rockwell Avenue Soldotna, AK 99669-7412 888-353-7574		
Homer	4141 Pennock Street Homer, AK 99603-7223 888-353-7574		
Juneau	709 West 9th Street, Federal Building, Suite 150 Juneau, AK 99801-1807 888-353-7574		

#### **Vet Centers for Mental Health Counseling**

Vet Center	Contact
Anchorage	4400 Business Park Blvd, Ste B-34 Anchorage, AK 99503 907-563-6966
Wasilla	851 E. Westpoint Dr, Ste 102 Wasilla, AK 99654 907-376-4318
Fairbanks	540 4th Avenue, Ste 100 Fairbanks, AK 99701 907-456-4238
Kenai	43299 Kalifornsky Beach Rd, Ste 4 Soldotna, AK 99669 907-260-7640

## Additional Resource for Veterans, Caregivers, and Families

For **caregivers** of veterans enrolled in VA healthcare, Alaska VA has a comprehensive <u>Caregiver Support Program</u>. The VA Caregiver Support Program (CSP) offers clinical services to caregivers of eligible and covered veterans enrolled in the VA care system. It provides services and support to caregivers of Veterans with TBI of all eras.

The <u>VA Polytrauma/TBI System of Care</u> website also offers fact sheets for caregivers and a guide for Caregivers of Service Members and Veterans.

In addition, several Alaska and national organizations provide support to veterans and their families.

- American Legion
- Veterans of Foreign Wars (VFW)
- Disabled American Veterans (DAV)
- Iraq and Afghanistan Veterans of America (IAVA)
- Alaska Veterans Organization for Women (AVOW)
- Team Red, White and Blue
- Student Veterans of UAA
- Alaska Healing Hearts
- Project Healing Waters
- Veterans Health Library
- Make the Connection

#### **Veterans with Vision Impairment or Neurological Visual Impairment**

Traumatic Brain Injuries could also result in having a visual impairment or neurological visual impairment. Veterans have access to a <u>VIST (Visually Impaired Service Team)</u> Coordinator. This person will be able to coordinate and advocate for specific training related to low vision or blindness related challenges. The VA has multiple <u>Blind Rehabilitation Centers</u> around the country, and Traumatic Brain Injury <u>Polytrauma</u> based centers both outpatient and inpatient.

Blind and Low Vision Rehabilitation and PolyTrauma Centers have Blind Rehabilitation Specialists available as a resource even if a veteran does not lose their vision or consider themselves to be blind.

The specialists range in discipline from Low Vision Rehabilitation, Orientation and Mobility, Vision Rehabilitation for Daily living, and Assistive Technology Specialists.

Generally, many Alaska Veterans have the opportunity to go to American Lake Blind Rehabilitation Center in Puget Sound of Washington, or receive training in Alaska through a third party vendor of the VA when approved by the VIST Coordinator. The Veterans PCP can make a referral to the VIST Coordinator, or the Veteran can initiate a conversation with the VIST Coordinator.

Alaska VA Healthcare System and Regional Office 2925 DeBarr Road Anchorage, AK 99508-2989 VIST Coordinator: 907-257-3776

## **Domestic Violence/Intimate Partner Violence Resources**

TBIs from intimate partner violence are likely underreported in Alaska. The following organizations offer resources and support:

- State of Alaska Department of Law Directory of Shelters & Victim Advocates
- Alaska Department of Transportation and Public Facilities Domestic Violence Shelters and Crisis Lines
- Alaska Network on Domestic Violence and Sexual Assault
- Abused Women's Aid In Crisis
- Alaska Housing Finance Corporation
- AWARE Resources
- Alaska Legal Services Corporation Domestic Violence Protection

# **Legal Resources**

Legal resources can be crucial for individuals who have suffered a concussion or brain injury, as these injuries can lead to numerous challenges that extend beyond just medical concerns. Individuals may face difficulties in their personal and professional lives, such as navigating insurance claims, seeking compensation for medical expenses, and addressing potential long-term disabilities.

