CONCUSSION & CTE
FOUNDATION

The CTE Guidebook

For Patients & Caregivers



If you are concerned that you or someone you care about has suspected Chronic Traumatic Encephalopathy (CTE), please know that you are not alone. Help is available, and hope is right here.

Since 2007, the Concussion & CTE Foundation (formerly the Concussion Legacy Foundation) has been at the forefront of scientific research, awareness, and advocacy for patients and families impacted by brain trauma. We understand how overwhelming it can feel to face CTE.

We designed this guidebook to equip patients, caregivers, and families with tools and resources to support yourself or a loved one.

Navigating This Resource

Whether you are just starting to explore concerns about CTE or CTE concerns have been on your radar for years, this resource can help you find a path forward.

Think of this guidebook as your bedrock for developing action plans and making informed decisions. Read from the beginning to build upon key concepts step-by-step, such as fundamental knowledge, finding support, choosing evidence-based treatments, guidance for caregivers, and reasons to stay hopeful – or – navigate between sections using the hyperlinked Table of Contents.

A Note on Terminology

CTE cannot yet be diagnosed with a known level of statistical accuracy in living patients and can only be definitively diagnosed through neuropathological brain tissue analysis after death. Research is ongoing to find biomarkers and imaging techniques that might allow for an earlier definitive diagnosis. Until then, clinicians must rely on the patient's clinical history and symptom presentation to establish a presumptive diagnosis.

The term "suspected" CTE is used as a presumptive diagnosis to guide symptom management plans. While not a defined medical diagnosis, it can help provide clarity when other possible causes of symptoms have been ruled out through comprehensive clinical assessments with knowledgeable healthcare providers.

Since this guidebook is designed to support patients and caregivers during life, the terms CTE and suspected CTE are used interchangeably.

Concussion & CTE Foundation HelpLine

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

Our **HelpLine** provides free, personalized support to those struggling with the outcomes of brain injury.

Patients and caregivers navigating suspected CTE can reach out for assistance finding healthcare providers, understanding treatment options, or getting connected to Concussion & CTE Foundation's peer-to-peer support network.

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01 Navigating Suspected CTE as a Patient



If you are concerned you may have CTE, maintaining hope is essential. Remember, the symptoms you are experiencing do not define your future. Many individuals have lived full, meaningful lives while managing symptoms associated with CTE.

Treatments focused on your symptoms can significantly improve your quality of life, and there are resources to support both you and your family throughout this journey. Building a strong knowledge base and support network can make it easier to maintain hope.

Patient Playbook

This section provides practical steps and summary information to help you navigate CTE. The remainder of the guidebook delves deeper into these topics, offering additional insights and resources to support your journey.

Get educated: Chronic Traumatic Encephalopathy (CTE) is a degenerative brain disease found in athletes, military veterans, and others with a history of repetitive brain trauma. Currently, CTE can only be definitively diagnosed by autopsy after death. Symptoms reported in those diagnosed with CTE include mood and behavior symptoms, cognitive symptoms, and sleep symptoms. These symptoms typically emerge years after the brain trauma occurred and, in the case of cognitive symptoms, often worsen over time.

We urge you to keep in mind there is a significant chance you do not have CTE, and the symptoms you are experiencing could have various other causes. For example, symptoms could be related to a recent brain injury, mental health disorders, sleep disturbances, substance use, post-traumatic stress disorder (PTSD), or other treatable conditions. Working with knowledgeable healthcare providers who can help get to the bottom of your symptoms and coordinate appropriate treatments is crucial to improving your quality of life. For more information on these and other possible causes, refer to the Noteworthy Topics & FAQs section.

Assemble a care team: One of the most critical steps in finding a care team is identifying qualified medical and mental health providers for appropriate assessments and treatments. The type of provider best suited to your needs will depend on factors such as your age, history of exposure to repetitive head impacts, and specific symptoms. In general, finding providers who specialize in the symptoms you are dealing with and have knowledge of brain injuries is the best approach. For more guidance on selecting the right providers, refer to the Finding Quality Care section. You can also reach out to the Concussion & CTE Foundation HelpLine to assist you in locating qualified professionals in your area.

Get evaluated: A baseline health screening conducted by your primary care doctor, or more advanced evaluations and assessments with specialists, will provide valuable insights into potential causes of your symptoms. Since CTE cannot be definitively diagnosed during life, clinicians utilize multiple assessment techniques, such as clinical examination, neuropsychological testing, imaging, blood work, and lumbar punctures, to make the most accurate diagnosis possible and identify the best path forward. For more information on these and other diagnostic techniques, refer to the Assessments section.

Get treatment & support: Researchers are searching for ways to definitively diagnose and treat CTE during life, but these advancements are not yet available. Current treatment strategies focus on managing symptoms and enhancing your quality of life. Many evidence-based treatments have been shown to effectively reduce or improve symptoms associated with CTE.

Adopting healthy lifestyle habits, such as maintaining a balanced diet, exercising regularly, getting adequate sleep, staying socially connected, and engaging in activities that stimulate your mind can help you regain quality of life and have a positive impact on your overall well-being. For detailed information about evidence-based options, refer to the Treatment section.



02 Navigating Suspected CTE as a Caregiver



Patients struggling with suspected CTE are not the only ones in need of support. Spouses, partners, parents, children, extended family, and close friends in caregiving roles are also impacted while supporting a loved one.

Whether you have been caregiving for years or you are newly stepping into a support role, it is important that you and your loved one remain hopeful.

Many symptoms of CTE are treatable, and there are tools, resources, and techniques to help you navigate the challenges ahead. As much as possible, strive to set realistic expectations, be compassionate with yourself, and put your needs first.

Remember - you can do this, and you are not alone.

Caregiver Playbook

This section provides practical steps and summary information to help you navigate caregiving for CTE. The remainder of the guidebook delves deeper into these topics, offering additional insights and resources.



Get educated: By learning about this condition, you can help your loved one make more informed decisions. An advocate who understands CTE can speak up when a patient may not be able to. Having someone in their corner while they navigate this journey will increase their chances of finding effective support.

Chronic Traumatic Encephalopathy (CTE) is a degenerative brain disease found in athletes, military veterans, and others with a history of repetitive brain trauma. Currently, CTE can only be definitively diagnosed by autopsy after death. Symptoms reported in those diagnosed with CTE include mood and behavior symptoms, cognitive symptoms, and sleep symptoms. These symptoms typically emerge years after the brain trauma occurred and, in the case of cognitive symptoms, often worsen over time.

It is important to understand the symptoms your loved one is experiencing could have various causes that may be unrelated to CTE. For example, symptoms could be related to a recent brain injury, mental health disorders, sleep disturbances, substance use, post-traumatic stress disorder (PTSD), or other treatable conditions. Working with knowledgeable healthcare providers can help get to the bottom of their symptoms and coordinate appropriate treatments. For more information on these and other possible causes, refer to the Noteworthy Topics & FAQs section.

Look after yourself first: Being a suspected CTE caregiver can present enormous challenges, and caregivers are often so busy looking after their loved ones they forget – or don't have enough time – to care for themselves. Try to remember that caring for yourself is not selfish. It is a critical practice to ensure you have the energy and capacity to support your loved one.

Make time for activities that nurture your physical, emotional, mental, and spiritual health. Set and hold boundaries to preserve your safety and well-being. Put your own healthcare needs first. Allow yourself moments of joy and laughter. Lean on trusted friends and family. If you feel overwhelmed, anxious, depressed, or burned out, consider reaching out to a licensed counselor or support group for guidance and encouragement. To explore more suggestions and guidance, refer to the Being a Caregiver and Advocate section.

Build a resource toolkit: You may find yourself frequently searching for new resources to navigate tough questions, major obstacles, and recurring challenges. As you proactively search for options or stumble upon promising avenues, keeping track of them all can be a challenge.

Compiling resources in a personalized toolkit is a good ongoing practice. Gradually develop your own way to organize options to help reduce stress, build a sense of security, and ensure you can find what you need when you need it. Think of a resource toolkit as your "just in case" list of supportive organizations and services tailored to your family's specific needs. This toolkit might include names and contact information for clinicians, healthcare navigation services, financial assistance programs, and crisis resources and hotline numbers. For ideas about what to include in your list, refer to the Additional Support and Resources section.



