

CLF Peer Support Volunteer Training Guidebook

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).

Please familiarize yourself with these important topics before your first connection:

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

Our team relies on your self-reported preferences and life experiences to determine what type of peer support match will be best for you and a potential 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.

How to Be a Good Peer Support Volunteer

This section provides introductory concepts to help you excel as a CLF Peer Support Volunteer. For more information, please visit CLF's <u>Peer Support Volunteer Resource Hub</u>, which offers additional training, videos, and answers to frequently asked questions.

Values & Expectations

As a Peer Support Volunteer, you are part of a dedicated community working to support individuals and families navigating outcomes of brain trauma. This community thrives on mutual respect, shared learning, and empathy.

Our values guide how we support Partners and how we engage with one another:

- Respect for different opinions, experiences, identities, and perspectives
- Patience, understanding, and humility
- Openness in sharing experiences and offering hope
- Commitment to growth

Strive to maintain a supportive environment by upholding the following expectations:

- Listen actively and with empathy
- Respond with encouragement and without judgment
- Engage in discussions with curiosity and compassion
- Respect personal boundaries and maintain confidentiality
- Lead by example to foster a positive and inclusive environment

Know the Role

A peer-to-peer connection is a supportive relationship between individuals who have lived through similar experiences. These relationships are particularly important during times of stress or uncertainty. Peer support reduces feelings of isolation and uncertainty through:

- Understanding, empathy, and hope
- Normalization of difficult experiences
- Sense of belonging
- Information, education, and empowerment

As a Peer Support Volunteer, you provide social and emotional connection for someone navigating struggles you understand better than the average person. Your role entails:

- Take the lead on outreach and scheduling conversations
- Stay in touch virtually (phone, video, text, email)
- Meet your Partner "where they are" and help them feel heard
- Listen and share experiences
- Talk through problems together
- Brainstorm ways to use resources and make progress

Peer-to-peer connections can be a great complement to medical and mental health support; however, these relationships are not a replacement for professional care. Be sure to understand the key differences outlined in this PSV training supplement: How Peer Support Differs from Professional Mental Health Care

Listen, Ask Questions, & Share Experiences

Build a relationship with your Peer Support Partner by looking for opportunities to make them feel heard and understood. You can start by simply listening and asking questions. Try to ask questions that will help you gain a deeper understanding of your Partner's unique struggles. Then, consider sharing something about your own life experiences you think they might find helpful or relatable.

Here are a few examples of questions to ask:

- Can you tell me more about what you've been through?
- What is the hardest part of this experience for you right now?
- What has been the most difficult part of this experience overall?
- What do you feel is most important for me to know about your journey?
- What would help you feel more supported?
- What helps you find small moments of joy?
- Would it be helpful if I shared something similar from my own experience?
- Are you able to talk with friends or family about your feelings?
- Do you feel your healthcare providers understand what you're going through?
- How would you describe your feelings about what you're experiencing?
- Would you like to reconnect with the <u>HelpLine</u> team for additional resources?

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 PCS, navigating suspected CTE, or supporting a loved one can be a daunting, frustrating, and exhausting experience. Your Partner may not know what options are available; they may feel like they have tried every possible treatment; or they may feel like they are on the right track but not improving quickly enough.

Peer Support Volunteers can help by listening with sincerity. Then, when it feels appropriate, suggest small ways to build momentum. Examples of activities that build momentum include:

- Journal thoughts and feelings
- Discuss goals while staying flexible in the face of setbacks
- Commit to lifestyle changes
- Track daily symptom severity
- Acknowledge and celebrate progress out loud

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. 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.

Avoid Negativity or 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, such as:

- Criticism of past mistakes or missed opportunities
- Sarcasm with unclear meaning (even if intended as humor)
- 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:

- Acknowledge the difficulties your Partner is experiencing are real and valid
- Show that you understand, at least in part, what they're going through
- Emphasize the importance of persistence, optimism, and ongoing professional support
- Express your belief that progress is possible or that quality of life can improve

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. Be patient, sympathetic, and flexible, leaving plenty of space for your Partner to work through these difficult emotions.

Partner Engagement & Connection

Peer Support Volunteers play a unique role by offering connection through lived experience, not professional expertise. Your role is to listen, share, and walk alongside a Partner, while leaving medical, legal, and financial matters to licensed professionals. Boundaries protect you and your Partner, build trust, and keep the connection focused on what peer support does best.

Within the Scope of Support

- Share personal experiences and stories
- Listen with empathy in a judgment-free manner
- Strategize together, build rapport, and explore new ideas
- Suggest resources that have helped you
- Communicate virtually (calls, texts, audio or video messages)

Outside the Scope of Support

- Give medical opinions, diagnoses, or advice
- Coordinate care or perform in-depth resource navigation
- Provide legal or financial advice
- Offer financial support of any kind
- Meet up in person

If a Partner asks for support outside your scope, gently reaffirm your role as a Peer Support Volunteer and let them know CLF can connect them with additional resources. Reach out to our team if you need support in re-establishing boundaries.

