

# CTE Healthcare Navigation Form

The purpose of this document is to provide a useful form to help people potentially suffering from CTE (Chronic traumatic encephalopathy) or PCS (Post-concussion syndrome), and their family, navigate a visit to their healthcare provider. The goal is to provide timely information, and to make that visit as productive and helpful as possible.

We are not doctors or scientists. We are an awareness organization. The information we provide is based on our experience in this new frontier and is meant to serve as a tool to aid in seeking recovery.

This form may be especially important for military veterans, and those with a history of contact sports and/or domestic abuse.

## CTE Healthcare Navigation Form

Dear Patient:

The attached form was created to help you navigate the healthcare system and, hopefully, find much needed help. Going to a doctor's appointment can be a stressful process for anyone, but for someone dealing with symptoms of CTE or PCS it can be even tougher.

The goal of this form is to help your doctor understand what is going on with you physically and emotionally. It may be helpful to have someone close to you work with you to complete this form. Brain health is a new frontier for today's busy doctors, and the field of Chronic Traumatic Encephalopathy (CTE) is even newer. As you begin your journey for medical assistance for your CTE or PCS symptoms, it is very important to be patient. It may take some time to find the right doctor to help you.

You will probably start by seeing your primary care physician, who will then refer you to specialists.

Because your time with your doctor may be brief, and because you have so much to share, it is important to be prepared.

You can do some research in advance by using the internet to Google "CTE doctor near me". Discuss what you find with your doctor. They may also have other referrals. In some cases you may be the one helping educate the doctor about CTE. If they are willing to listen and learn about your symptoms and head impact history, your actions will pave the way for others with your CTE challenges. Don't look at it as a frustration, but as a way to help others with CTE, while helping yourself as well.



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Your goal, simply, is to get help. If you feel your doctor's visit is not putting you on a good road to recovery, try a different road. You want to find a doctor to fit your needs. For you this is personal. Relief may take time, so continue to be strong and vigilant and you will eventually find yourself on a better course.

Your doctor will provide you with therapy appointments or other support you will need. It will help if you sign medical releases so members of your support network can communicate with each other to get you the care you need at a pace that is helpful for you.

Also contact your local brain injury association or alliance for doctor suggestions, support groups, and maybe even financial assistance. Google "biausa.org" or "usbia.org" to find one in your state.

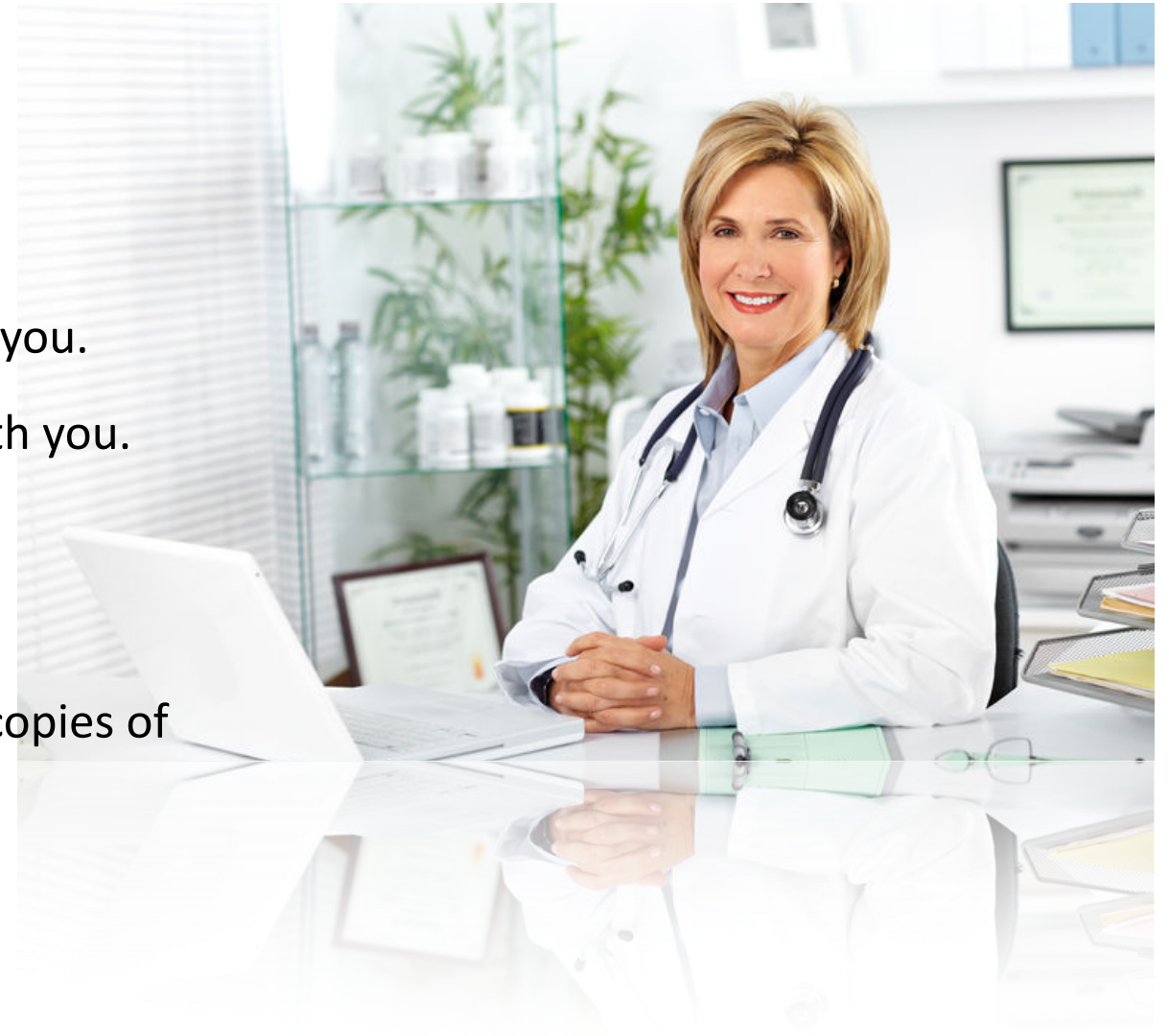
The Concussion Legacy Foundation has a helpline for you if you are unable to find the assistance you need. Google "CLF Helpline".

