



CLF Peer Support Volunteer Training

Thank you for your interest in becoming a dedicated Peer Support Volunteer! In this role, you will have the opportunity to help patients and caregivers navigate the many challenges posed by concussion, persistent post-concussion symptoms (PPCS), also known as, Post-Concussion Syndrome (PCS), and suspected Chronic Traumatic Encephalopathy (CTE).

This **CLF Peer Support Volunteer Training** accompanies the **CLF Peer Support Volunteer Agreement** and **CLF Crisis Response Resources** documents.

Please be sure to read these sections carefully before your first connection:

1. How to Be a Good Peer Support Volunteer
2. Understanding Concussion, PCS, and CTE
3. Responding to Emotional Crisis, Suicide Risk, and Emergency Situations
4. Recognizing and Reporting Child Abuse or Neglect
5. Peer Support Volunteer Self Care
6. Peer Support Partner Engagement & Connection Summaries

Match Types

CLF relies on your self-reported preferences and life experiences to determine what type of Peer Support matches will be best for you and a prospective Peer Support Partner. Before moving forward with a match, CLF will always check with you to confirm your availability and level of comfort with the details of a potential match.

Matches between Peer Support Volunteers (PSV) and Peer Support Partners may be one of the following combinations:

Peer Support <u>Volunteer</u> Category	Peer Support <u>Partner</u> Category
Concussion Patient	Concussion Patient
Concussion Patient	Concussion Caregiver
Concussion Caregiver	Concussion Caregiver
Concussion Caregiver	Concussion Patient
CTE Caregiver	Suspected CTE Caregiver
CTE Non-Patient Volunteer	Suspected CTE Patient

Due to inherent challenges experienced by suspected CTE patients, CLF does not offer connections between two patients experiencing suspected CTE symptoms. Suspected CTE patients may be matched with a CTE Non-Patient Volunteer, meaning a volunteer who has deep knowledge of suspected CTE but does not have symptoms or concerns about developing symptoms, or a CTE Caregiver Volunteer depending on the circumstances.

How to be a Good Peer Support Volunteer

This section provides introductory concepts to help you excel as a Peer Support Volunteer. For more information, please visit CLF's [Peer Support Volunteer Resource Hub](#) with additional trainings, videos, and answers to frequently asked questions.

Listen, Ask Questions, & Share Experiences

The CLF Peer Support Connection program is designed to help Partners feel like they are not alone by connecting them with someone else who knows what they are going through. Look for opportunities to make them feel heard and understood.

The key to identifying your Partner's needs is listening and asking questions. Ask questions to gain a deeper understanding of a Partner's unique struggles. Then, consider sharing something about your life experiences, injury, treatment trials and errors, social life, or recovery that you think your Partner might be able to relate to.

Here are a few examples of questions to ask:

- Have you noticed a (significant) change in your symptoms for the better or worse?
- What do you feel are your biggest challenges as a caregiver?
- Do you like the medical or mental healthcare providers you are seeing?
- Do you feel like your healthcare providers understand what you are going through?
- What is the hardest part of this experience for you right now?
- How would you describe how you are feeling about what you are going through?
- Are you able to talk to your friends and family about your feelings?
- Which symptoms are you struggling with the most?
- What has been the most difficult part of this experience for you overall?
- What do you wish people knew about Post Concussion Syndrome?
- What do you wish people knew about suspected CTE?
- Do you encounter misconceptions when sharing your experiences with others?
- What helps you find the most relief from your symptoms?
- When do you feel the most supported?
- What would help you feel more supported?
- Do you want to reconnect with CLF's HelpLine team for more resource options?
- Are you able to find little moments of joy despite the challenges you are experiencing?
- Do you want to hear about an experience I had that is like what you described?

Build Momentum

More than anything else, Peer Support Volunteers should convey **relentless optimism** that a Partner can and will find a strategy to help manage their own or their loved one's symptoms.

Recovering from a concussion, navigating suspected CTE, or helping a loved one navigate the patient experience can be a daunting, frustrating, and exhausting experience for a Partner. They may not know what options are available to them, they may feel like they have tried every

possible treatment without seeing improvement, or they may feel like they are on the right track but not improving quickly enough.

