



# Suspected CTE

# Caregiver Guidebook



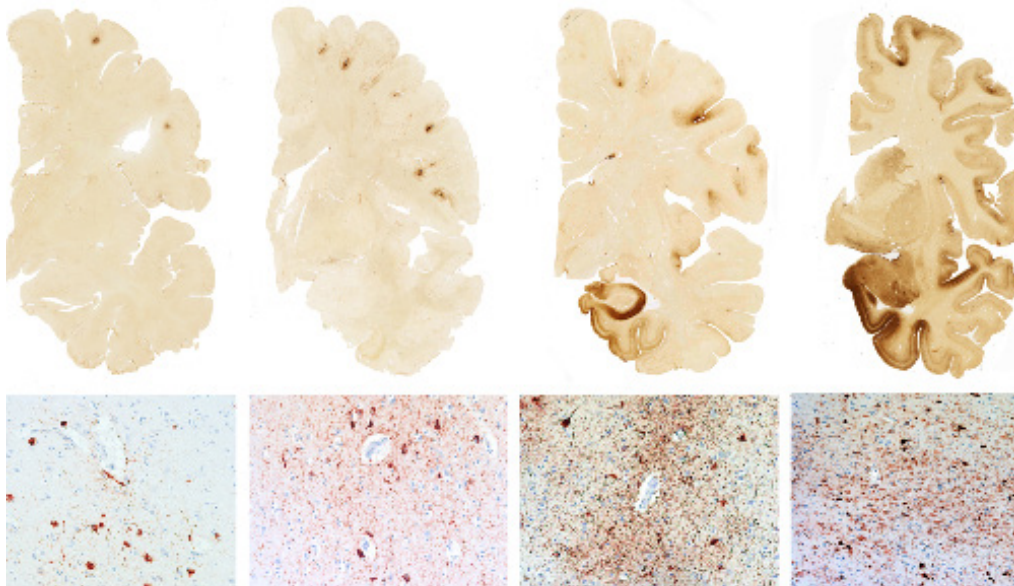


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## What is CTE?

Chronic Traumatic Encephalopathy (CTE) is a degenerative brain disease found in athletes, military veterans, and others with a history of repetitive brain trauma. CTE is caused in part by repeated traumatic brain injuries (TBI), which include which include concussions and nonconcussive impacts. In CTE, experts believe a structural protein in neurons called tau misfolds and malfunctions, causes adjacent proteins to misfold, and sets off a chain reaction where this malfunctioning tau slowly spreads throughout the brain, killing brain cells. Right now, CTE can only be definitively diagnosed by autopsy after death. CTE has been diagnosed in people who died as young as 17, but symptoms do not generally begin appearing until years after the onset of head impacts.



*Photo Credit: Ann McKee, MD*

## What Causes CTE?

CTE is caused in part by repeated TBIs, which include concussions and nonconcussive impacts. This does not mean a handful of concussions, in the absence of other hits to the head, puts you at risk for CTE; most people diagnosed with CTE suffered hundreds or thousands of head impacts over the course of many years playing contact sports, serving in the military, or, more rarely, as victims of interpersonal violence. The causal relationship was explored thoroughly in in the 2022 article [Applying the Bradford Hill Criteria for Causation to Repetitive Head Impacts and CTE](#), published in *Frontiers in Neurology*.



## What is “Nonconcussive” Impact?

To understand what a nonconcussive impact is, we first need to understand what a concussion is. Simply put, concussions are TBIs that change the way the brain functions in a way that causes symptoms or observable signs. Concussions have symptoms because the brain is shaken violently enough that brain cells are damaged to the point where they don't work properly.



Nonconcussive hits, also known as sub-concussive hits, are impacts to the head or body that do not result in symptoms or observable signs of concussion. The science is clear that nonconcussive impacts can be greater than concussive impacts and can cause unnoticed changes in brain function and microscopic changes to brain structure that cannot be measured without sophisticated tests.

## How is CTE Diagnosed?

Currently, CTE can only be definitively diagnosed after death through brain tissue analysis. Doctors with a specialty in brain diseases examine brain tissue using special chemicals to make the abnormal tau protein visible. They then systematically search areas of the brain for tau in the unique pattern specific to CTE. The process can take several months to complete, and the analysis is not typically performed as a part of a normal autopsy.

## Can CTE be Diagnosed During Life?



While a definitive diagnosis during life is not yet possible, patients with extensive history of repetitive head impacts who are experiencing symptoms can and should speak with their doctor about suspected CTE. Specialty providers such as neurologists, neuropsychiatrists, and neuropsychologists can conduct tests and assessments to rule out other diseases or conditions that may be causing symptoms. If no other causes are suspected or identified and the patient has an extensive history of repetitive head impacts, it may be appropriate to consider CTE as a possibility.

*Former NFL player Mike Adamle with wife and caregiver Kim Adamle*

Symptoms commonly associated with CTE can have many other causes including neurodegenerative diseases such as Alzheimer's Disease, Parkinson's Disease, and ALS or conditions such as hormonal imbalance, nutritional deficiency, sleep disorder, a recent traumatic brain injury, or even the normal effects of aging. Symptoms attributed to CTE can also be caused by treatable mental health disorders, post-traumatic stress disorder, substance abuse, or career transition. Whenever possible, patients should consult with medical specialists before forming conclusions or pursuing treatment.



## What are the Symptoms of Suspected CTE?

The symptoms and observable signs of CTE can vary person to person. Among individuals diagnosed with CTE, some first report mood and behavior symptoms that can appear as early as the patient’s 20s. Most patients with CTE eventually experience progressive problems with thinking and memory. Cognitive symptoms tend to appear later in life, sometimes beginning in a patient’s 40s or 50s, and are frequently the first symptom reported.