03 Understanding CTE

Jump to section

- What Is CTE?
- What Causes CTE?
- Noteworthy Topics & FAQs



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. In CTE, experts believe a structural protein in brain cells called tau misfolds and malfunctions, setting off a chain reaction where this malfunctioning tau slowly spreads throughout the brain, killing neurons. Right now, CTE can only be definitively diagnosed by autopsy after death.

What are the symptoms of CTE? Symptoms of CTE can vary but fall into a few main categories.

Mood and Behavior Symptoms

Among individuals diagnosed with CTE after death, some report mood disorders and changes in behavioral regulation that can appear as early as the patient's 20s, including:

- Impulse control problems
- Aggression
- Mood swings
- Depression
- Paranoia
- Anxiety
- Addiction
- Suicidal thoughts

However, these symptoms are non-specific and can have many other causes other than CTE. Rather than being related to the presence of CTE, they can be treatable consequences of concussions or repetitive head impacts, or they could be completely unrelated to head impacts.

Cognitive Symptoms

Most patients with CTE eventually experience progressive disorders of thinking and memory that appear years or decades after the cessation of repetitive head impacts, including problems with:

- Executive function
- Judgment
- Short-term memory

Cognitive symptoms related to CTE tend to appear later in life, most frequently in a patient's 60s or 70s. If cognitive symptoms appear in early or midlife, they could have another, more treatable cause than CTE. Sleep disorders and neuroendocrine disorders from damage to the pituitary gland can cause treatable cognitive changes, or symptoms could be related to concussions or brain changes due to head impacts that are not CTE.

Dementia

When symptoms progress far enough to impair activities of daily living, a doctor might diagnose them with dementia. Dementia is defined as a condition that makes someone unable to remember, think clearly, or make decisions while doing everyday activities.[1]

Sleep Symptoms

A 2020 study from the UNITE Brain Bank suggests that some cases of rapid eye movement (REM) behavior disorder may be related to CTE pathology. REM behavior disorder is a sleep disorder that occurs during the phase of sleep where rapid eye movements occur, characterized by acting out dreams during REM sleep, like walking, talking, shouting, or punching and kicking. Other sleep disorders like obstructive sleep apnea, which can cause cognitive symptoms, may not be related to CTE and can be effectively treated.

What Causes CTE?

CTE is caused in part by repeated traumatic brain injuries (TBIs), including concussions and non-concussive 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 repetitive head impacts (RHI) over the course of many years playing contact sports, serving in the military, or, more rarely, as victims of interpersonal violence.

In recent years, the National Institute Neurological Disorders and Stroke (NINDS), which is part of the United States National Institutes of Health (NIH), and the US Centers for Disease Control and Prevention (CDC) formally acknowledged repetitive head impacts as the definitive cause of CTE. This causal relationship was explored thoroughly in the 2022 Frontiers in Neurology article led by Concussion & CTE Foundation CEO Dr. Chris Nowinski, "Applying the Bradford Hill Criteria for Causation to Repetitive Head Impacts and CTE."

What are non-concussive impacts? Many people are surprised to hear that there have been cases of CTE discovered in athletes who have never been diagnosed with a concussion. Currently, the best available evidence suggests non-concussive impacts, rather than concussions, are the driving force behind CTE. In fact, a 2023 study found the odds of developing CTE are most related to the number and strength of head impacts experienced over a lifetime.

Previously known as sub-concussive impacts, a non-concussive impact is simply a hit to the head that does not result in a diagnosed concussion, which is a type of traumatic brain injury that results in signs that are observable (loss of consciousness, loss of balance, disorientation) or symptoms that are felt (headache, dizziness, double vision, amnesia, feeling foggy). Even without signs or symptoms, non-concussive impacts can still cause changes within the brain.



Examples of these types of impacts include most tackles and collisions on the football field; headers in soccer; checks or collisions with the boards or other players in ice hockey; and body checks in lacrosse.

Who is Most at Risk for CTE?

Almost every person diagnosed with CTE has one thing in common: a known history of repetitive hits to the head. CTE is most frequently found in contact sport athletes and military veterans.

The UNITE Brain Bank has diagnosed CTE in individuals whose primary exposure to head impacts was through tackle football, military service, 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. While the number and strength of repetitive head impacts are the only known risk factor for CTE, it is not fully clear why some people develop CTE whereas others do not. Other factors, like genetics or the age of first exposure to repetitive head impacts, appear to influence the age of symptom onset, severity of symptoms, and the speed of progression of symptoms.

Noteworthy Topics & FAQs

This section is designed and formatted to quickly address important topics or common questions for patients and families navigating suspected CTE.

Living well with CTE: If you or someone you care for is concerned about CTE, it is important to know that life can still be meaningful and enjoyable. Many symptoms of CTE can be addressed with strategies, tactics, and treatments to improve quality of life today and reduce risks in the future. People have varied experiences living with suspected CTE. While some struggle, others live long and fulfilling lives with the proper interventions. Of course, CTE can pose challenges, but there are many tools to help you fight. Remember, there are resources, support, and advancements happening every day to help people live well with CTE.

Other possible causes of symptoms: We cannot definitively diagnose CTE in the living, and CTE-like symptoms may have different underlying causes. Some alternative explanations are serious, but others can be treated or even resolved.

Symptoms commonly associated with CTE are also associated with:

- Outcomes of brain trauma including lingering concussion symptoms, changes to white matter in the brain, vascular tissue damage, or hormonal imbalances.
- Conditions such as nutrient deficiency, disordered sleep, mental or behavioral health disorders, post-traumatic stress disorder, substance abuse, or even the normal effects of aging.
- Other neurodegenerative diseases such as Alzheimer's or Parkinson's disease.

The following alternative explanations may cause or contribute to symptoms that appear similar to CTE. While this list is not exhaustive, it can help patients and caregivers identify other possible causes of symptoms to discuss with a qualified healthcare provider.

Normal Aging

Changes in cognitive abilities can be affected by changes to the brain associated with normal aging. These changes often affect areas such as memory, attention, and problem-solving and may occur independent of a medical condition.

Vitamin and/or Nutrient Deficiency

A lack of essential vitamins and/or nutrients in the body, either through insufficient intake or absorption issues, can lead to various challenges with mood and cognition. If you are experiencing any concerns or suspect deficiencies, consider reaching out to a dietitian for support, personalized advice, and appropriate testing.

Hormonal Irregularity

Neuroendocrine disorders from damage to the pituitary gland can occur following brain injuries and lead to hormonal imbalances that may not show for months or years after injury. These deficiencies can cause physical, cognitive, and emotional symptoms and overlap with other acute and chronic brain injury symptoms.[2]

Additionally, natural aging significantly impacts hormone production and regulation as the endocrine system undergoes changes over time.[3] Relevant overlapping symptoms include mood swings and fatigue. Changes can begin in your 30s but typically become more noticeable in the 40s and 50s and vary widely based on genetics, lifestyle, and health. While these changes are a natural part of aging, effective treatments are available to help alleviate symptoms.

Post-Concussion Syndrome (PCS)

Post-Concussion Syndrome (PCS), also known as persistent post-concussion symptoms (PPCS), is the persistence of concussion symptoms beyond the normal course of recovery, sometimes for months or years. Unlike PPCS, CTE symptoms usually do not appear until many years after an individual was exposed to repetitive head impacts.

White Matter Abnormality

White matter is a type of tissue responsible for communicating with different regions of the brain. Abnormalities in white matter may cause symptoms like memory problems, slow walking, balance issues, difficulty multitasking, and depression. Changes in white matter can result from aging or traumatic brain injury. On neuroimaging studies such as MRI or CT scans, these can be visualized as white matter hyperintensities and are also a common finding in individuals with a history of stroke or dementia.[4]

Alzheimer's Disease and Related Dementia (ADRD)

Dementia is not a specific disease but is rather a general term for the impaired ability to remember, think, or make decisions that interferes with activities of daily living. Alzheimer's disease (AD) is the most common type of dementia. AD initially affects short-term memory and progressively affects long-term memory, cognition, and mood. AD risk increases with age, typically affecting individuals over 60 years old. Although rarer, it can start in younger patients as early-onset AD. The cause of AD is believed to be multifactorial, with a family history of AD or the presence of a known genetic risk factor being the strongest predictors of its development [5].