Peer Support Volunteers can help by sincerely listening to these feelings. Then, when it feels appropriate, by suggesting small everyday ways to build momentum. Examples of activities that build momentum include:

- Journaling thoughts and feelings
- Talking about goals with emphasis on staying flexible in the face of setbacks
- Committing to daily light exercise (a short walk, yoga, breathing exercises)
- Tracking daily symptom severity
- Verbally celebrating progress

Avoid Negativity & Blind Positivity

You can be an active listener by asking questions and providing constructive feedback. Do your best to avoid negative feedback that might grind the momentum of a conversation to a halt. Be mindful that some feedback can create negative feelings in a Partner, such as:

- Criticism of the Partner for past mistakes or missed opportunities
- Sarcastic remarks with unclear meanings (even if the intent is humor, not harm)
- Pessimistic predictions about the future

On the opposite end of the spectrum, be mindful not to unintentionally invalidate the challenges your Partner is experiencing with “blind,” or uncompromising, positivity. While it is important to convey there are real, evidence-based reasons to be optimistic about the future, try to remember that concussion, PCS, or suspected CTE can be extremely daunting for patients and caregivers. In these situations, an effective approach can look like:

- **Acknowledging** the difficulties your Partner is experiencing are valid
- **Confirming** you can understand what they are going through, even partially
- **Highlighting** the importance of persistence, optimism, and ongoing support from medical or mental health professional healthcare providers
- **Expressing** your belief that a path to concussion recovery or, separately, long-term suspected CTE symptom management is possible and improvements to patient or caregiver quality-of-life are obtainable

Meet Trauma with Compassion

Asking questions is a great way to connect with your Partner; however, be mindful that the questions you ask may bring up traumatic experiences that are difficult for them to navigate and retell. Leave plenty of space for your Partner to work through these difficult emotions by being patient, sympathetic, and flexible.

Understand that Recovery or Symptom Management is not Linear

The road to recovery or symptom management often contains false starts and setbacks that must be handled with patience and compassion. It is helpful to acknowledge hardship and validate difficult experiences; however, try to help your Partner remain positive or avoid letting a difficult day derail their progress. You can point out that bad days, weeks, and months are not uncommon, and it is normal to take a few steps back before moving forward.

Understanding Concussion, PCS, & CTE

The resources below include educational videos, webpages, and webinar recordings to help Peer Support Volunteers understand PCS and suspected CTE. They also provide more information on how to help patients advocate for themselves. Please review them closely to understand the differences between concussion, PCS, and suspected CTE.

Concussion

- [What is a Concussion?](#)
- [What to do after a concussion](#)
- [Concussion Support & Resources](#)
- **Video:** [What happens when you have a concussion?](#)
 - CLF worked with TED Ed to create this educational video on concussions, PCS, sub-concussive impacts, and CTE.

Post Concussion Syndrome (PCS)

- [What is PCS?](#)
- [PCS Treatments](#)
- [Coping with PCS](#)
- [PCS Support & Resources](#)
- **Video:** [Managing Post-Concussion Syndrome](#)
 - This webinar provides an overview of concussion and PCS treatment options with emphasis on ways to manage symptoms. Here is what to watch:
 - **9:30-15:05** – Volunteer Gracie Hussey on PCS coping tips and strategies
 - **15:05-21:00** – Volunteer James Schorn on what to keep in mind during PCS recovery
 - **23:00-39:00** – Dr. Robert Cantu on PCS Treatments and managing symptoms

Chronic Trauma Encephalopathy (CTE)

- [What is CTE?](#)
- [Living With CTE](#)
- [Caregiving For CTE](#)
- [CTE Treatments](#)
- [The Science of CTE](#)

- **Video:** [Coping with Suspected CTE](#)
 - This webinar provides information about suspected CTE treatment options and coping strategies that may be useful for suspected CTE patients or caregivers. Here's what to watch:
 - **00:00-25:54** – Dr. Robert Cantu on Managing and Treating Suspected CTE
 - **26:35-36:17** – Super Bowl Champion Leonard Marshall on suspected CTE symptoms
 - **37:00-46:45** – Dr. James Castle discusses Treating Suspected CTE

Responding to Emotional Crisis, Suicide Risk, & Emergency Situations

A common symptom of traumatic brain injury is difficulty regulating emotions. It is important for Volunteers and *Partners* to know this is common. Therapeutic interventions such as Cognitive Behavioral Therapy (CBT) have been shown to improve these symptoms. Look for opportunities to communicate the treatment information on our [PCS Treatments](#) and [Living with CTE](#) pages.