In some cases, symptoms worsen with time even if the patient suffers no additional head impacts. In other cases, symptoms may remain stable for years and mood symptoms can dissipate with treatment. Symptoms and observable signs reported in individuals diagnosed postmortem with CTE fall into a few main categories:

Cognitive	Behavioral
<ul style="list-style-type: none"> <li>▶ Impaired Memory</li> <li>▶ Impaired Attention</li> <li>▶ Executive Dysfunction</li> <li>▶ Difficulty Writing (Dysgraphia)</li> </ul>	<ul style="list-style-type: none"> <li>▶ Explosivity</li> <li>▶ Loss of Control</li> <li>▶ Short Fuse</li> <li>▶ Impulsivity</li> <li>▶ Paranoid Delusions</li> </ul>
Mood	Motor
<ul style="list-style-type: none"> <li>▶ Depression</li> <li>▶ Hopelessness</li> <li>▶ Anxiety</li> <li>▶ Fearfulness</li> <li>▶ Irritability</li> <li>▶ Apathy</li> </ul>	<ul style="list-style-type: none"> <li>▶ Loss of Coordination (Ataxia)</li> <li>▶ Slurred or Slow Speech (Dysarthria)</li> <li>▶ Parkinsonism</li> <li>▶ Tremor</li> <li>▶ Masked Facies</li> <li>▶ Rigidity</li> </ul>
Vestibular / Ocular	Sleep
<ul style="list-style-type: none"> <li>▶ Balance Issues</li> <li>▶ Blurred Vision</li> <li>▶ Double Vision</li> <li>▶ Dizziness</li> </ul>	<ul style="list-style-type: none"> <li>▶ REM Behavior Disorder</li> </ul>

## Who is Most at Risk for CTE?

Every person diagnosed with CTE\* has one thing in common: a history of repetitive hits to the head. CTE is most frequently found in contact sport athletes and military veterans. CTE has been found at the [UNITE Brain Bank](#) in individuals whose primary exposure to head impacts was through tackle football, the military, hockey, boxing, rugby, soccer, pro wrestling, and, in fewer cases, baseball, basketball, intimate partner violence, and individuals with developmental disorders who engaged in head banging behaviors.

Importantly, not everyone who has suffered repetitive hits to the head will develop CTE. There are several risk factors at play that make some people more prone to develop CTE than others, including the age of first exposure to head impacts, the number of years of exposure, and genetics.

\* A 2023 review found 97% of CTE cases have confirmed exposure to repetitive head impacts. There are only 3 cases in the literature where CTE is reportedly diagnosed in the absence of head impacts in individuals where sports history is known. <https://www.bumc.bu.edu/busm/2023/02/10/review-article-strengthens-evidence-that-repetitive-head-impacts-can-cause-cte/>



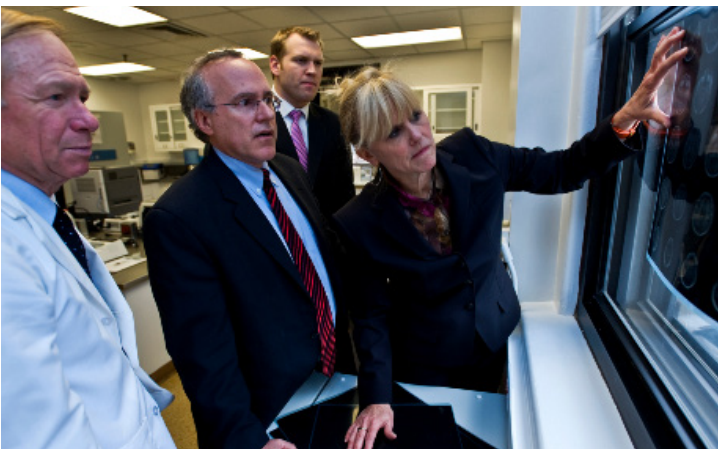


# Building a Foundation of Medical Support

If you are concerned that you or someone you care about has CTE, you are not alone. There is help. Many symptoms of CTE are treatable, and resources are available to help you find support and live a full life. It is also important to know that people who appeared to have CTE while alive have been found not to have CTE upon post-mortem examination of their brain.

One of the most important steps toward caring for your loved one is establishing a foundation of medical and mental health providers and treatments. No two suspected CTE cases are exactly alike. Similarly, no two treatment approaches are exactly alike.

## Finding the “Right” Doctor



*(L-R) Robert Cantu, MD; Robert Stern, PhD; Chris Nowinski, PhD; Ann McKee, MD*

Finding doctors who are familiar with CTE is a challenge. Medical education and training are still catching up with the latest research, so there are not many providers familiar with CTE and far fewer who advertise expertise in CTE.

When searching for a specialist to help treat suspected CTE, try looking for a clinician who specializes in evaluating and treating brain disorders involving cognitive, mood, and behavioral difficulties. This doctor may be a neurologist (especially a cognitive or behavioral neurologist), a psychiatrist (especially a neuropsychiatrist), a psychologist (especially a neuropsychologist), or a physiatrist (especially

one that specializes in brain injury).

Because CTE is a neurodegenerative disease, a clinician who specializes predominantly in concussions or TBI may not be appropriate for older patients. Rather, a clinician who understands disorders such as Alzheimer’s disease, frontotemporal dementia, and related conditions may be more appropriate.

However, individuals in their 20s and 30s with a history of concussion may be best served by an expert in concussions or TBI. Experts believe that symptoms sometimes attributed to CTE in younger people may instead be caused by other consequences of head impacts, including damage to the white matter of the brain and vascular changes. If you are struggling to find the right doctor, reach out to the [CLF HelpLine](#) to find providers in your area.