Frontotemporal Dementia (FTD)

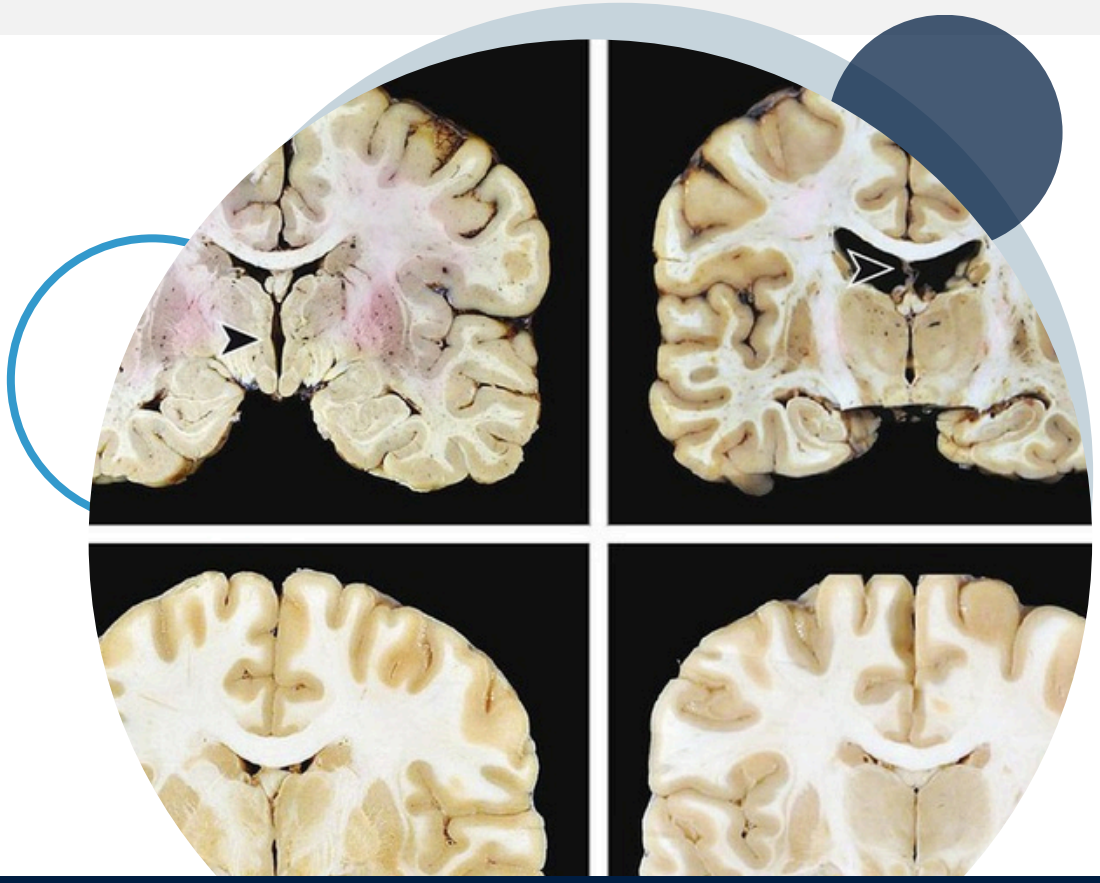
Frontotemporal dementia is caused by a group of disorders that gradually damage the regions of the brain responsible for thinking and behavior. Symptoms can include emotional problems, trouble communicating, challenges with work, and difficulty walking. This progressive disease is rare and, unlike other dementias, usually begins in a younger population.[6]

Lewy Body Dementia

Lewy Body Dementia is the second most common type of dementia behind Alzheimer's disease. This progressive brain disease is characterized by protein deposits in the brain called Lewy Bodies. These deposits are usually found in areas of the brain that affect thinking, memory, and movement. Individuals may experience symptoms such as visual hallucinations, Parkinson's-like symptoms, and memory problems. This disease is known to affect more men than women and develops in those over the age of 60. Individuals with a family history of Lewy Body dementia are at an increased risk.[7]

Parkinson's Disease

Parkinson's disease (PD) is a movement disorder of the nervous system. As brain cells in a specific part of the brain are damaged, weaken, or die, patients may experience tremors, widespread muscle stiffness, or impaired balance. The exact cause of this disease is unknown; however, it is more likely to develop in men, in those over the age of 60, and those with a genetic risk factor.[8]



Quick Answers About Diagnosis and Treatment:

Can CTE be diagnosed during life?

No, CTE cannot yet be diagnosed during life. Research is ongoing to find a diagnostic tool, such as biomarkers in the blood or brain imaging techniques, that might allow for an earlier definitive diagnosis. Until then, experts led by the team at the Boston University CTE Center are developing criteria for diagnosing a clinical syndrome associated with CTE in living patients. Currently, researchers are evaluating the use of Traumatic Encephalopathy Syndrome (TES) criteria to capture symptoms caused by CTE during life. Unfortunately, TES criteria are still limited to research studies and not yet used by doctors. Clinicians currently rely on the patient's clinical history and symptom presentation to establish a presumptive diagnosis. The process involves detailed interviews to piece together history of head trauma and the timeline of symptom development. Neurological examinations, cognitive tests, and functional capacity assessments can also help inform CTE's likelihood.

How is CTE diagnosed?

Currently, CTE can only be definitively diagnosed after death through brain tissue analysis. Neuropathologists examine brain tissue using chemical stains to make the abnormal tau protein visible. This analysis is not typically performed as a part of a normal autopsy and can take months to complete.

What is "suspected" CTE?

The term "suspected" CTE is used because CTE cannot yet be diagnosed in living patients. This term is not a defined medical diagnosis but instead a presumptive diagnosis of CTE. It can be used to guide symptom management plans when other possible causes of symptoms have been ruled out through comprehensive clinical assessments with knowledgeable healthcare providers. Since this guidebook is designed to support patients and caregivers during life, the terms CTE and suspected CTE are used interchangeably.

Quick Answers About Diagnosis and Treatment:

Is CTE treatable?

While there have been very few scientific studies on how to treat the clinical symptoms of CTE, there are many therapies available that allow patients to have a better quality of life. Under the care of the right doctor, alongside lifestyle changes, most patients will see improvements. Treatments are focused on addressing your symptoms whether they are from CTE, concussions, or unrelated to brain trauma.

What does "evidence-based" mean when referring to assessment or treatment options?

"Evidence-based" refers to assessment and treatment options that are supported by peer-reviewed scientific studies. Careful thought is warranted when considering options that are relatively new, not covered by insurance, or have existed for a long time but have not demonstrated safety and effectiveness through repeated studies in academic journals with rigorous peer-review. For more information on how to identify credible sources of information, visit the Office of the Surgeon General Health Misinformation guidance page.

What type of doctor should I choose for assessment and treatment?

There are not many providers familiar with CTE because medical education and training is still catching up with the latest research. If you are struggling to find the right doctor, reach out to the Concussion & CTE Foundation HelpLine for recommendations in your area.

In general, look for clinicians specializing in brain disorders involving thinking, mood, and behavioral difficulties such as a cognitive or behavioral neurologist, neuropsychiatrist, neuropsychologist, or physiatrist. Because CTE is a neurodegenerative disease, a clinician who understands disorders such as Alzheimer's disease, dementia, and related conditions may be a good option.

Younger individuals in their 20s and 30s with a history of concussions may be best served by an expert in concussion 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.

04 Building a Foundation of Medical Support

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- Finding Quality Care
- Types of Providers
- Talking With Healthcare Providers
- Assessment
- Treatment



If you are concerned that you or your loved one has CTE, it is crucial to build a foundation of care with knowledgeable medical and mental health professionals.

Build your care team by starting with evaluations and assessments. Use the information gained from testing and guidance from clinicians to decide on next steps, such as specialist referrals, targeted treatment approaches, and long-term support.

The journey may feel overwhelming at times. Remember, you are not alone, and help is available. This section provides information on how to start, what to know, and where to find evidence-based options.

Finding Quality Care

For most patients, a primary care physician can be a good starting point to begin the referral process. Several key factors will shape next steps, including recent brain injury, history of exposure to repetitive head impacts (RHI), symptoms, and age.

Finding the Right Doctor

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

Clinicians who specialize in evaluating and treating brain disorders involving cognitive, mood, and behavioral difficulties can be strong options even if their prior knowledge of CTE is limited. Their experience with similar disorders may still provide valuable information.