Please know you are not alone. There are many former athletes, veterans, and domestic abuse victims dealing with CTE symptoms, both male and female. And there are many wonderful researchers working on cures and treatments. Tremendous progress is being made. A better future is very possible. We wish you the best possible outcome.



## Patient Checklist:

- Remember your appointment.
- Bring your medical cards with you.
- Bring your current medications or a list of them with you.
- Bring a list of current and past medical conditions with you.
- Bring a list of brain trauma history with you.
- Bring a friend, family member, or mentor if possible.
- Complete and bring this form with you. Make extra copies of this completed form for future doctor visits.





## Dear Health Care Provider:

The following information is intended to better enable you to help me.

I am here because I am experiencing many symptoms of Chronic Traumatic Encephalopathy, (CTE) and/or Post-concussion Syndrome (PCS). CTE is a degenerative neurological disease possibly caused by repetitive trauma to the brain.

I would like help with understanding and managing these symptoms. Please take note of my immediate concerns listed below.

### **PATIENT: Concerns (Check all that apply)**

- ☐ Loud noises, heavy music, chaos, or crowded waiting areas are very disturbing and cause confusion. Please help me avoid these.
- ☐ Bright lights are very disturbing and cause headaches. Please offer a darkened room if possible.
- ☐ I may not be able to endure a long visit and may need to split my exam into several sessions.
- ☐ If I am alone I will need help reading text and filling out forms. Can someone walk through the necessary forms with me? (I much prefer the forms to be read out loud to me)
- ☐ Every now and then I feel confused so please talk to me and explain all procedures and write down any directives I need to follow
- ☐ Please include me in decision making and understand I may need encouragement and follow up.

## Patient:

Please check all symptoms you are experiencing and if possible the approximate date when they started. Please explain whether the symptoms are improving, staying the same or getting worse. This will be extremely useful for your physician.

✓	SYMPTOMS	DATE OF ONSET	IMPROVING, STAYING THE SAME OR GETTING WORSE?
	Quick Temper, Anger, Irritability		
	Physical & Verbal Outbursts		
	Impulsivity, Lack of Self Control		
	Inappropriate Behavior, Aggressiveness		
	Addictive Behavior		
	Memory Problems		
	Poor Judgment		
	Trouble Concentrating & Learning		
	Difficulty Following Verbal Exchanges		
	Trouble Prioritizing, Planning & Organizing		
	Difficulty Putting Ideas on Paper		
	Difficulty Reading		
	Deficient Handwriting		
	Depression, Feeling Hopeless, Helpless		
	Anxiety, Feeling of Doom		
	Lack of Motivation, Initiative		
	Feeling Worthless, Low Self Esteem		
	Feeling Misunderstood & Looked Down Upon		
	Reclusiveness		

## Patient:

Please check all symptoms you are experiencing and if possible the approximate date when they started. Please explain whether the symptoms are improving, staying the same or getting worse. This will be extremely useful for your physician.

✓	SYMPTOMS	DATE OF ONSET	IMPROVING, STAYING THE SAME OR GETTING WORSE?
	Suicidal Thoughts		
	Ugly or Scary Thoughts		
	Paranoia		
	Apathy		
	Poor Grooming		
	Trouble Sleeping		
	Frequent Headaches		
	Unexplained Localized Pain in Different Parts of Body		
	Muscle Spasms		
	Slurred Speech		
	Tapping Fingers, Bouncing Legs		
	Ringing in Ears		
	Sensitivity to Light		
	Sensitivity to Noise		

**Patient:**

Which of the above symptoms are causing you the most trouble in life?

Have you stopped doing certain chores, such as shopping or finances, because you can't do them anymore?

Are you consuming alcohol? Are you taking any non prescription drugs?

What is your diet like?

Is there family history of dementia or other neurological diseases such as Alzheimer's, ALS or Parkinson's disease?

What is your support network like?



## **Healthcare Provider:**

The patient submitting this form is in a fragile state of mind, and has made a huge effort just to be able to see you. All of this is exceptionally challenging for a person with cognitive issues. Your patience and sensitivity will go a long way toward helping this individual. The stress of the healthcare system and venturing away from their safe homes can bring out some of their worst personality traits. They need your help to get back to their best selves.

### **Possible suggestions...**

- Vision test
- Hearing test
- Cognitive test
- Complete Blood Count (CBC)
- Metabolic Panel
- Lipid Panel
- Glycated hemoglobin (A1C) test
- Thyroid test
- Antinuclear Antibody (ANA) test, Sed rate (ESR) test, C-reactive protein (CRP) test
- Fasting blood test for prolactin, T-4, TSH, ACTH, cortisone, growth hormone, testosterone, and B12, B9, B6 & D.
- EEG
- CT Scan or Diffusion Tensor Imaging MRI for Vascular dementia, Hydrocephalus, Tumors, Subdural Hematoma, etc.
- Check current medications and possibly change

### **Possible needs:**

- Vision Therapy
- Vestibular Therapy
- Cognitive Behavioral Therapy
- Cognitive Rehabilitation
- Psychological Support
- Emotional Support
- Pain Management Therapy
- Mediterranean diet and avoidance of alcohol
- Pharmacological help with routine surveillance and follow-up
- CBD?