## Suspected CTE Treatments

There have been very few studies on how to treat the clinical symptoms of CTE, and even fewer clinical trials exploring innovative therapies that could slow or stop the progression of the disease. Part of the reason for the lack of studies on CTE is because CTE cannot yet be diagnosed with a known level of statistical accuracy in living patients.



The good news is that there are many therapies available to treat the symptoms associated with CTE so that patients can have a better quality of life. If you suspect your loved one may have CTE, it is also important to remember they may be dealing with another condition that presents similar symptoms and might not have the disease. Therefore, focusing on treating the symptoms is currently the best approach.

## Evidence-Based Treatment Practices

The treatments listed in the tables below are supported by peer-reviewed scientific studies for addressing symptoms associated with dementia, mild cognitive impairment, and behavioral health challenges which may or may not be due to suspected CTE.

At this time, CLF is not listing experimental or off-label therapies that lack peer-reviewed evidence. If you are thinking about trying therapies not listed below, it is important to consider if the potential benefits are worth both the risks, time, and costs. Be skeptical of treatments that are expensive and not covered by insurance, especially therapies that have existed for a long time and have still not produced enough peer-reviewed evidence of effectiveness to be reimbursed by insurance for treatment of dementia or mild cognitive impairment.

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

Treatment	Symptoms Targeted	Typical Providers
<b>Cognitive Behavioral Therapy (CBT)</b>		
A psychological therapy frequently used to treat mood and behavior.	<ul style="list-style-type: none"> <li>▶ Depression</li> <li>▶ Anxiety</li> <li>▶ Impulsivity</li> </ul>	<ul style="list-style-type: none"> <li>▶ Clinical Psychologist</li> <li>▶ Mental Health Counselor</li> <li>▶ Social Worker</li> <li>▶ Occupational Therapist</li> </ul>
<b>Cognitive Rehabilitation Therapy (CRT)</b>		
Also known as cognitive therapy. A goal-oriented rehabilitation approach to restoring and improving functional cognitive skills.	<ul style="list-style-type: none"> <li>▶ Attention</li> <li>▶ Memory</li> <li>▶ Executive functioning</li> <li>▶ Word-finding skills</li> <li>▶ Cognitive decline</li> </ul>	<ul style="list-style-type: none"> <li>▶ Speech and Language Pathologist</li> <li>▶ Occupational Therapist</li> </ul>
<b>Diet</b>		
<p>Healthy diet is important because vascular disease, hypertension, obesity, and diabetes are risk factors for dementia.</p> <p>The Mediterranean Diet with vegetables, leafy greens, lean meats, and fish is recommended. Avoid an “atherogenic” diet, frequent consumption of red meats, and food high in cholesterol.</p>	<ul style="list-style-type: none"> <li>▶ Overall physical health and wellbeing</li> <li>▶ Heart &amp; vascular health</li> </ul>	<ul style="list-style-type: none"> <li>▶ Primary Care Physician</li> <li>▶ Physician Nutrition Specialist</li> <li>▶ Registered Dietician Nutritionist</li> </ul>



Treatment	Symptoms Targeted	Typical Providers
<b>Endocrinology</b>		
Specifically, neuroendocrine assessment of pituitary function to determine if an initial TBI has caused hormonal imbalance.	Treatment resistant: <ul style="list-style-type: none"><li>▶ Brain fog</li><li>▶ Fatigue</li><li>▶ Listlessness</li><li>▶ Depression</li></ul>	▶ Endocrinologist
<b>Exercise</b>		
Aerobic and resistive exercise under the guidance of a medical professional.	<ul style="list-style-type: none"><li>▶ Anxiety</li><li>▶ Mood</li><li>▶ Cognitive decline</li><li>▶ Lethargy</li></ul>	<ul style="list-style-type: none"><li>▶ Physiatrist</li><li>▶ Physical Therapist</li><li>▶ Athletic Trainer</li></ul>
<b>Medication</b>		
Certain pharmacologic interventions are available to treat physical, mood, behavior, and cognitive symptoms.	<ul style="list-style-type: none"><li>▶ Memory loss</li><li>▶ Trouble thinking/ concentrating</li><li>▶ Depression</li><li>▶ Headache</li><li>▶ Anxiety</li><li>▶ Agitation/rage</li><li>▶ Sleep</li></ul>	<ul style="list-style-type: none"><li>▶ Psychiatrist</li><li>▶ Neurologist</li><li>▶ Primary care</li></ul>
<b>Meditation</b>		
Meditation is a practice where an individual uses a technique such as mindfulness to train attention and awareness to achieve a mentally clear and emotionally calm and stable state.	<ul style="list-style-type: none"><li>▶ Sleep disturbances</li><li>▶ Anxiety</li><li>▶ Attention deficits</li></ul>	<ul style="list-style-type: none"><li>▶ Licensed counselor trained in mindfulness or meditation</li><li>▶ Apps: Calm, Headspace, Insight Timer to find a guided meditation practice.</li></ul>
<b>Neuropsychology</b>		
A branch of psychology focused on how the brain and nervous system influence a person's cognition and behavior.	<ul style="list-style-type: none"><li>▶ Memory</li><li>▶ Word finding</li><li>▶ Concentration</li><li>▶ Motor function</li><li>▶ Multitasking</li><li>▶ Depression</li><li>▶ Anxiety</li><li>▶ Impulsivity</li></ul>	▶ Neuropsychologist