Recognizing Crisis Situations

In rare circumstances, a Partner may experience an emotional crisis that escalates to the level of imminent suicide risk or other life-threatening situations. While we do not consider this to be a common part of the Peer Support Volunteer experience, the connection between brain trauma and emotional crisis is now well documented and warrants preparation.

[Recent data has shown](#) that patients diagnosed with concussion had double the risk of suicide, a higher risk of suicide attempts, and higher risk for suicidal thoughts than people without brain injuries.

Peer Support Volunteers must know how to navigate conversations that show signs of an emotional crisis. Be sure to thoroughly read CLF's **Crisis Response Resources** guide and internalize the strategies and tactics for navigating emotional crisis presented in the webinars below.

Video: [Suicidality and Crisis Training](#)

- Dr. Ciara Dockery, former director of the NFL Life Line, presents on the factors that contribute to suicidality and severe emotional crisis. The goal of this webinar is to understand how to respond if suicide comes up in conversation.

Video: [Helping Concussion and Suspected CTE Patients in Crisis.](#)

- This webinar is helpful for understanding a concussion or suspected CTE patient's perspective. It is a good dive into what patients go through and how friends, loved ones, and Peer Support Volunteers can provide the support and recommendations they need to overcome the tough times.

Definition of Crisis

We define “crisis” as a situation where it becomes clear a CLF Partner’s life is in immediate danger. Some examples of life-threatening situations that a Peer Support Volunteer may encounter in a Partner include:

- Active planning and intention to die by suicide
- An attempt at suicide
- Intimate partner violence or domestic violence
- Drug overdose or alcohol abuse
- Driving while intoxicated

What to do if a Partner Shows Signs of a Crisis

If you believe or have reason to suspect your Partner is in immediate danger, notify staff immediately by emailing support@concussionfoundaiton.org.

CLF staff will activate the crisis response protocol and work with the Peer Support Volunteer until the crisis is resolved.

Calling Emergency Services / 911

The first step a Peer Support Volunteer should take if they suspect a Partner is in crisis is to notify CLF staff.

A Peer Support Volunteer may choose to call 911 before contacting CLF if either of the following conditions are true:

1. The Partner clearly confirmed in words or actions that their life is in immediate and certain danger, the volunteer knows the Partner’s exact location, and any delay could be consequential
2. The Partner consents to emergency services being called

For all other situations, CLF staff will work with the Peer Support Volunteer to activate the protocols in the CLF Crisis Response Resources.

The Importance of Following Up After Crisis

Perhaps the most impactful action a Peer Support Volunteer can contribute to a Partner’s recovery from an emotional crisis is simply following up. Once CLF staff has intervened to stabilize the situation and shared updates with you, following up via text or phone shows the Partner that you are invested in their wellbeing, you care how they are doing, and you are available to help them see the next step in their recovery.

In short, you provide **hope**. [Studies have shown](#) that following up with a patient who has been discharged after an emotional crisis or attempt at suicide dramatically reduced the risk of repeat

crisis. When in doubt about a Partner's emotional wellbeing, notify CLF staff by emailing support@concussionfoundation.org.

Reporting of Child Abuse or Neglect

In rare circumstances, a Peer Support Volunteer may recognize the signs of child abuse or neglect when interacting with a Partner.

It is the policy of the CLF Peer Support Connection Program to adhere to the Federal Child Abuse Prevention and Treatment Act (CAPTA), state, and local requirements for the reporting of known or suspected instances of child abuse or neglect ([found here](#)).

Definition of Child Abuse or Neglect

At the Federal level, the Child Abuse Prevention and Treatment Act (CAPTA) has defined child abuse and neglect as "any recent act or failure to act on the part of a parent or caregiver that results in death, serious physical or emotional harm, sexual abuse, or exploitation, or an act or failure to act that presents an imminent risk of serious harm."