Navigating the legal intricacies of these processes can be challenging, and seeking professional legal guidance becomes essential to ensure fair compensation for medical expenses, lost wages, and potential long-term disabilities. Please see Appendix for legal resources.

# **Concussion Legacy Foundation (CLF) HelpLine**

The <u>Concussion Legacy Foundation (CLF) HelpLine in Alaska</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 having 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: <a href="https://creativecommons.org/linearing-concussions-symptoms">CLFHelpLineAK.org</a>

#### **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 that you are not alone.

## **PCS Recovery Corner**

The Concussion Legacy Foundation launched this IGTV series, PCS Recovery Corner, featuring CLF Chief of Staff 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.

#### Videos & Webinars

- <u>Helping Your Child Cope with Post-Concussion Syndrome Pt. 1</u>: Learn strategies from parents on how to help your child cope with PCS.
- Helping Your Child Cope with Post-Concussion Syndrome Pt. 2: Learn strategies from parents on how to help your child cope with PCS.
- <u>Helping Concussion and Suspected CTE Patients in Crisis</u>: 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.
- <u>Dr. Robert Cantu on Management and Treatment of Post-Concussion Syndrome:</u> How to medically manage and treat PCS, and advice for those who are recovering from PCS.
- <u>Impact of Concussion on Vision with Dr. Len Messner</u>: How brain injuries can disrupt the visual system.
- <u>Neuroendocrine Dysfunction after Concussion: What Patients & Families Should Know:</u> If you
  or your loved one is experiencing PPCS 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.



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



<u>Caty Hastings:</u> A decade of concussions led to a series of emotional, mental, and physical challenges and a struggle to find doctors who understood concussions and the mental health symptoms they cause.



<u>Erin Payne</u>: A young gymnast's 2-year battle with PCS including providers and treatments.



<u>Jamie Martin</u>: 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 year-long 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.

# 9. CONCLUSION



The concussion recovery or caregiving journey can be incredibly challenging. From staying positive throughout your recovery or advocating for your loved one to preparing for the impact persistent symptoms can have on the whole family, the journey requires organization, patience, compassion and resourcefulness.

One of the most valuable resources for patients and caregivers 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.

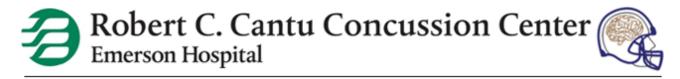
Remember that you are not alone – explore and reach out to the resources described in this guidebook if you need recommendations, support, or guidance.

# 10. APPENDIX & HELPFUL TEMPLATES

- 1. Symptom Log
- 2. Academic Accommodations & Return to School | Play
  - a. 504 Plans
  - b. IEP Plans
  - c. Brain Injury Accommodations Form
  - d. Progressive Return to School Protocol (Example)
- 3. Legal Resources
  - a. How to Select an Attorney
  - b. Questions to Ask
- 4. TBI and Alaska's Workers' Compensation System
  - a. General Principles of Workers' Compensation Law
  - b. Workers' Compensation Practical Pointers

# **Symptom Log**

<u>Click here</u> to download the PDF from the Dr. Robert C. Cantu Concussion Center at Emerson Hospital.



## TIME OF INJURY CONCUSSION SIGNS / SYMPTOMS CHECKLIST

Enter an "X" for the symptoms you experienced within 48 hours of your most recent injury/concussion.