Treatment	Symptoms Targeted	Typical Providers
<b>Neuropsychological Testing</b>		
<p>Includes cognitive testing, dementia rating scales, mood scales, behavioral scales, and sleep to assess patient deficits.</p>	<ul style="list-style-type: none"> <li>▶ Impaired memory</li> <li>▶ Impaired attention</li> <li>▶ Executive dysfunction</li> <li>▶ Depression</li> <li>▶ Suicidality</li> <li>▶ Anxiety</li> <li>▶ Irritability</li> <li>▶ Apathy</li> <li>▶ Physical violence</li> <li>▶ Verbal violence</li> <li>▶ Explosivity</li> <li>▶ Loss of control</li> <li>▶ Short fuse</li> <li>▶ Impulsivity</li> <li>▶ Paranoid delusions</li> </ul>	<ul style="list-style-type: none"> <li>▶ Neuropsychologist</li> </ul>
<b>Occupational Therapy (OT)</b>		
<p>The therapeutic use of everyday activities to help patients develop, recover, improve and maintain the skills needed for daily living and working.</p>	<ul style="list-style-type: none"> <li>▶ Fatigue</li> <li>▶ Headache</li> <li>▶ Dizziness</li> <li>▶ Sleep</li> <li>▶ Memory loss</li> <li>▶ Concentration</li> <li>▶ Processing speed</li> <li>▶ Language</li> <li>▶ Communication</li> <li>▶ Executive function</li> <li>▶ Vision impairment</li> </ul>	<ul style="list-style-type: none"> <li>▶ Occupational Therapist</li> </ul>
<b>Physical Therapy</b>		
<p>A wide discipline of medicine treating ailments through physical means.</p>	<ul style="list-style-type: none"> <li>▶ Motor symptoms</li> <li>▶ Parkinsonism</li> <li>▶ Ataxia</li> <li>▶ Tremor</li> <li>▶ Rigidity</li> <li>▶ Atrophy</li> </ul>	<ul style="list-style-type: none"> <li>▶ Psychiatrist</li> <li>▶ Physical Therapist</li> </ul>
<b>Psychiatry</b>		
<p>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.</p>	<ul style="list-style-type: none"> <li>▶ Personality changes</li> <li>▶ Anger/Rage</li> <li>▶ Depression</li> <li>▶ Sustained hyperactivity (Mania)</li> <li>▶ Paranoia</li> <li>▶ Detachment from reality (Psychosis)</li> <li>▶ Substance abuse &amp; addiction</li> </ul>	<ul style="list-style-type: none"> <li>▶ Psychiatrist</li> </ul>



Treatment	Symptoms Targeted	Typical Providers
<b>Vestibular Therapy</b>		
A wide range of techniques, including habituation exercises, gaze stability training, and balance training.	<ul style="list-style-type: none"> <li>▶ Persistent dizziness</li> <li>▶ Vertigo</li> <li>▶ Balance problems</li> <li>▶ Headaches</li> </ul>	<ul style="list-style-type: none"> <li>▶ Neurologist</li> <li>▶ ENT</li> <li>▶ Physiatrist</li> <li>▶ Physical Therapist</li> </ul>
<b>Vision Therapy</b>		
Range of techniques designed to help train specific aspects of the visual system.	Sensitivity to motion Eye strain Headaches Nausea Dizziness/balance Sensitivity to light Blurry vision Double vision Peripheral vision Convergence issues	<ul style="list-style-type: none"> <li>▶ Neuro-Ophthalmologist</li> <li>▶ Neuro-Optometrist</li> <li>▶ Physiatrist</li> <li>▶ Physical Therapist</li> <li>▶ Occupational Therapist</li> </ul>

## Types of Providers

The providers listed below can be relied upon for assessments and evidence-based treatment practices to address dementia, mild cognitive impairment, and behavioral health challenges that may or may not be due to suspected CTE.

Provider Type	Function	Relevant Specializations
<b>Case Manager</b>		
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 caregiving.	<ul style="list-style-type: none"> <li>▶ Advocacy and mediation</li> <li>▶ Appointment reminders</li> <li>▶ Insurance coverage</li> <li>▶ Connection to resources</li> <li>▶ Medical record transfers</li> </ul>
<b>Clinical Psychologist</b>		
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.	<ul style="list-style-type: none"> <li>▶ Adjustment issues</li> <li>▶ Emotional and psychological problems</li> <li>▶ Interpersonal or social problems and dysfunction</li> <li>▶ Behavioral problems</li> <li>▶ Intellectual, cognitive, and neurological conditions</li> </ul>