Connection Summaries

After a phone call, video chat, text, or email, you are welcome to share updates with CLF about how the connection went and how your Partner seems to be doing. Connection summaries are not mandatory. If you choose, you can send updates to our team at support@concussionfoundation.org.

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.

Understanding Concussion, PCS, & CTE

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

Concussion

- Concussion Guidebook
- What is a Concussion?
- What to do After a Concussion
- Concussion Support & Resources
- **Video**: What happens when you have a concussion?

Post-Concussion Syndrome (PCS)

- What is PCS?
- PCS Treatments
- Coping with PCS
- PCS Support & Resources

Chronic Trauma Encephalopathy (CTE)

- The CTE Guidebook
- What is CTE?
- Living with Suspected CTE
- Caregiving for CTE
- Suspected CTE Treatment Methods

Responding to Emotional Crisis & 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.

Research has shown that patients diagnosed with concussion had double the risk of suicide, a higher risk of suicide attempts, and a higher risk for suicidal thoughts than people without brain injuries.

Peer Support Volunteers must know how to recognize signs of an emotional crisis and articulate concerns to peer support staff for possible escalation.

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: <u>Helping Concussion and Suspected CTE Patients in Crisis</u> - 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 with 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@concussionfoundation.org.

While CLF is not equipped to provide crisis intervention services, our team responds quickly to assess risk and provide connection to appropriate crisis response experts. CLF staff will activate the crisis response protocol and work with the Peer Support Volunteer until the situation has stabilized.

Calling Emergency Services / 911

In most situations, if you suspect a Partner is in crisis, notify CLF immediately at support@concussionfoundation.org.

Contact emergency services before CLF only if one of the following is true:

- 1. The Partner has clearly confirmed in words or actions that their life is in immediate and certain danger, you know their exact location, and any delay could be consequential.
- 2. The Partner gives consent for emergency services to be called.

For all other situations, CLF staff will work with you to activate the crisis response protocol.

Follow-Up After Crisis

Perhaps the most impactful action a Peer Support Volunteer can take to contribute to a Partner's recovery from an emotional crisis is simply following up. <u>Studies have shown</u> that following up with a patient who has been discharged after an emotional crisis or attempt at suicide dramatically reduces the risk of a repeat crisis.

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 well-being, 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**.

When in doubt, message our team: support@concussionfoundation.org.

Recognizing & Reporting 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.

CLF adheres to the Federal Child Abuse Prevention and Treatment Act (CAPTA) and state/provincial and local requirements for the reporting of known or suspected instances of child abuse or neglect (<u>United States</u> and <u>Canada</u>).

Definition of Child Abuse or Neglect

In the United States, the Child Abuse Prevention and Treatment Act (CAPTA) defines 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."

In Canada, the Canadian Child Welfare Research Portal defines child abuse and neglect as "acts of commission or omission by a parent or other caregiver that result in harm, potential for harm, or threat of harm to a child. The five primary forms of maltreatment are physical abuse, sexual abuse, physical neglect, emotional maltreatment and exposure to domestic violence."

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 at support@concussionfoundation.org.

CLF will ask you to provide more details. Staff will escalate your concerns for review and may activate CLF's mandatory reporting of child abuse or neglect protocol. If necessary, CLF staff will work with the Peer Support Volunteer to report the details to the appropriate state or local child protective services.

Recognizing Child Abuse or Neglect

Review the warning signs of abuse and neglect compiled by the <u>Mayo Clinic</u>. These signs warrant discussion with CLF staff. For more information, extensive resources for the identification of child abuse or neglect are listed on the <u>U.S. DHHS Children's Bureau</u> and <u>Children First Canada</u> website.

The presence of warning signs may not necessarily mean that a child is being abused. Nonetheless, report warning signs to CLF Staff via email as soon as they are recognized. For more information, read our <u>PSV Child Safeguarding Guidelines FAQs</u>.

Peer Support Volunteer Self-Care

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 our team 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 <u>Self-Care Assessment Worksheet</u> to start mapping out a self-care routine.

Another great self-care option is meditation and mindfulness. Legacy Family Community Member Dr. Shannon Albarelli led a session for CLF that you can <u>watch here</u>.

Mental Health Support

Consulting with a trained mental health professional, such as a psychologist or psychiatrist, is a great way to enhance self-care.

You can search for a mental health professional by location or particular issues you would like to discuss and covered by your insurance with <u>Psychology Today's Search Tool</u>. Alternatively, our team is available to provide confidential support through the <u>HelpLine</u>.

Conclusion

This role offers a unique opportunity to connect with people who are living with the effects of brain trauma and guide them toward better outcomes.

You will make an enormous difference in a Partner's life just by being there and helping them feel heard. Time and again, patients and caregivers have reported that connecting with a Peer Support Volunteer who understood their struggle made a huge difference.

CLF is grateful for your commitment to improving the lives of individuals navigating the effects of brain trauma. Thank you!

Program Contacts

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