	None	7 197	חוואו	1	Ivionerate	Severe			None		Moderate		Severe		
	0	1	2	3	4	5	6		0	1	2	3	4	5	6
Feeling In A Fog								Balance Issues							
Confusion								Blurred Vision							
Difficulty Concentrating								Double Vision							
Difficulty Remembering								Dizziness							
Don't Feel Right/ Dinged/Bell Rung								Sleeping More than Usual							
Feeling Mentally Slowed Down								Sleeping Less than Usual							
Headache/Head Pressure								Drowsy							
Numbness/Tingling								Fatigue/Low Energy							
Nausea/Vomiting								Trouble Falling Asleep							
Sensitivity to Light								Sadness							
Sensitivity to Noise								Nervous/Anxious							
Neck Pain								Irritable							
Ringing in the Ears								Feeling More Emotional							

Date	Time	Patient's Name						
For Office Use Only:								
C/6	SO	V/4 SL/5 E	_/4					
C/36	SO/42	V/24 SL/30 E	_/24					
Total Symptom Load _		mptom Score/156						
Date:	Time:	Signature:	_					
© Capyright – Na reproduct	ions without permission							

# <u>Academic Accommodations & Return to School | Play</u>

#### 504 Plans

Plans may be evaluated and adjusted annually, or at any time the team feels necessary if symptoms/ performance change. There is not a specific time frame for a student to continue to have a 504 plan, however, it should be a team mutual agreement for the plan to continue annually or discontinue.

Generally speaking, there is a 504 coordinator within the schools. The school administrator, nurse, counselor, or designated teacher may be the 504 coordinator. It is best for the temporary accommodations to be trialed first prior to establishing and implementing a plan to determine which accommodations are most beneficial for the student to be successful in the classroom. Parents/ Caregivers are able to initiate a conversation with the 504 coordinator to consult the necessity for a plan to be established.

The following excerpt is from the Alaska Department of Education and Early Development website:

Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive Federal financial assistance from the U.S. Department of Education (ED). Section 504 provides: "No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . . ."

The Office of Civil Rights (OCR) enforces Section 504 in programs and activities that receive Federal financial assistance from ED. Recipients of this Federal financial assistance include public school districts, institutions of higher education, and other state and local education agencies. The regulations implementing Section 504 in the context of educational institutions appear at 34 C.F.R. Part 104.

The Section 504 regulations require a school district to provide a "free appropriate public education" (FAPE) to each qualified student with a disability who is in the school district's jurisdiction, regardless of the nature or severity of the disability. Under Section 504, FAPE consists of the provision of regular or special education and related aids and services designed to meet the student's individual educational needs as adequately as the needs of nondisabled students are met.

For additional information, please contact the Office for Civil Rights.

#### **IEP Plans**

The local school district will have school psychologists, educators, and other specialists to conduct assessments for eligibility purposes. Upon completion of the evaluation process and if a student is determined eligible for special education services, the team will meet to establish and implement an Individualized Educational Program (IEP). The IEP should be created and mutually agreed upon by the academic team and family. The IEP consists of accommodations needed for the student to be successful in the classroom, along with goals/objectives for the student to achieve in one year, and a list of special education service minute provisions, all based on the eligibility evaluations. The IEP process and implementation must be followed according to the Federal OSEP (Office of Special Education Programs), IDEA, FAPE, and FERPA.

In some cases, a school may establish a 504 and later determine to start the IEP process, or a student may have both plans (although it's not as common). A parent/caregiver may also request to

move to an IEP and request for evaluation to determine eligibility. It is best for the parent/caregiver to share all history with the team for background information whether it is medically documented or not, for the specialist to better understand and evaluate the student's performance and abilities. If a medical provider has provided a medical diagnosis of concussion/mTBI, anoxic brain injury, cancer, stroke, etc. it is best to share the medical records with the specialists for eligibility purposes.

Students with a traumatic brain injury (TBI) may also benefit from being evaluated by a Speech and Language Pathologist, Teacher of the Visually Impaired, or Occupational Therapist, within the educational setting. This will help determine if the TBI has an adverse effect on the student's education, in order to determine eligibility for special education services.