A clinician who specializes predominantly in concussions or TBI may not be best for older patients who have not suffered a brain injury in recent years because CTE is a neurodegenerative disease. Instead, 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 will be better 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, vascular changes, or neuroendocrine dysfunction.

Specialist referrals

If the patient ***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 the patient's age, a TBI specialist will be best equipped to evaluate and address symptoms, especially if the patient 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 the patient ***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 specific symptoms:

- **For mood and behavioral symptoms,** such as anxiety, depression, or anger, providers trained in neuropsychiatry, psychiatry, neuropsychology, psychology, and mental health counseling may be good options.
- **For memory or cognitive symptoms,** providers trained in behavioral neurology, neuropsychiatry, or neuropsychology may be good options.

Additionally, patients older than middle-age with cognitive symptoms may consider looking for referral to dementia or neurodegeneration specialists at a Memory and Aging Care facility, for example.



Reach out to the Concussion & CTE Foundation HelpLine for support finding these types of providers.

Thank you for urging me not to give up hope.

Types of Providers

The providers listed below can be relied upon for evaluations or 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
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	Provide guidance, find resources, and navigate healthcare systems to help you access quality care.	• Advocacy and mediation • Appointment reminders • Connection to resources • Insurance coverage navigation • 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.	Treat behavioral, emotional, and mental disorders through cognitive behavioral therapy (CBT), psychoanalytic therapy, etc.	• Adjustment issues • Emotional and psychological problems • Interpersonal or social problems & dysfunction • Behavioral problems • Intellectual, cognitive, and neurological conditions
Neurologist		
A medical doctor with specialized training in managing disorders of the brain and nervous system.	Evaluate and treat disorders of the brain, spinal cord, nerves, and muscles. Evaluate and treat disorders in thinking, memory, mood, or behavior.	• Neurologic assessments • Neurodegeneration • Behavioral dysregulation • Memory loss • Headache & seizures • Blood panels • CT/MRI scans • Sleep disturbances

Provider Type	Function	Relevant Specializations
Neuro-Ophthalmologist		
A medical doctor who subspecializes in neurology and ophthalmology	Evaluate and treat visual problems related to the nervous system (vision problems that do not necessarily come from the eyes themselves).	• Neuro-Optometric • Rehabilitation therapy • Rehabilitation referrals • Broad medical or surgical options • Vision therapy • Eye training
Neuro-Optometrist		
An optometrist with an additional year of training to specialize and work in vision therapy and neuro-optometry.	Evaluate and treat issues with vision and motor function.	• NORA neuro-optometric rehabilitation therapy • Vision therapy • Eye training • Corrective lenses
Neuropsychologist		
A licensed clinical psychologist specializing in how the brain affects behavior.	Evaluate and treat disorders in thinking, memory, mood, or behavior.	• Neuropsychological assessments of cognitive function • Clinical psychotherapy
Occupational Therapist		
A medical professional who specializes in activities of daily living.	Help patients develop, recover, improve, and maintain the skills needed for daily living.	• Adaptive equipment recommendations for home • Cognitive rehabilitation • Vision therapy
Physiatrist (Physical Medicine and Rehabilitation Specialist)		
A medical doctor specializing in the field of physical medicine and rehabilitation.	Evaluate and 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.	• Physical rehabilitation • Vestibular rehabilitation • Neck pain • Headache

Provider Type	Function	Relevant Specializations
Physical Therapist		
A medical professional who specializes in rehabilitative medicine.	Provide services that help restore body function, improve mobility, relieve pain, and limit permanent physical disabilities from an injury.	• Physical rehabilitation • Vestibular rehabilitation • Neck pain • Headaches
Primary Care Provider (PCP)		
A medical doctor or advanced-training clinician who practices general healthcare and addresses a wide variety of health concerns. **Other titles:** Family Practice Internal Medicine Nurse Practitioner Physician Assistant	Evaluate, treat, and coordinate ongoing care for all general medical needs.	• First-line care and guidance • Referral to specialists • Care coordination and centralization • Medication management
Psychiatrist		
A medical doctor specializing in preventing, diagnosing, and treating mental illness.	Evaluate and treat disorders in thinking, memory, mood, or behavior.	• Psychotherapy • Medication management
Social Worker		
A mental health professional trained to evaluate and treat mental illnesses and offer support to address external or material challenges.	Provide therapies and guidance to help patients navigate mental health and daily living challenges.	• Psychotherapy/ counseling • Patient & family advocacy • Case management • Resource facilitation

Provider Type	Function	Relevant Specializations
Speech Language Pathologist (SLP)		
A health professional who specializes in language and communication.	Develop personal rehabilitation plans for cognition, communication, and swallowing disorders.	• Reestablishing communication • Adaptive technologies for work or school • Cognitive therapy • Memory training

Talking With Healthcare Providers

Communicating with healthcare 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 for a caregiver to obtain a medical release, or permission, to communicate with providers in compliance with HIPAA regulations. Ask your loved one about this option and obtain the necessary paperwork from medical providers.

If a caregiver is not able to join appointments or communicate with providers, they can still help with remembering appointment times and gathering helpful information ahead of a visit.



Talking with healthcare providers can be a challenge, especially with memory difficulties. Here are a few tips:

1

Compile history of exposure to head injury and repetitive head impacts (RHI)

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

2

Compile history of symptoms

Think about what changes are getting in the way of daily life. Symptoms may include 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 your normal patterns of living. If you can, note how long you have been experiencing these symptoms and whether they are getting worse over time. Here, a caregiver can help by sharing the signs they have observed and asking the patient to describe symptoms they are experiencing.

3

Compile history of medical assessments and treatments

If you have already undergone assessments or treatments, do your best to track down records.

What assessments have been conducted, if any? For example, information about CT or MRI scans, blood work, and neurological or neuropsychological testing may be helpful even if they were not directly related to present concerns.

What treatments have been tried, if any? Note whether the treatments were effective for addressing symptoms.

4

Keep an open mind

Lastly, remain open to discussing other possible causes of symptoms with your doctor. It is important to explore whether symptoms could be explained by another root cause. Try to be patient through this process, do your best to participate fully, and ask questions when you need more information.

Assessment

Comprehensive assessment is an essential step for clinicians to find the most accurate explanation for symptoms. Many possibilities need to be considered before assuming CTE is a likely cause.

There is no test, scan, or symptom that can diagnose CTE in the living, and no diagnosis is definitive without post-mortem brain tissue analysis. Therefore, clinicians must gather relevant information through an array of assessment techniques such as clinical evaluations, neurological or neuropsychological testing, imaging, and blood work. These tests are important because they can help diagnose or rule out other conditions; however, they cannot be used to definitively diagnose CTE, and ongoing research is exploring the use of these techniques for future diagnostic purposes.



Clinical Evaluation & Examination

A clinician's first step is to gather information about the patient's exposure to brain trauma and symptoms through interviews, evaluations, and standardized assessments. This should be conducted by qualified medical professionals with advanced training such as neurologists, psychiatrists, and neuropsychologists.

Assessment typically begins with clinical interviews of the patient and family to understand the history of head trauma and the timeline of symptom development. For example, the clinician may ask targeted questions about the patient's memory concerns, focusing on when the symptoms began and how they progressed over time. Other interview questions may focus on family medical history and social history. These conversations allow the clinician to rule out any potential diagnoses that do not match the patient's genetic, risk exposure, or symptom profile.

From here, the clinician may conduct neurological or neuropsychological assessments on thinking, memory, behavior, or other functions to explore whether and to what degree abnormalities are present.

After initial evaluation, the clinician will determine whether further testing is appropriate.

Imaging

In general, brain imaging is currently best utilized to identify or rule out other diseases or brain abnormalities as a potential alternative explanation for symptoms. Importantly, brain imaging cannot yet be used to definitively diagnose CTE. More research is needed to understand how imaging can better inform diagnostic predictions.

The list below provides basic summaries on types of brain imaging patients are most likely to encounter when searching for information about CTE, along with the current state of research into their usefulness. Be sure to discuss options with a trusted, qualified medical professional since these tests can be very expensive and may not be covered by insurance.

This section is intended only as a resource to support informed decision-making with a qualified medical professional.