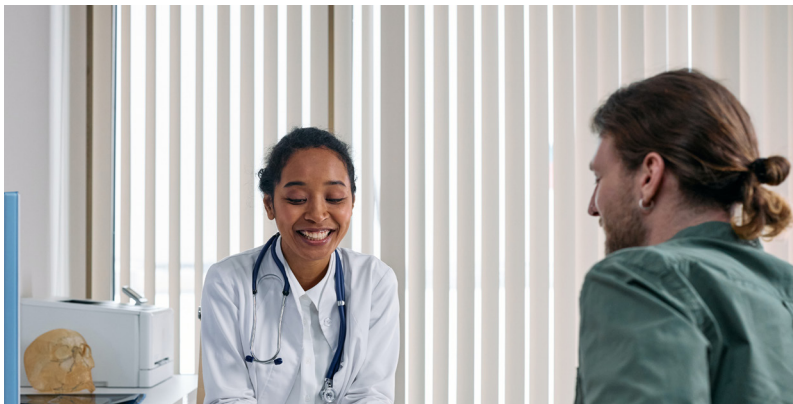
Provider Type	Function	Relevant Specializations
<b>Neurologist</b>		
A medical doctor with specialized training in managing disorders of the brain and nervous system.	Treat disorders of the brain, spinal cord, nerves, and muscles.	<ul style="list-style-type: none"><li>▶ Neurologic assessments</li><li>▶ Neurodegeneration</li><li>▶ Behavioral dysregulation</li><li>▶ Memory loss</li><li>▶ Headache</li><li>▶ Seizures</li><li>▶ Blood panels</li><li>▶ CT/MRI scans</li><li>▶ Sleep disturbances</li></ul>
<b>Neuro-Ophthalmologist</b>		
A medical doctor who sub-specializes in neurology and ophthalmology.	Diagnose and treat visual problems related to the nervous system (vision problems that do not necessarily come from the eyes themselves).	<ul style="list-style-type: none"><li>▶ Neuro-Optometric Rehabilitation therapy</li><li>▶ Rehabilitation referrals</li><li>▶ Broad medical or surgical options</li><li>▶ Vision therapy</li><li>▶ Eye training</li></ul>
<b>Neuro-Optometrist</b>		
An optometrist with an additional year of training to specialize and work in vision therapy and neuro-optometry.	Comprehensive evaluations of sensory motor, visual field, accommodative, and oculomotor function.	<ul style="list-style-type: none"><li>▶ Neuro-Optometric Rehabilitation therapy</li><li>▶ Vision therapy</li><li>▶ Eye training</li><li>▶ Corrective lenses</li></ul>
<b>Neuropsychologist</b>		
A licensed clinical psychologist specializing in how the brain affects behavior.	Administer certain types of cognitive and emotional tests.	<ul style="list-style-type: none"><li>▶ Neuropsychological assessments of cognitive function</li><li>▶ Clinical psychotherapy</li></ul>
<b>Occupational Therapist</b>		
A medical professional who specializes in activities of daily living.	Assess patients' needs and help patients develop, recover, improve, and maintain the skills needed for daily living and working by the adaptation of movement, improving motor skills, hand-eye coordination, or learning to do tasks in new ways.	<ul style="list-style-type: none"><li>▶ Adaptive equipment recommendations for home</li><li>▶ Cognitive rehabilitation</li><li>▶ Vision therapy</li></ul>



Provider Type	Function	Relevant Specializations
<b>Physiatrist (Physical Medicine and Rehabilitation Specialist)</b>		
A medical doctor specializing in the field of physical medicine and rehabilitation.	Treat problems of all the major systems in the body and medical conditions affecting the brain, spinal cord, joints, bones, nerves, tendons, ligaments, and muscles.	<ul style="list-style-type: none"><li>▶ Physical rehabilitation</li><li>▶ Vestibular rehabilitation</li><li>▶ Neck pain</li><li>▶ Headache</li></ul>
<b>Physical Therapist</b>		
A medical professional who specializes in rehabilitative medicine.	Provides services that help restore body function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities from an injury.	<ul style="list-style-type: none"><li>▶ Physical rehabilitation</li><li>▶ Vestibular rehabilitation</li><li>▶ Neck pain</li><li>▶ Headaches</li></ul>
<b>Primary Care Provider (PCP)</b>		
A medical doctor who practices general healthcare and addresses a wide variety of health concerns. Other titles: Family Practice Physicians Internal Medicine Physicians Clinical Nurse Practitioners Physician Assistants	Coordinates the ongoing care of all your family member's general medical needs.	<ul style="list-style-type: none"><li>▶ First-line care and guidance</li><li>▶ Referral to specialists</li><li>▶ Care coordination and centralization</li><li>▶ Medication</li></ul>
<b>Psychiatrist</b>		
A medical doctor specializing in preventing, diagnosing, and treating mental illness.	Assess the mental and physical aspects of psychological problems.	<ul style="list-style-type: none"><li>▶ Psychotherapy</li><li>▶ Medication</li><li>▶ Medication management</li></ul>
<b>Social Worker</b>		
A mental health professional trained to evaluate and treat mental illnesses and offer support to address external or material challenges.	Trained in psychotherapy and help individuals deal with mental health and daily living problems.	<ul style="list-style-type: none"><li>▶ Psychotherapy/ counseling</li><li>▶ Patient &amp; family advocacy</li><li>▶ Case management</li><li>▶ Resource facilitation</li></ul>
<b>Speech Language Pathologist (SLP)</b>		
A health professional who specializes in language and communication.	Evaluates and diagnoses underlying problems. Develops personal rehabilitation plans for cognition, communication, and swallowing disorders.	<ul style="list-style-type: none"><li>▶ Reestablishing communication</li><li>▶ Adaptive technologies for work or school</li><li>▶ Cognitive therapy</li><li>▶ Memory training</li></ul>



## Talking With Medical & Mental Healthcare Providers



Communicating with providers is another important step to receiving proper assessment and care. Coming prepared for the first appointment will help.

If your situation allows, it can be helpful to obtain a [medical release](#), or permission, to communicate with your loved one's providers. Ask your loved one about this option and obtain the necessary paperwork from their medical provider.

If you are not able to join your loved one's appointments or communicate with their providers, you can still help them remember their appointment times and gather the best information ahead of the visit.

It can be a challenge, especially if they are experiencing memory loss. Here are a few tips:

### 1. Compile the history of exposure to repetitive head impacts (RHI)

One of the first things a doctor will ask for is a summary of your loved one's history of exposure to brain trauma. This should include cumulative exposure to repetitive head impacts from contact sports, military service, intimate partner violence, domestic abuse, occupational hazard, or similar. List the types of exposure and the number of years. Include concussions, TBIs, or any other possible causes of symptoms such as acquired brain injuries.