# Alaska Return to Learn/School Following Brain Injury Accommodations

<u>Click here</u> to download the Alaska Brain Injury Accommodations Form:

#### **Return to School Protocol**

Click here to download this <u>CATT</u> tool, adapted from <u>PedsConcussion</u>:

#### **Return to School**

This tool is a guideline for managing a student's return to school following a concussion and does not replace medical advice. Every concussion is unique, and recovery is very different for each individual. Not everyone will require a Return to School Strategy. Timelines and activities may vary based on direction from a doctor, nurse practitioner, or licensed healthcare professional with relevant training. Note: For information about returning to activities that pose risk of head contact, please refer to Return to School or Return to Activity.

STEP 1:	STEP 2:	STEP 3:	STEP 4:
Activities of daily living and relative rest*  • Maximum of 24-48 hours  • Activities at home such as social interactions and light walking that do not result in more than mild and brief** exacerbation (worsening) of concussion symptoms.  Examples:  • Preparing meals  • Housework  • Light walking  • Minimize screen time for the first 24-48 hours following concussion.  • Avoid driving during the first 24-48 hours after a concussion.  Contact school to create a Return to School plan.	School activities (as tolerated)  Returning to school as soon as possible (as tolerated) is encouraged.  Reading or other cognitive activities at school or at home. Goal: Increase tolerance to cognitive work, and connect socially with peers.  Take breaks and adapt activities if concussion symptom exacerbation (worsening) is more than mild and brief.**  Use of devices with screens may be gradually resumed, as tolerated.  Clearance from your doctor is not required to return to low-risk in-person or at-home school activities.  A complete absence from the school environment for more than one week is not generally recommended.  Communicate with school on student's progression  Return to school as soon as possible, as tolerated	Part-time or full-time days at school with accomodations (if needed)  Gradually reintroduce schoolwork.  May require accomodations, such as: Partial school days with access to breaks throughout the day Academic accommodations (extratime to complete work, reduced workload) to tolerate the classroom or school environment.  Communicate with school on student's progression.  Gradually reduce accommodations and increase workload	Return to school full-time Return to full days at school and academic activities without requiring accommodations (related to the concussion).  Note: Medical clearance is NOT required to return to school For returning to P.E. or sports, please refer to Return to Sport protocol.  Full academic load (no academic accommodations related to the concussion)
After a maximum of 24-48 hours after injury, BEGIN STEP 2	If can tolerate school activities, BEGIN STEP 3	If can tolerate full days without concussion- related accommodations, BEGIN STEP 4	Return to School completed

Students should begin a gradual increase in their cognitive load with the goal of minimizing time away from the school environment. The return to school should not be restricted if the student is tolerating full days. Progression through the strategy may be slowed when there is more than a mild and brief symptom exacerbation\*\*; however, missing more than one week of school is not generally recommended. Driving should resume after consultation with a doctor, nurse practitioner, or healthcare professional.

# www.cattonline.com

Adapted from: Zemek, R., Reed, N., Dawson, J., et al. "Living Guideline for Pediatric Concussion Care." <a href="www.pedsconcussion.com">www.pedsconcussion.com</a> © BCIRPU. All rights reserved | Version 13: Updated September 2023





<sup>\*</sup>Relative rest: activities of daily living including walking and other light physical and cognitive activities are permitted as tolerated.
\*\*Mild exacerbation (worsening) of symptoms: No more than a 2-point increase when compared with the pre-activity value on a 0-10-point symptom severity scale.\*\*\* "Brief" exacerbation of symptoms: Worsening of

<sup>\*\*\*0-10</sup> point symptom severity scale: Please see the <u>Visual Analog Scale</u> for an example of a 0-10 symptom severity scale.