MRI | Magnetic Resonance Imaging

MRI is being explored to assist in the diagnosis of CTE. In older individuals, MRI can identify patterns of atrophy, or shrinkage, in the brain associated with neurodegenerative diseases like Alzheimer's. In addition, the presence of a tissue abnormality called a cavum septum pellucidum can help inform a diagnosis. In all patients, MRI can identify severe complications from a TBI such as a skull fracture, brain bleeds, or brain swelling, and can identify or rule out other brain abnormalities as a potential alternative cause for symptoms.[9] Comparison of baseline MRI results to later repeated MRI results may provide limited information about structural changes in the brain over time to help understand symptom progression.

PET | Positron Emission Tomography

PET imaging is a highly sensitive brain scan that utilizes a biomarker to highlight specific molecules within the brain to identify disease. Research is ongoing to identify a biomarker to analyze tau protein in the brain as a potential method for diagnosing CTE in the living[9]; however, a CTE-specific biomarker has yet to be identified. Your doctor may order a PET scan to rule out Alzheimer's disease by looking for the presence of beta-amyloid plaque, a hallmark of Alzheimer's disease that is not diagnostic for CTE. PET imaging offers great promise to identify a biomarker specific for diagnosing CTE, and studies are ongoing.

CT | Computed Tomography

CT imaging can identify severe complications from a TBI such as a skull fracture, brain bleeds, or brain swelling, and can identify or rule out other brain abnormalities as a potential alternative cause for symptoms. A CT scan is not sensitive enough to identify the cellular changes that occur within the brain due to repetitive head impacts and cannot identify CTE.[9]

EEG | Electroencephalogram

EEG imaging can show electrical activity occurring within the brain and how it changes in the presence of injury and/or disease. Recent research has shown promise in using EEG as a diagnostic tool and it is frequently used in epilepsy, which can also be present in individuals exposed to TBI. More research is needed to determine how useful this imaging technique will be in diagnosing various neurodegenerative diseases, including CTE.[10]

qEEG | Quantitative electroencephalogram

qEEG imaging is an EEG with further analysis. qEEG imaging has shown promise as a potential diagnostic tool for traumatic brain injury.[11] More research is needed to determine how useful this imaging technique will be in diagnosing various neurodegenerative diseases, including CTE.

fMRI | Functional Magnetic Resonance Imaging

A functional MRI scan measures brain activity by tracking blood flow within the brain and has shown promise as way to identify changes within the brain following TBI.[12] More research is needed to determine how useful this imaging technique will be in diagnosing various neurodegenerative diseases, including CTE.

SPECT | Single-Photon Emission Computed Tomography

SPECT imaging analyzes blood flow within the brain using contrast from a radioactive tracer to highlight specific brain regions. There is currently no evidence that SPECT is helpful in the diagnosis of CTE, and we do not recommend paying for SPECT scans out-of-pocket for suspected CTE.

Blood work

A full blood panel can identify hormonal imbalances or nutrient deficiencies. If any abnormalities are present, the results could provide more information about the cause of symptoms and inform a treatment approach. For example, brain trauma can cause hormonal imbalances and neuroendocrine dysfunction from damage in the pituitary gland. Pituitary dysfunction can result in CTE-like symptoms, such as disturbances in mood or thinking, that can be effectively treated. Other abnormalities in hormones and nutrition unrelated to brain trauma can also impact brain function.

Importantly, blood tests cannot currently be used to definitively diagnose CTE. Researchers are in the process of investigating a blood test to detect CTE through a study called BANK CTE.

Treatment

Because CTE cannot yet be diagnosed with a known level of statistical accuracy in living patients, there have been very few scientific 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.

However, there are many known therapies available to treat the symptoms associated with suspected CTE that allow patients to have better quality of life. Under the care of the right doctor, alongside lifestyle changes, most patients will see improvements through targeted treatments that focus on addressing symptoms.

This section provides information about evidence-based options and how you can start to feel and live better.



Management of CTE symptoms

Management of CTE symptoms requires a comprehensive approach that addresses both physical and cognitive symptoms. Individualized care plans focus on improving the quality of life for those affected, while cognitive therapies help improve functioning and assist individuals in adapting to their limitations.

Behavioral therapies have been proven effective for addressing the emotional and psychological challenges of CTE, providing techniques to cope with mood swings, depression, and potential aggression.

Physical therapy also plays a pivotal role in managing motor symptoms, helping to preserve mobility and function.

Pharmacological Treatments

The pharmacological factors for managing CTE include a range of medications, each targeting specific symptom clusters.

- **Cognitive enhancers:** Medications like Aricept (donepezil) and Namenda (memantine) are used to mitigate memory loss and confusion.
- **Antidepressants:** These medications play a key role in managing the complex emotional landscape of CTE, from lifting the fog of depression to curbing rage and anxiety.
- **Mood stabilizers:** Used to smooth the ups and downs of emotional volatility, mood stabilizers can make a big difference in the lives of those with suspected CTE experiencing bipolar-like symptoms.
- **Sleep:** Melatonin and other sleep aids are sometimes prescribed to combat the sleep disturbances commonly reported in CTE cases, aiding in a more restful sleep cycle.

Treatment Approaches for Younger Patients

Younger individuals often encounter a cluster of behavioral issues, including anxiety, depression, rage, and sleep disturbances. Their cognitive challenges primarily involve short-term memory loss and difficulty in executive functions that disrupt daily living and normal activities.

Experts now believe that, in most cases, these symptoms are not primarily driven by CTE, if CTE is present at all. Instead, these symptoms are more likely to be related to suffering multiple concussions, or they could be unrelated to head impact history. That means these symptoms are not progressive and they should be treatable.

A comprehensive care plan that promotes healthy lifestyle choices can have a significant impact on brain health and overall well-being for younger individuals who may be dealing with suspected CTE.

- **Regular physical activity:** Following a structured exercise routine not only aids in maintaining physical fitness but has also been shown to improve mood and cognitive function. Aerobic exercises, strength training, and yoga can play a vital role in neuroprotection.
- **Cognitive engagement:** Taking part in activities that stimulate the mind, such as puzzles, reading, learning new skills, or engaging in any form of creativity, can improve neural pathways and potentially slow the progression of symptoms.
- **Diet:** Due to its anti-inflammatory properties, the Mediterranean Diet has been shown in research to be effective in maintaining brain health. The Mediterranean Diet emphasizes plant-based foods and protein with healthy fats, with very little red meat consumption.
- **Weight loss:** Many former athletes have reported symptom improvement after weight loss. Being overweight can contribute to chronic pain, limit one's ability to exercise, and can impact sleep.
- **Sleep:** The link between sleep and cognitive health has been clearly established. Optimize your sleep with a regular sleep schedule; a dark, quiet, and cool sleep environment; and relaxation techniques, such as meditation, to reduce anxiety and promote restful sleep.

Evidence-based treatment practices

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

At this time, Concussion & CTE Foundation 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 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. You can learn more on the Concussion & CTE Foundation CTE Treatments page.

Treatment	Symptoms Targeted	Typical Providers
Cognitive Behavioral Therapy (CBT)		
Psychological therapy frequently used to treat mood and behavior.	• Depression • Anxiety • Impulsivity	Clinical Psychologist Mental Health Counselor Social Worker Occupational Therapist
Cognitive Rehabilitation Therapy (CRT)		
Also known as cognitive therapy. A goal-oriented rehabilitation approach to restoring and improving functional cognitive skills.	• Executive functioning • Word-finding skills • Cognitive decline	Occupational Therapist
Endocrinology		
Specifically, neuroendocrine assessment of pituitary function to determine if an initial TBI has caused hormonal imbalance.	**Treatment resistant:** • Brain fog • Fatigue • Listlessness • Depression	Endocrinologist

Treatment	Symptoms Targeted	Typical Providers
Medication		
Certain pharmacologic interventions are available to treat physical, mood, behavior, and cognitive symptoms.	• Memory loss • Trouble thinking/ • concentrating • Depression • Headache • Anxiety • Agitation/rage • Sleep	Psychiatrist Neurologist Primary care
Meditation		
A practice where an individual uses a technique such as mindfulness to train attention and awareness to achieve a mentally clear and emotionally calm and stable state.	• Sleep disturbances • Anxiety • Attention deficits	Counselor or instructor trained in mindfulness or meditation **Resources:** LoveYourBrain Calm Headspace Insight Timer
Neuropsychology		
A branch of psychology focused on how the brain and nervous system influence a person's cognition and behavior.	• Memory • Word finding • Concentration • Motor function • Multitasking • Depression • Anxiety • Impulsivity	Neuropsychologist