### 2. Compile the history of symptoms

Here, you can help your loved one by sharing the signs you have observed and asking them to describe symptoms they are experiencing.

Ask your loved one what changes they notice getting in the way of daily life. They may describe trouble thinking or concentrating, forgetfulness, difficulty with planning daily tasks, substance abuse, emotional outbursts, depression, anxiety, or social withdrawal. Note these and any other symptoms that are disrupting the patient's life. If you can, note how long they have been experiencing these symptoms and whether they are getting worse over time.

### 3. Compile the history of medical assessments and treatments

If your loved one has already undergone assessments or treatments, do your best to track down records.

What, if any, other assessments have been conducted? Relevant information about CT or MRI scans, blood work, neurological or neuropsychological assessments will be helpful.

What, if any, treatments have been tried? If your loved one received medical or mental health care previously, it will be helpful to note what was tried and whether the treatments were effective or ineffective for addressing their symptoms.



## 4. Consider other possibilities

Lastly, it's important to consider whether symptoms could be partially or fully explained by or attributed to another cause.

What, if any, other issues are they experiencing? What, if any, family history of similar issues does your loved one have?

## Considerations for Finding Medical Care to Address Symptoms of Suspected CTE

When pursuing assessments and treatments for CTE, consider your loved one's age and history of exposure to repetitive head impacts (RHI). For most patients, a primary care physician can be a good starting point to begin the referral process for assessment and treatment options.

If your loved one has experienced a concussion or TBI within the last several years, look for a referral to a concussion or TBI specialist in neurology, neuropsychology, physical medicine and rehabilitation, sports medicine, or psychiatry for behavioral health concerns. Regardless of your loved one's age, a TBI specialist will be best equipped to address symptoms from a TBI within the last few years, especially if your loved one does not have a history of exposure to RHI from sources such as contact sports, military service, intimate partner violence or domestic violence, or similar.

If your loved one has not experienced a concussion or TBI within the last several years, but does have a history of exposure to RHI, look for a referral to specialists to address the specific symptoms they are experiencing. For mood and behavior symptoms, such as anxiety, depression, or anger, providers trained in neuropsychiatry, psychiatry, neuropsychology, psychology, and mental health counseling are good options. For memory or cognition symptoms, providers trained in behavioral neurology and neuropsychiatry may be good options.

If it has been decades since your loved one experienced a concussion or TBI, and they have a history of exposure to RHI, also look for a referral to providers to address the specific symptoms they are experiencing. Additionally, patients older than middle-age may consider looking for referral to dementia or neurodegeneration specialists at a Memory and Aging Care facility, for example. Reach out to the [CLF HelpLine](#) for support finding these types of providers.





# Living With Suspected CTE

It is important to know that people who appeared to have CTE while alive have been found not to have CTE upon post-mortem examination of their brain. Nonetheless, when a patient with extensive history of exposure to brain injury and symptoms associated with CTE has consulted a team of medical professionals who rule out other possible causes, it may be appropriate to consider suspected CTE as a possibility.

Remember that CTE is not a death sentence, and you are not alone. Targeting symptoms with treatments can dramatically improve quality of life and resources are available to help.



*Former NFL player Mike Adamle with wife and caregiver Kim Adamle*

## Tips for Daily Living

If you are concerned your loved one is dealing with suspected CTE, there is much they can do to help maintain a healthy and enjoyable life. The following are tips for daily living you can work on with your loved one:

### **1. Write things down**

Writing things down can help with productivity and maintaining a sense of control over daily life. Whether you keep a notebook, use voice memos, or put in calendar reminders on your phone, a system can help.

### **2. Develop a routine**

Create a structured environment by planning tasks to complete and goals to accomplish. The goal is to create a sense of stability. Whether it's sleep, cooking breakfast, or going for a nature walk, developing a routine and approaching tasks one at a time can make life more manageable.



### **3. Recognize and control impulsive behaviors**

Studies show CTE can damage parts of the brain that regulate impulsive behaviors. Be cognizant of unhealthy habits like gambling, overspending money, using alcohol, drugs, or other addictive substances to cope with problems. Avoid these activities as needed or seek professional help.

### **4. Self-regulate**

Managing emotion, anxiety, and stress is an important learned skill. Practice relaxation techniques like deep breathing, meditation, or counting to 10 to help ensure emotions don't spiral out of control. Encourage your loved one to seek professional help to find the right techniques.

### **5. Build a support system**

Reaching out to people you trust can help get you through moments of stress. Friends, family, colleagues, a church community, a hobby or sport, or a crisis hotline like the [Suicide & Crisis Lifeline](#) can all serve as sources of support.

### **6. Get good sleep**

Encourage your loved one to get good sleep. Your body needs a full night of rest every night to function at its best. Sleep disorders like sleep apnea can cause mental foggy, and poor sleep can affect self-regulation and emotion. Strive to be disciplined in your sleep habits and seek professional help to develop good sleep hygiene or address sleep disorders.

### **7. Exercise**

Regular exercise can relieve stress, help with pain, and improve overall well-being. Brain health and heart health are closely related - what is good for the heart is also good for the vascular system in the brain. Regular aerobic and resistive exercises are best. Consult a doctor before beginning a program.

### **8. Diet**

Vascular disease, hypertension, overweight, and diabetes are independent risk factors for dementia and should be avoided. Maintaining a well-balanced diet can help improve mood and regulate energy levels. Studies have shown the Mediterranean diet with lots of green vegetables and fish, avoiding red meat and foods high in cholesterol, is helpful. Consider consulting a dietitian.