## **Legal Resources**

## How to Select an Attorney for Your Brain Injury Case

Brain injuries are complex and can have lasting effects on an individual's cognitive, physical, and emotional well-being. Finding an experienced and knowledgeable attorney is crucial to ensuring that you receive the proper support and compensation. Here's how to find the right attorney:

#### Step 1: Understand the Importance of Experience & Brain Injury Knowledge

Not all personal injury lawyers have expertise in brain injuries. Brain injury cases require a deep understanding of the brain, how it can be injured, how injury will present, and how often it is missed or under-appreciated by medical providers. In Alaska, where there are few resources to identify and treat brain injury, it is even more important to have an attorney who understands how these injuries occur, how they present, how they can be demonstrated through modern technologies, and the long-term effects of such injuries. The lawyer you choose should have a track record of handling similar cases and should be well-versed in the nuances of brain injury law.

#### Step 2: Research Potential Lawyers & Look for Experienced Attorneys

Contact brain injury resources in Alaska to get referrals for attorneys who are experienced in evaluating and making claims for brain injury. An internet search will normally not help as anyone can say they represent individuals with brain injuries but few lawyers have significant experience in this area.

#### Step 3: Schedule Consultations

Any Alaska lawyer who represents brain-injured individuals and or their families in personal injury litigation will not charge you for a consultation. Also, they will work on what is called a "contingency fee," meaning that they will only be paid if there is a recovery. Beware of any lawyer who wants to charge you to consult or proposes being paid by the hour for filing a personal injury lawsuit.

In the initial consultation, try to schedule it in person or by Zoom so you can see the lawyer, and she or he can see you. This will give you the best opportunity to see if you will be able to communicate and trust the attorney to do the work necessary for your case. Prepare a list of questions in advance to ensure that you cover all the necessary ground during these meetings.

#### Questions to Ask:

- How much experience do you have handling brain injury cases?
- Have you worked with medical experts in brain injury cases before?
- Can you provide examples of past cases similar to mine?
- What were the outcomes of those cases?
- How do you approach building a case for someone with a brain injury?
- What challenges do you anticipate in my case?
- How will you communicate with me throughout the process, given my cognitive impairments?

#### Step 4: Evaluate Their Experience and Resources

Experience with Experts: A knowledgeable brain injury attorney should have experience working with medical experts, including neurologists, neuroradiologists, neuropsychologists, and rehabilitation

specialists. These experts play a crucial role in establishing the extent of the injury, its impact on your life, and the future care and support you will need.

Brain Injury Cases are Expensive: Preparing a brain injury case for trial in Alaska is particularly expensive. Proving brain injury requires a team of experts, from neurologists to neuropsychologists. All are expensive. Preparing a case for trial can easily exceed \$100,000 in costs paid for experts, travel, and depositions.

#### Step 5: Consider Their Understanding of Lifetime Consequences

Comprehension of Long-Term Effects: Brain injuries can have lifelong effects, affecting your ability to work, engage in social activities, and live independently. The effects are both from the organic injury to the brain and the psychological/emotional consequences of the injury. Your attorney should understand and be able to articulate how these long-term consequences will impact your life.

Future Needs and Compensation: The lawyer should have experts (vocational rehabilitation, psychology, economists, and life care planners) to identify your long-term needs and associated costs.

#### Step 6: Assess Communication Skills and Empathy

The attorney's office should also be accessible and supportive, providing regular updates on your case and being responsive to your questions and concerns. They should offer various means of communication, such as phone calls, emails, or video conferences, to accommodate your preferences and abilities.

## Step 7: Check References and Past Client Testimonials

Ask the attorney for references or testimonials from past clients who have suffered brain injuries. Speaking directly with former clients can provide valuable insight into the attorney's capabilities, demeanor, and success in handling similar cases.

#### Step 8: Make Your Decision

After completing all these steps, you will have everything necessary to select an attorney with the skill, experience, and resources to help you.

# TBI and Alaska Workers' Compensation System

An injured worker with a brain injury can gain significant benefits under Alaska's Workers' Compensation law. The Alaska workers' comp system is very technical and too detailed for this article. However, below are some general principles applicable in all Workers' Compensation cases and some practical pointers for injured workers navigating the system.