Treatment	Symptoms Targeted	Typical Providers
Neuropsychological Testing		
Includes cognitive testing, dementia rating scales, mood scales, behavioral scales, and sleep to assess patient deficits.	• Executive dysfunction • Depression • Suicidality • Anxiety • Irritability • Apathy • Physical violence • Verbal violence • Explosivity • Loss of control • Short fuse • Impulsivity • Paranoid delusions	Neuropsychologist
Occupational Therapy (OT)		
The therapeutic use of everyday activities to help patients develop, recover, improve and maintain the skills needed for daily living and working.	• Fatigue • Headache • Dizziness • Sleep • Memory loss • Concentration • Processing speed • Language • Communication • Executive function • Vision impairment	Occupational Therapist
Psychiatry		
The medical specialty devoted to the diagnosis, prevention, and treatment of mental health disorders. Psychiatrists assess both the mental and physical aspects of psychological problems.	• Personality changes • Anger/Rage • Depression • Sustained hyperactivity (Mania) • Paranoia • Detachment from reality (Psychosis) • Substance abuse and addiction	Psychiatrist Psychiatric Nurse Practitioner

Treatment	Symptoms Targeted	Typical Providers
Vestibular Therapy		
A wide range of techniques, including habituation exercises, gaze stability training, and balance training.	• Persistent dizziness • Vertigo • Balance problems • Headaches	Neurologist ENT Physiatrist Physical Therapist
Vision Therapy		
Range of techniques designed to help train specific aspects of the visual system.	• Sensitivity to motion • Eye strain • Headaches • Nausea • Dizziness/balance • Sensitivity to light • Blurry vision • Double vision • Peripheral vision • Convergence issues	Neuro-Ophthalmologist Neuro-Optometrist Physiatrist Physical Therapist Occupational Therapist



Nuances Among Emerging, Experimental, or Alternative Treatments

This section includes treatment practices with limited or absent evidence showing whether it is safe and effective for managing symptoms associated with CTE based on scientific research publications in academic journals subject to rigorous peer review.

The list summarizes common emerging, experimental, or alternative treatment practices and highlights the current state of research for each. While not exhaustive, it serves as a framework to help patients evaluate the supporting evidence for a given course of action.

This section is intended only as a resource to support informed decision-making in consultation with a qualified medical professional and does not imply endorsement of experimental or alternative treatments. Before pursuing any treatment, carefully consider the supporting evidence and weigh the potential benefits against the risks, time, and costs involved.

TMS: Transcranial Magnetic Stimulation (TMS) is a non-invasive and generally safe therapy using an electromagnet to create low intensity pulses that stimulate brain cells. TMS research has shown increasing evidence for effectiveness managing symptoms and conditions such as treatment resistant depression, anxiety with depression, migraines, and obsessive-compulsive disorder (OCD). Certain applications of TMS therapy are FDA-approved for individuals over age 15.[13]

Ibogaine: Ibogaine is a Schedule I controlled substance and psychedelic compound. Limited research trials have been FDA-approved to investigate the safety and efficacy of ibogaine. A study published in 2024 out of Stanford showed benefits for military veterans with diagnosed TBI, but this treatment is not yet available in the United States outside of research studies. Additional research interests center on possible applications for psychological trauma, depression, and substance use disorders. Research has documented that ibogaine can cause severe adverse reactions, including seizures, increased psychosis symptoms, and even death.[13] More research is needed into the safety and efficacy of Ibogaine.

EMDR: Eye Movement Desensitization and Reprocessing (EMDR) is a psychotherapy technique intended to help reprocess traumatizing memories closely associated with adverse mental health symptoms. Currently, EMDR is considered experimental because its efficacy has not yet been verified by a sufficient body of research and is not FDA-approved. Research suggests some potential for treating mental health conditions such as anxiety, depression, and stress.[13]

Neurofeedback: Neurofeedback, a type of biofeedback, is a noninvasive and generally safe technique using electrical sensors or computer programs to monitor bodily functions during mind-body awareness and control exercises. Typically, neurofeedback monitors brain activity during exercises with audio and/or visual stimuli. Certain applications of neurofeedback techniques and devices are FDA-approved. Research has shown promising results managing conditions and symptoms such as depression, anxiety, insomnia, ADHD, and Schizophrenia. However, research has also shown that individuals with a history of traumatic brain injury may experience adverse effects from neurofeedback treatment.[17]

Acupuncture: Acupuncture is a technique that involves the insertion of fine needles into the skin to help treat various health problems such as neck pain, joint pain, and headaches/ migraines.[18]Acupuncture needles are regulated as FDA-approved medical devices; however, the practice of acupuncture is not. More research is needed to assess whether it is an effective method for managing symptoms associated with CTE.

HBOT: Hyperbaric Oxygen Therapy (HBOT) entails breathing pure oxygen within a pressurized chamber. The objective of this technique is to achieve therapeutic benefits by increasing oxygen levels throughout the body. Research has shown that HBOT is not an effective method for management of TBI or symptoms commonly associated neurodegenerative diseases like CTE.[19] HBOT is FDA approved for certain conditions associated with wounds, skin and bone infections, and decompression sickness.[20]

Cryotherapy: Whole-body cryotherapy (WBC) entails brief exposure to extremely low temperatures. The FDA has issued warnings about potential health risks from WBC and this technique is not FDA-approved as safe or effective to treat any medical condition. Research is extremely limited on WBC's effectiveness as a treatment option for those with neurodegenerative disorders.[21]

Functional Neurology: Functional neurology, also known as chiropractic neurology, is performed by chiropractors. This practice employs techniques that are intended to promote healing through neuroplasticity, or the brain's natural ability to change and adapt. Functional neurology differs from traditional medical neurology and is not performed by a board-certified medical doctor (MD/DO). Recent analysis on a large body of clinical studies examining the safety and effectiveness of various functional neurology interventions for a range of medical conditions, including TBI, found the interventions lack sufficient scientific evidence.[22]

NAD+ IV: Nicotinamide adenine dinucleotide (NAD+) is a compound that occurs naturally within living cells. NAD+ therapy introduces more of this compound to the body through intravenous (IV) fluid infusion. NAD+ IV therapy is considered experimental and not FDA-approved. The conceptual basis for this treatment centers on research showing NAD levels in human cells decrease with age and theorizes IV supplementation could potentially support cell function and survival. Research is ongoing in preclinical and clinical studies with NAD+ supplementation to explore impacts on premature aging and neurodegenerative diseases.[23-24]

Ketamine: Ketamine is a Schedule III controlled substance that is FDA-approved for induction and maintenance of general anesthesia. A similar more potent chemical compound known as esketamine was FDA-approved in 2019 for treatment-resistant depression.[25] Recent research into the uses for Alzheimer's disease and depression indicates that ketamine may reduce neuropsychiatric symptoms and may have neuroprotective qualities.[26] More research is needed to better understand the safety and efficacy of ketamine treatment for symptoms associated with CTE.

Psilocybin: Psilocybin is a Schedule I controlled substance and psychedelic compound. Highly publicized studies have been FDA-approved for limited, experimental "breakthrough therapy" research trials to investigate psilocybin in drug-assisted psychotherapy models, but not as a stand-alone drug treatment. Research has analyzed psilocybin's potential as a treatment option for depression, substance use disorders, and cancer-related psychiatric distress. Results have yet to be replicated in those with neurodegenerative diseases and more research is needed into the safety and efficacy of psilocybin.

MDMA: MDMA is a Schedule I controlled substance. It is a synthetic compound with stimulant and psychedelic effects. Highly publicized studies have been FDA-approved for limited, experimental "breakthrough therapy" research trials to investigate MDMA-assisted therapy as a potential treatment for PTSD and depression. MDMA has not been studied in those with neurodegenerative disease and more research is needed into the safety and efficacy of MDMA.

05 Living With Suspected CTE

Jump to section

- Taking Control of Brain Health
- Being a Caregiver and Advocate
- Research



Taking Control of Brain Health

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. YOU are still in control of your brain health.

This section covers strategies and tactics that can help you feel better today and lower your risk of problems in the future.

Lifestyle changes and tips for daily living: Taking control of your brain health is a daily practice that involves introducing or maintaining key lifestyle changes. The following tips for daily living can help support a healthy and fulfilling life with suspected CTE:

Exercise: Regular exercise can relieve stress, help with pain, and improve overall well-being. Anecdotally, many individuals with suspected CTE have reported to Concussion & CTE Foundation that starting the day with exercise has helped them regulate their mood and be more productive. 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 your doctor before beginning a program and consider enlisting the support of professionals such as physical therapists or personal trainers.