What to do if You Suspect Child Abuse or Neglect

The first step a Peer Support Volunteer should take if they suspect an underage Partner is the victim of abuse or neglect is to notify CLF by emailing support@concussionfoundation.org.

CLF will ask you to provide the details of the circumstance, at which point CLF staff will escalate and may activate CLF's mandatory reporting of child abuse or neglect protocol. CLF staff will work with the Peer Support Volunteer to report the details to the appropriate [state or local child protective services](#) if necessary.

Identification of child abuse or neglect

For the purposes of the CLF Peer Support Connection Program, review the warning signs of abuse and neglect compiled by the [Mayo Clinic](#). These signs warrant discussion with CLF staff. For more information, extensive resources for identification of child abuse or neglect are listed on the [U.S. DHHS Children's Bureau](#) website.

The presence of warning signs does not necessarily mean that a child is being abused. Nonetheless, report warning signs to CLF Staff via email as soon as they are recognized.

Peer Support Volunteer Self-Care Resources

Remember that your health is also a priority. Helping another person navigate physical and mental health struggles can take a toll on you. Please communicate with CLF's Peer Support Coordinator if you feel overwhelmed or under-supported. We are here for you as well.

One great way to stay in touch with your physical and mental health is to adopt and track self-care habits. Try this [Self-Care Assessment Worksheet](#) to start mapping out a self-care routine.

Another great self-care option is mediation and mindfulness. Legacy Family Community Member Dr. Shannon Albarelli lead a session for CLF that you can watch [here](#).

Professional Mental Health Support

Consulting with a trained mental health counselor, such as a psychologist or psychiatrist, is a great way to take self-care to the next level.

You can search for a counselor by location, particular issues, you would like to discuss and covered by your insurance with [Psychology Today's Search Tool](#). Alternatively, you can ask CLF's Peer Support Coordinator for assistance connecting with a mental health professional.

Partner Engagement

There are certain elements of forming a new Peer Support relationship that fall within the acceptable scope of support and some that fall outside the scope of support. For instance, all advice Peer Support Volunteers share with Partners should be shared with the understanding it is based on personal experience not professional experience.

Here are some additional example boundaries for connections to aid you in developing a strong Peer Support connection:

Within the scope of support

- Sharing treatment experiences and personal stories
- Listening to concerns in an empathic and judgement free manner
- Strategizing, casually bonding, finding additional resources together
- Phone calls, text messages, audio messages, letters, video calls

Outside the scope of support

- Providing professional medical opinions or diagnoses
- Providing professional legal or financial advice
- Giving financial support in the form of money or material assets
- In-person meetings

Connection Summaries

After a scheduled phone call, video chat, text exchange, or email exchange, please update CLF about how the connection went and how your Partner seems to be doing. You will be given instructions for completing these summaries by the Peer Support Coordinator.

This is a great time to highlight the Partner’s progress or major challenges. Please also use this as an opportunity to inform CLF if a Partner requests your assistance with something that falls outside the scope of support.

Conclusion

The CLF Peer Support Volunteer role offers a unique opportunity to connect with individuals and caregivers who are living with the effects of brain trauma and guide them toward the resources they need.

You will make an enormous difference in a Partner’s life just by being there and helping them feel heard. Time and again, CLF Partners have reported that connecting with a Peer Support Volunteer who understood their struggle changed their life completely.

CLF is grateful for your commitment to improving the lives of individuals and caregivers navigating the effects of brain trauma.

Program Contacts

CLF Peer Support	support@concussionfoundation.org	Primary Contact for Full Team	
Tyler Ambrose	tambrose@concussionfoundation.org	USA Coordinator	(209) 436-2808
Taya Leforte	tleforte@concussionfoundation.org	CAN Director	(339) 230-7718
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About the Concussion Legacy Foundation

The Concussion Legacy Foundation is a 501(c)(3) nonprofit organization. It was founded by Robert Cantu, MD, and Chris Nowinski, PhD to support athletes, Veterans, and all affected by concussions and CTE; achieve smarter sports and safer athletes through education and innovation; and to End CTE through prevention and research. For more information, please visit ConcussionFoundation.org.