#### **General Principles of Workers' Compensation Law**

- 1. Entitlement to workers' comp benefits is not based on fault. If the injury arises from employment, it is a worker's comp injury.
- 2. If the injury is work-related, it is presumed to be covered by workers' comp insurance, unless the employer rebuts the presumption with significant evidence.
- 3. Medical benefits for treatment of the work injury are paid until the worker reaches medical stability. Medical stability is measured by whether the workers have stopped showing signs of objective improvement from the medical care provided for a period of 45 days. If additional medical treatment is likely to bring about additional objective improvement, the worker is not medically stable.
- 4. TTD or TPD (temporary total disability or temporary partial disability) benefits are paid every two weeks while the injured worker suffers a work-related disability.
- 5. Disability is defined as "incapacity because of the injury to earn wages which the employee was receiving at the time of injury in the same or any other employment."
- 6. Time loss benefits are paid until the medical provider releases the injured worker back to work. Sometimes, benefits are paid until the worker reaches medical stability.
- 7. Once an injured worker reaches medical stability, if they have permanent impairment because of the injury, they will receive a PPI (permanent partial impairment) rating and be paid a lump sum benefit. The amount of the payment is based on the percentage of permanent impairment.
- 8. An injured worker may be entitled to limited retraining benefits depending on their circumstances. An evaluation will be ordered by the board to determine if the worker is eligible for reemployment benefits if the employee is unable to return to work for 120 days. The employee should tell the board they want an evaluation.
- 9. An employer's denial of benefits is known as a controversion. The employer must have a factual basis to support a controversion to avoid penalties for a bad faith denial of benefits.
- 10. A controversion is frequently based on the opinion of a physician hired by the insurer to conduct an evaluation for the employer or its insurance company. This is commonly referred to as an IME (independent medical evaluation).
- 11. When disputes over workers' comp benefits arise, the dispute is resolved at a hearing before the board, not a court of law.
- 12. Injured workers frequently cannot obtain legal counsel until their case has been controverted because attorneys are paid only if they obtain benefits for injured workers which had been denied by the insurance company.

- 13. All legal fees charged by an employee's attorney must be approved by the board.
- 14. Legal fees are paid to the attorney by the insurance company at the end of the case and are not deducted from the injured workers' benefits.
- 15. Workers' compensation cases are typically resolved by a negotiated settlement between the insurance company and the injured worker or by a decision from the board after a hearing at which evidence is presented.

This is just a general overview of some principles applicable to Workers' Compensation law in Alaska. For more information, review the materials on the Alaska Workers' Compensation Board website, particularly the electronic brochure entitled Workers' Comp and You - Info for Injured Workers.

#### **Workers' Compensation Practical Pointers**

- 1. All work injuries should be reported to the employer even if it does not seem to be a significant injury. If the employer resists the employee's efforts to report the injury, the injured worker should report the injury to the board by calling (907) 269-4980 and speak with a technician.
- 2. Report the injury to the board even if the employer is not insured. Benefits can be obtained from the Alaska Workers Compensation Benefits Guarantee Funds, though this is not as simple as a claim against an insurance company.
- 3. A worker who suffers an injury of any significance should promptly see a physician. The cost of medical treatment is covered by workers' comp insurance.
- 4. A worker who has suffered a concussion should be evaluated for a TBI as soon as they consult with a physician. If the physician is not experienced in evaluating a TBI, ask for a referral to a physician knowledgeable about TBIs.
- 5. The injured worker should a provide complete history of the injury and symptoms to their provider as soon as possible. If communication is difficult for the injured worker, they should bring a friend or a family member to medical appointments to help with the communication.
- 6. The injured worker should ask that objective testing be performed as soon as possible unless it is not medically recommended. The legal reason for having objective testing performed promptly is to avoid a situation where benefits are denied before testing can be completed by the treating medical provider. Once benefits are denied, the injured worker probably will be unable to afford the cost of a neuropsychological evaluation which is beneficial for treatment and to fight denial of workers' comp benefits.
- 7. Get and organize copies of all medical reports as you undergo treatment; you will need them if your claim is ever denied.
- 8. Have your healthcare provider issue off-work slips for the time you should not be working.
- 9. Have your provider issue notes describing the limitations of physical activities if applicable.
- 10. Collect and organize all out-of-pocket expense receipts; you will need them to get reimbursed from the insurance company.
- 11. List all medical travel, including dates of travel, starting and ending locations, purpose of the

travel, and distance traveled. This is necessary to be reimbursed for travel expenses.