### **9. Maintain hope**

It is crucial that someone who is concerned they may be living with CTE remains hopeful. CTE is not a death sentence. Not everyone with CTE experiences rapid decline or mental health crisis. Do not give up. There are ways to feel better, to communicate better, to stop repeating harmful behaviors, and to get to the next day. Every day is an opportunity to feel better and experience improved quality of life with loved ones or activities that bring joy.

### **10. Ask for help**

It is okay to feel anxious or worried if you believe you or a loved one may have CTE. But you don't have to cope alone. If you are in emotional crisis or concerned about a loved one, call the [Suicide & Crisis Lifeline](#) at 988 to connect with a trained counselor. It's free, confidential, and available to everyone in the United States. You or your loved one do not need to be suicidal to call. Reach out to the [CLF HelpLine](#) for more support and resources.



# Being a Caregiver and Advocate

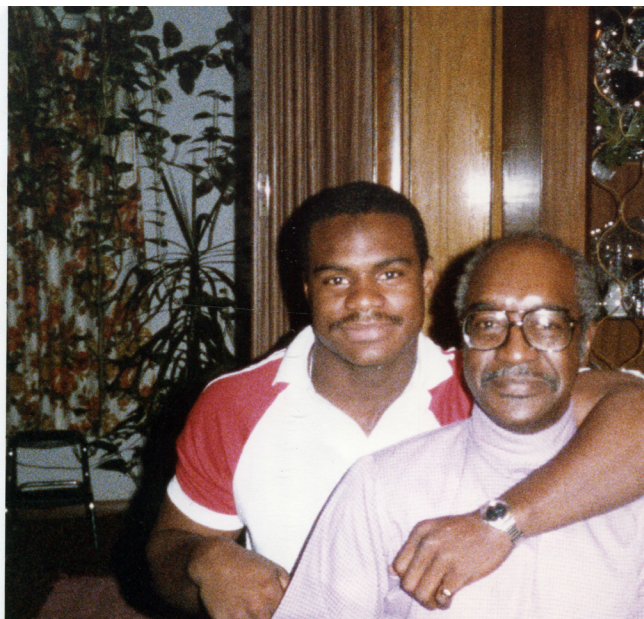


Being a CTE caregiver can present enormous challenges, and caregivers are often so busy looking after their loved one they forget, or do not have enough time, to care for themselves. We understand how overwhelming this can feel. We want to equip you as a caregiver with the tools and resources you need to support yourself and your loved one with suspected CTE.

## Anticipating Challenges

CTE is a complex condition with many unique challenges. It can be helpful to understand what to expect early in the caregiver journey. This is a list of some of the common challenges patients and families face:

- ▶ Because CTE is an “invisible” disease others may not understand or be aware of what’s going on. Caregivers often report feelings of isolation and helplessness.
- ▶ Some clinicians are not educated about CTE, and there is no diagnosis during life yet. You may have a negative experience with a provider who either does not understand or will not address your loved one’s concerns.
- ▶ Safety can be a concern for family & professional caregivers. In comparison to other neurodegenerative diseases and causes of dementia, suspected CTE often affects younger men who are usually larger and stronger than average.
- ▶ CTE can strike during the productive years of having a family and career. This can cause disruption for patients and families at particularly vulnerable times.
- ▶ Some problems from CTE can lead to or exacerbate alcohol and other substance abuse. This makes recovery more difficult and relapse more likely; substances can worsen symptoms.
- ▶ CTE may exaggerate other mental health struggles such as PTSD and/or TBI. It can be difficult to differentiate the cause of symptoms, and research is ongoing to understand how these disorders can relate to each other, and how that might impact treatment.



*Former NFL player and CLF Legacy Donor Dave Duerson (left)*



## Communicating With Suspected CTE Patients

Many patients with suspected CTE have trouble with interpersonal communication. It's important to keep this in mind as you work with your loved one.

### **Common Obstacles**

- ▶ **Cognitive Impairment:** Your loved one may not be able to remember new information, think logically, or reason flexibly. They may not be able to plan, organize, or multitask well at all.
- ▶ **Neurobehavioral Dysregulation:** Your loved one may lose the ability to filter thoughts or emotions. Escalating anger and rage may become a problem. The ability to control behavior and emotion may be reduced and underlying mental health or interpersonal issues may be exacerbated.

You deserve to be treated with respect when caring for your loved one. The following are tips to help control the escalation cycle, maintain clear communication, and ensure your own health and safety are prioritized.

### **Whenever possible, avoid the following situations:**

- ▶ **Arguing** with your loved one. They may not remember the conversation later or may not be able to understand your perspective.
- ▶ **Applying logic** to misunderstandings or arguments. What seems logical to you may not make sense to them.
- ▶ **Belittling** or treating your loved one like a child if their behavior is immature or childlike.
- ▶ **Expecting your reality** as a caregiver to make sense to your loved one.
- ▶ **Saying things like**, “remember...” or “I just told you.” They may not remember, and it may frustrate you and your loved one.
- ▶ **Blaming** your loved one with suspected CTE instead of blaming your loved one's disease.
- ▶ **Discussing topics ahead of time** that may make them anxious, upset, or excited.

### **Whenever possible, try to:**

- ▶ **Understand** your loved one's reality is not the same as yours.
- ▶ **Redirect emotions or arguments.** Your loved one is living in the “here and now.” Change what is here and what is now by redirecting frustration toward fun, crying toward laughter, lost toward found. Having photos, DVDs, or music on hand that your loved one associates with joy or happiness can help.
- ▶ **Break cycles of escalation.** Remove yourself at the beginning or before escalation. Use a prompt like, ‘I'm leaving the room now.’ Choose a calm time and try accepting responsibility. When you feel you may escalate the discussion, use as little emotion as possible in your tone. Do not match their response.