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.

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 is sleep, cooking breakfast, or going for a nature walk, developing a routine and approaching tasks one at a time can make life more manageable.

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 or seek professional help as needed.

Self-regulate: Managing emotion, anxiety, and stress is an important learned skill. Some simple relaxation techniques like deep breathing, meditation, or counting to 10 can be developed through your own self-paced practice. Other more durable techniques for processing and regulating emotions can be achieved through working with mental health professionals. Therapists and counselors can help you start from scratch, reinforce your existing strengths, or learn proven-effective ways to help ensure emotions don’t spiral out of control.

Build a support system: Intentionally socializing with trusted friends and relatives can help reduce feelings of isolation and support your overall well-being. Reaching out to these support networks can also 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 for both patients and caregivers.

Get good sleep: Quality sleep is essential. Your body needs a full night of rest to function at its best every day. Sleep disorders like sleep apnea can cause mental fogginess, 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. Optimize your sleep with a regular sleep schedule; a dark, quiet, and cool sleep environment; and relaxation techniques, such as meditation, to reduce anxiety and promote restful sleep.

Diet: Vascular disease, hypertension, obesity, and diabetes are independent risk factors for dementia and should be prevented as much as possible. Alongside regular exercise, maintaining a well-balanced diet can help improve mood and regulate energy levels. Studies have shown the Mediterranean diet, which includes lots of green vegetables and fish, avoiding red meat and foods high in cholesterol, is helpful. Consult a dietitian or nutritionist for specific advice and counseling.

Maintain hope: It is crucial that anyone concerned they may be living with CTE remain 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, communicate better, stop repeating harmful behaviors, and get to the next day. Every new day is an opportunity to feel better and experience improved quality of life with loved ones or activities that bring joy.

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. Work with loved ones to create positive communication strategies and reinforce your support networks. 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 is free, confidential, and available to everyone in the United States. You or your loved one do not need to be suicidal to call. You can also reach out to the Concussion & CTE Foundation HelpLine for 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 tools and resources to help you advocate for your loved one, address challenges, and avoid burnout.

Advocating For Your Loved One

Educate Yourself on the Basics

While day-to-day needs can feel like the highest priority when caring for a loved one with CTE, it is important to learn about CTE symptoms experienced by your loved one so you can make decisions that incorporate this understanding. An advocate who understands CTE symptoms can speak up when their loved one may not be able. Having someone in their corner while they navigate this journey will lower the likelihood that they try to push through symptoms and will help them accept support.

Work on Communication

Communication and shared trust are crucial in your caregiver journey. Making dedicated time to speak with your loved one can reaffirm your shared goal in managing symptoms and encourage them to take an active role in their health journey.

Seek Family Resources

Finding and using resources designed to support the whole family can sometimes be challenging and may not always feel like a high priority. Nonetheless, this is an invaluable way to bolster your loved one's support system and help protect your own well-being. This may involve working with your own personal therapist, trying out family counseling, exploring respite care, tapping nonprofit or government programs, working through educational resources, or developing literacy in how to access support services in the first place. If you need ideas about where to start, the Concussion & CTE Foundation HelpLine is here to assist and your loved one's healthcare providers can also help you find resources for the whole family.

Explore Financial Resources

Navigating CTE can bring added financial challenges, from medical expenses to home accommodations or estate planning, that increase the caregiving burden. Don't do it alone. Beyond specialized financial advisors, healthcare and social service practitioners like case managers, care coordinators, social workers, benefits specialists, and patient advocates can provide guidance and assistance.

Anticipating Challenges

CTE is a complex condition. Related challenges can look very different across patients and families. Most often, it is best to focus your energy on issues you are already facing; however, mentally preparing for potential challenges in moderation can help you spot them early and utilize strategies discussed throughout this guidebook.

While not exhaustive, the following list includes common unexpected challenges reported by families during their loved one's illness:

- **Isolation:** In some ways, CTE is an "invisible" disease that friends and extended family may find difficult to understand or support you through. Finding a strong support system for both you and your loved one may help alleviate feelings of loneliness.
- **Poor Quality of Care:** Many clinicians are not adequately informed about CTE. You may encounter negative experiences with providers who do not understand or cannot address your loved one's needs.
- **Safety:** Compared to other neurodegenerative diseases, CTE more frequently affects younger men who are larger and stronger than average. This can present unique concerns for families & professional caregivers. It can be particularly challenging to find skilled nursing or assisted living options for patients with advanced disease due to safety concerns if there is a documented history of physically threatening or violent behavior, whether perceived or actual.
- **Age of Impact:** CTE symptoms often emerge or escalate during conventionally "productive" years of life. The strain on careers, childcare, or family relationships can therefore be especially disruptive.
- **Children:** Being a child of a parent with behavioral and cognitive changes due to CTE can be confusing and upsetting. Talking with your child about what may be behind a parent's changing behavior is a first step toward helping them understand and process difficult experiences. Enlisting the support of professional counselors, support groups, and peer-to-peer connections are great ways to find resources to fit your family's situation.
- **Finances:** Executive dysfunction may emerge before noticeable memory issues, increasing the risk of impulsive spending, risky investments, or falling victim to financial exploitation. To prepare for this, consider proactively monitoring finances and working with financial professionals to establish safeguards that ensure major financial decisions require your oversight or input.

- **Substance Abuse:** Substance use can worsen CTE symptoms. Beyond this, CTE symptoms may compound existing substance use disorders, complicate addiction recovery, or contribute to the development of new unhealthy dependencies. Awareness and early intervention can help mitigate these risks.
- **Legal Considerations:** As your loved one's decision-making capacity declines, you may need to take steps to ensure their medical and financial affairs are properly managed. This could include establishing power of attorney for healthcare and financial matters or setting up advance directives. For more information, visit Alzheimer's.gov, which provides guidance on legal and financial planning after a dementia diagnosis.

Talking With Your Loved One

Many patients with CTE have trouble with interpersonal communication, so patience and understanding are key. Simply trying your best each day is a meaningful step forward in supporting your loved one. Start by learning about the key factors that affect their communication so you can develop strategies to lessen the impact

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.

Communication Strategies

You deserve to be treated with respect when caring for your loved one. The following tips and suggestions can help manage escalations, maintain clear communication, and ensure your own health and safety are prioritized.

As much as possible, strive to avoid:

- Arguing with your loved one.
- Assuming your reality as a caregiver will make sense to your loved one.
- Belittling or dismissing your loved one if their behavior is immature or childlike.
- Blaming your loved one instead of your loved one's disease.
- Demanding urgent conversations that may make them anxious or upset.
- Expecting logic will resolve misunderstandings or arguments.
- Unloading frustration with tone or phrases such as "Don't you remember?.."
- or "I just told you…" They may truly not remember, and what seems obvious to you may be hard for them to comprehend.

Whenever possible, try to:

- Disrupt cycles of escalation. Plan when to introduce important conversations around times your loved one is most likely to feel safe and comfortable. If you feel yourself pulled toward escalation, try not to match their response. Calmly removing yourself when tensions rise by using a prompt like, "I'm leaving the room now," can be a useful tool.
- 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.
- Practice self-care and remember you have your own life beyond caregiving. Take the time to pursue your interests and support your personal needs.
- Redirect emotions or arguments. Your loved one is living in the "here and now." Change what is here and what is now. Redirect frustration toward fun, crying toward laughter, absence toward presence. Keeping photos, movies, or music on hand that your loved one associates with joy or happiness can help.
- Understand your loved one's reality is not the same as yours, but common ground can still be found.

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, but we encourage you to remember you will be better prepared to help your loved one when you first help yourself.

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

- Regular exercise, even for short periods at a time
- Stress reduction through meditation, mindfulness, yoga, or breathing techniques
- Taking time to enjoy reading, music, cooking, and other healthy activities
- Prioritizing rest and eating a healthy diet
- Socializing with friends and family and seeking their support when you need it



Remember that you are not alone. Caregiving for someone with suspected CTE can be an isolating experience, especially when those around you don't understand the nature of this journey. If you would like to be connected with other caregivers who understand what you are going through, please submit a Concussion & CTE Foundation HelpLine request and our team will reach out with more information about our peer-to-peer support network.