- 12. Ask your healthcare provider to document any cognitive impairments they observe.
- 13. If testing will help document cognitive impairment, ask them to order testing. Objective evidence of impairments, to the extent it exists, strongly supports a claim for injury. The absence of objective evidence will be used against you by the insurance company.
- 14. Do not blindly trust the claims adjuster you are dealing with. Their primary obligation is to resolve your claim for as little as possible.
- 15. If a nurse case manager has been assigned to help manage your case, document communications with nurse case managers just as you would the insurance adjuster.
- 16. When possible, communicate with the insurance adjuster and nurse case manager by email so there is a record. Keep these emails.
- 17. Do not allow the insurance adjuster or nurse case manager to meet with your healthcare provider without you being present. Sometimes misrepresentations are made to treating providers which can result in the provider turning against their own patient. If you attend the meeting with the healthcare provider and the adjuster or nurse case manager, you can correct misrepresentations. Also, this allows you to know what the insurance company is thinking about your case.
- 18. You have the right to meet with your healthcare provider without the nurse case manager or insurance adjuster present. Exercise this right whenever you have questions you want answered by the healthcare provider in private.
- 19. Injured workers have a duty to cooperate with the insurance company's investigation of the claim. This duty includes signing releases so medical and financial records can be gathered and attending appointments with the insurance company doctor. Failure to cooperate can be a legitimate basis for the insurance company to deny a claim.
- 20. In your interaction with the insurance company, the nurse case manager, or the physician hired by the insurance company, do not respond with anger or deception. Be truthful in responding to all questions. Don't answer questions not asked. If you do not know an answer, say "I don't know"; do not guess.
- 21. If you think your claim is about to be denied, start searching for an attorney who is experienced in handling workers' comp cases. Be aware of the following:
  - a. There is a shortage of qualified workers' compensation attorneys so it may take time to find an attorney willing to handle your case.
  - b. Most attorneys will not accept cases without reviewing the medical records so you will improve your chances of having your case accepted if you have the medical records readily available.
  - c. Reviewing medical records takes time so do not expect to have your case immediately accepted just because you have a compelling story.
  - d. Most attorneys will not accept a case until it has been "controverted," if there is a

reasonable basis to believe the case is about to be controverted, the attorney may be willing to conduct a review of your records so they can accept the case once it is controverted.

22. Brain injury clients have unique challenges in the worker's compensation system. Depending on the seriousness of the brain injury, the worker may be unable to accurately communicate with healthcare providers and lawyers. In some circumstances, a guardian may need to be appointed to help with the communication and decision-making. In less severe brain injury cases the injured worker may be able to communicate, but not with the detail which might be available to a person without a brain injury. Thus, the injured worker may be limited in their ability to work with healthcare providers and attorneys. Detailed documentation made concurrent with the events being documented is extremely valuable. Such documentation is more reliable than memories.

For general questions regarding workers' comp issues, call the <u>Alaska Workers' Compensation Board</u> and speak with a technician. They can be reached at the following board locations:

Fairbanks: 907-451-2889Anchorage: 907-269-4980Juneau: 907-465-2790

The Workers' Compensation Board maintains a list of attorneys who regularly practice before the board. The board will provide you with that list if you make a request. You can also call the <u>Alaska Bar Association</u> referral service for a referral to a worker's compensation attorney: 907-272-0352.

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