- ▶ **Maintain hope and optimism.** CTE is not a death sentence, and medical science is progressing. We are getting closer every day to better treatments that will help slow disease progression and possibly prevent symptoms. Seeking professional help and targeted therapies can help you and your loved one get to the next day.

Remember that you are not alone and can ask for help. We are here to support you in improving communication and deescalating anger or rage. You **can** laugh, reduce stress, and focus on your own wellbeing.

## Caregiving for Veterans



*CLF Legacy Donor Kevin Ash*

Traumatic Brain Injury (TBI) is the signature wound of modern warfare, with over 430,000 U.S. veterans diagnosed in the last 20 years. Research efforts focusing on TBI, PTSD, and CTE are among the most crucial for veterans and families experiencing the effects of these injuries. You may find the following resources helpful:

- ▶ [CLF Operation Brain Health](#)
- ▶ [Webinar: Understanding the Lasting Impact of Veteran Brain Injuries](#)
- ▶ [CLF Military Programs](#)
- ▶ [TBI Center of Excellence Patient and Family Resources](#)

# The Importance of Self-Care



As a caregiver for someone with suspected CTE, you have likely put your loved one's needs first for a long time. This is understandable and common within the caregiving community. We encourage you to remember that only when you help yourself will you most effectively help someone else.

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



*Former NFL player and CLF Legacy Donor John Mackey with wife and caregiver Sylvia Mackey.*

## Look After Yourself First

Setting aside time for self-care is an essential part of being an effective and supportive caregiver. You may find sources of physical, emotional, mental, and spiritual energy from the following activities and practices:

- ▶ Regular exercise
- ▶ Mental health counseling
- ▶ Meditation
- ▶ Mindfulness
- ▶ Reading
- ▶ Listening to music
- ▶ Cooking
- ▶ Proper rest
- ▶ Healthy diet
- ▶ Socializing with friends and family, and seeking their support when you need it

## Create a Support Network for YOU

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



# Create a Resource Toolbox

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

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

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

## Peer Support Groups

Joining a support forum or support group is another great way to connect with people who understand what you are going through. The goal of [CLF’s Suspected CTE Caregiver Zoom groups](#) or our [CTE Resources Facebook Group](#), for instance, is to build a community focused on providing resources, support, and hope to those affected by ongoing concussion symptoms and persistent post-concussion symptoms. Learn more about our Peer Support Groups and resources: [ConcussionFoundation.org/Peer-Support](https://ConcussionFoundation.org/Peer-Support)



## Peer Support Connections

### CLF Peer Support Connection Program: Connect with Support



[The CLF Peer Support Connection Program](#) is an opportunity to connect with someone who understands the unique challenges of being a caregiver for someone with suspected CTE.

Our Peer Support Volunteers are former caregivers who have navigated similar challenges and want to give back to the brain injured community by sharing what their own journey taught them. Reach out to the [CLF HelpLine](#) to be connected.

# Additional Support and Resources



## CLF HelpLine

The CLF HelpLine provides personalized help to those struggling with the outcomes of brain injury. Patients and caregivers navigating suspected CTE can reach out for help finding the right doctor, understanding treatment options, or getting peer support.

If you or a loved one are seeking guidance on how to choose the right doctor, struggling with symptoms, or have questions, we want to hear from you.



## Videos & Webinars

### CTE Resources Playlist

CLF's compiled list of helpful videos and webinars.

### Dr. Shannon Albarelli on CTE Caregiving

Dr. Albarelli offers advice, coping strategies, and her own experiences.

### Kim Adamle on how CTE Caregivers Can Support Themselves

Kim shares ways caregivers can prioritize their health and needs.

### Caregiver for Suspected CTE with NFL wife Liz Nicholson Sullivan

Liz shares what it's like to be a caregiver for her husband.

### Losing a Husband and Father to CTE | The Greg Lens Story

A wife and daughter share their experiences caregiving for CTE.

### Family of fallen Marine Capt. Matt Brewer share struggles with PTSD, CTE symptoms

Matt's family share his struggles, and theirs.

## Stories of Hope & Resilience

### Living with Suspected CTE | The Mike Adamle Project: Rise Above

Mike & Kim Adamle share how they live with suspected CTE.

### Living with Probable CTE: The Curtis Smith Story

Curtis Smith discusses his athletic career and the importance of support.

### Finding Hope Living with Suspected CTE

Chris Boyce shares how he and his family find hope living with suspected CTE.

### How I got Support for Possible CTE

Danny Halverson talks about coping with symptoms and staying hopeful.

### Coping with Probable CTE: Steve Miller's Story

Steve Miller's wife shares their daily journey living with suspected CTE.



## [Research Update: 1,000 Reasons for Hope](#)

Read our [1,000 Reasons for Hope](#) report to learn about the first 1,000 brain donors studied at the UNITE Brain Bank since 2008 and how they have advanced research on concussions and CTE. The next 1,000 brain donors will answer critical questions that take us closer to preventing, diagnosing, and treating CTE and other long-term consequences of concussion and TBI.



Read our [Science of CTE](#) pages for more information.

If you would like to advance research on the diagnosis and treatment of CTE, consider enrolling your loved one in the [CLF Research Registry](#) and explore [studies actively recruiting](#).

## [Final Note](#)

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

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

CLF is grateful for your commitment to helping your loved one navigate the effects of suspected CTE. Remember that you are not alone – reach out to us through the [CLF HelpLine](#) if you need recommendations, support, or guidance.

## [Supporter](#)

Thank you to [The Dementia Society of America](#) for supporting the creation of this resource.