Research

The Science of CTE

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. The findings of the UNITE Brain Bank and the Concussion & CTE Foundation Global Brain Bank are published in peer-reviewed medical journals and have created an undeniable body of evidence that repetitive brain trauma can lead to devastating neurodegenerative disease.

You can find more information about what research breakthroughs have taught us here: Science of CTE.

Participating in research

Almost everything we know about CTE is the result of post-mortem brain tissue analysis or clinical research in living patients. Research is the key that unlocks our ability to prevent and treat the effects of brain trauma. Brain bank research has shaped our understanding of how repetitive brain trauma affects behavior, thinking and memory. Engaging with research is one way that you or your loved one can help us find answers about suspected CTE and contribute to future progress.

Brain donation is a generous act that is a proven effective accelerator of research on CTE among athletes and military veterans over the last decade. By showing how CTE has affected hundreds of military veterans and athletes across multiple sports, we have inspired the scientific community to invest in CTE research.

If you would like to advance research on the diagnosis and treatment of CTE, consider enrolling in the Concussion & CTE Foundation Research Registry.
By enrolling, you or your loved one will have the opportunity to pledge to donate their brain, express interest in clinical research participation, or both.

06 Additional Support and Resources

Jump to section

- Mental Health Crisis
- Concussion & CTE Foundation HelpLine
- Peer Support
- Military Resources & Programs
- Videos & Webinars
- Stories of Hope & Resilience



Mental Health Crisis

Feeling anxious or worried about CTE is understandable. However, if you believe you or your loved one may be experiencing a serious medical or mental health crisis, please don't wait to contact your local emergency services or a crisis support provider such as the National Suicide & Crisis Lifeline.

If you are concerned that someone you care about may be considering suicide, don't give up hope. There is no single cause of suicide. It is often the result of complex factors at the individual, interpersonal, community, and societal levels. But there are simple steps you can follow to communicate with someone who may be suicidal. The five #BeThe1To Steps provide clear guidance supported by evidence in the field of suicide prevention.

Additional Mental Health Crisis Resource Links:

- National Alliance on Mental Illness (NAMI) HelpLine
- Navigating a Mental Health Crisis
- Substance Abuse & Mental Health (SAMHSA) HelpLine
- VA Veterans Crisis Line
- Stop Soldier Suicide
- National Domestic Violence Hotline
- NFL Life Line
- COPLINE Law Enforcement Hotline



Concussion & CTE Foundation HelpLine

Our HelpLine provides personalized help to those struggling with the outcomes of brain injury. Patients and caregivers navigating suspected CTE can reach out for free, confidential 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.

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Peer Support

Connecting with others who truly understand your journey can make a world of difference. Concussion & CTE Foundation offers several Peer Support Programs designed for patients and caregivers.

Reach out to the Concussion & CTE Foundation HelpLine if you would like to be connected, or email support@concussionandcte.org to learn more.

Virtual Support Groups

Concussion & CTE Foundation support groups allow you to connect virtually with other patients and caregivers who are navigating CTE Symptoms. Our support groups aim to foster a strong sense of community while providing valuable resources, compassionate support, and renewed hope.

Concussion & CTE Foundation 1:1 Peer Support Connection Program

Concussion & CTE Foundation's Peer Support Connection Program offers 1-on-1 partnerships with trained volunteers who have "been there." Our Peer Support Volunteers include current or former caregivers and individuals with a history of brain trauma who have navigated similar challenges and want to give back by sharing wisdom and a listening ear.

Concussion & CTE Foundation CTE Resources Facebook group

The CTE Resources Facebook group is an online community focused on providing resources, support, coping strategies, and hope to those affected by suspected CTE.



Military Resources & Programs

TBI is the signature wound of modern warfare, with more than 430,000 U.S. veterans diagnosed in the last 20 years. TBI due to blast injury or exposure, as well as other service-related causes, is a significant problem in the military community. However, the scientific understanding of TBI and related disorders is in its infancy, and we lack both effective treatments and active diagnostic testing for living patients. This means that meeting the needs of active service members and veterans with a history of TBI, as well as their caregivers, is more important than ever.

Operation Brain Health

If you or your loved one is a veteran or service member suffering from the effects of brain trauma, know this: TBI, PTSD, and CTE don't control your future. YOU are still in control of your brain health. There are strategies, tactics, and treatments that can help you feel better today and lower your risk of problems in the future.

Operation Brain Health is our growing library of brain health resources designed for members of the military community. We've recruited the top medical experts to help you live your best and healthiest life:

- How Veterans Can Optimize Brain Health
- The Role of Caregivers for Veterans with TBI, PTSD & Suspected CTE
- Why Medical Care can Help Veterans with TBI
- Why Medical Care can Help Veterans with PTSD
- TBI & CTE in the Military



Addressing TBI and CTE in service members is a persistent challenge. Many have not been made fully aware of the issue, some may hesitate to report their symptoms due to concerns it will negatively impact their career or deployment status, and others had symptoms that were misdiagnosed or dismissed as common mental health issues. We hope these resources help guide more service members and families toward recovery and treatment options right now while further research efforts focusing on TBI, PTSD, and CTE continue to advance.

Project Enlist

Project Enlist is advancing critical research on CTE, PTSD, and TBI by recruiting veterans and service members to pledge to donate their brains to the UNITE Brain Bank.

Brain bank research is an essential step in understanding these conditions and their impact on members of the military community. Join more than 2,000 veterans and service members who have helped raise awareness to support these efforts by joining the Concussion & CTE Foundation Research Registry.

By signing up, you can stay informed about clinical studies you may be eligible for and play an active role in helping scientists find solutions for the long-term outcomes of brain trauma. For more information, visit our Project Enlist FAQ page.



Videos and Webinars



[Concussion & CTE Foundation Webinar: How to Optimize Your Brain Health]
Actionable tips for optimizing brain health, strategies to live a fuller life, and a brief guided meditation.



[Concussion & CTE Foundation Webinar: How CTE Can Impact Spouses, Parents, and Children]
A discussion on how CTE impacts families with caregivers sharing their experiences, wisdom, and insights.



[Concussion & CTE Foundation Playlist: CTE Resources]
Knowledge, lived experiences, and hope shared by researchers, educators, advocates, patients, caregivers, and families sharing.



[Concussion & CTE Foundation Playlist: Operation Brain Health]
Lifestyle changes, tips for daily living, and guidance to help you live your best and healthiest life.



[Concussion & CTE Foundation Playlist: Webinar Series]
Deep dives into the science of CTE, navigating life as a patient or caregiver, and the wider impacts of brain trauma.

Stories of Hope & Resilience

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

Click here to explore our full library of inspiring stories such as:

Making it Through the Perfect Storm

Dan suffered multiple concussions and non-concussive head injuries during his football career which he believes led to his significant mental health struggles, including addiction and suicidality.

Through vulnerability, therapy, & meaningful connections with others, he has found hope. Dan shares his story to advocate for mental health awareness and inspires others facing similar struggles, highlighting the power of resilience and the importance of seeking help.





Coping with Probable CTE as a Caregiver

Denise serves as the primary caregiver for her husband, Steve, who has been diagnosed with probable CTE by his doctor. He has had a slow progression of symptoms dating back to 1996. He has battled depression, migraines, substance abuse, memory loss, and impulsivity for decades. Through this long and difficult journey, Denise has come to understand that living with this disease requires resilience and the ability to take each day as it comes. By sharing her story, she hopes to inspire and encourage other families navigating similar struggles to keep moving forward, one day at a time.

07 Conclusion



Navigating suspected CTE can be an overwhelming and complex journey. Whether you are trying to find initial support, continuously advocating for yourself or a loved one, preparing for the impact suspected CTE can have on the whole family, or searching within yourself for the strength to keep fighting after a setback, it requires patience, perseverance, and resourcefulness. Know that your courage is recognized, and your cause is worthy.

Perhaps the most precious resource you can hold onto as a patient or caregiver is hope. Hope helps us keep going through our toughest challenges. Hope is the belief there can be a better future. Hope inspires us to take action. Hope has proven impacts on reducing depression and improving mental health. Hope is crucial for people struggling with symptoms, and hope can be contagious.

Simply refusing to give up the fight or still "being there" for your loved one can be enough to find a better path forward. Remember that you are not alone – reach out to us through the Concussion & CTE Foundation HelpLine if you need recommendations, support, or guidance.

08 References

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