

What is a peer support volunteer?

- Someone who has experienced disability due to stroke, directly or as a caregiver, who is now able to manage daily life roles independently or through caregiver, and is willing to share their experiences with others
- Someone willing to act as a role model and provide emotional support to someone going through a similar experience
- Someone who is willing to listen

Why is it an important service to offer?

- It is often easier to talk to someone who has been through similar situations, have similar interests, backgrounds, etc
- Often provides encouragement to see someone succeed after stroke

Responsibilities of a stroke peer support volunteer:

- Provide support and encouragement to peers provided by your institution
- Abide by policies and procedures of the institution
- Maintain confidentiality
- Connect survivors and caregivers to resources (NSA, AHA, etc)
- Encourage survivors and caregivers to complete follow up appointments

Things to remember what a Peer Support Volunteer is NOT:

- A licensed or professional counselor
- A go-between for patients and others
- Someone to give advice, medical or otherwise
- Someone to solve patient's problems
- A doctor, therapist, nurse or any other medical professional (*even if this is your profession, this is NOT your role in this capacity*)

Brain basics

- Definition of stroke: an interruption of blood supply to the brain
- CVA: Cerebral Vascular Accident
 - Two Types
 - Ischemic
 - Thrombotic: blockage in the vessel
 - Embolic: clot
 - Hemorrhagic
 - Bleed
- TIA: Transient Ischemic Attack
 - “mini stroke”
 - Blood flow in the brain is blocked or reduced for brief period of time
 - Symptoms are similar but temporary

Right side of the brain:

- Helps:
 - Make decisions and judgements
 - Make plans
 - Visually perceive the world
 - Show emotions
 - Solve problems
 - Remember
- Stroke can cause problems with:
 - Communication
 - Movement
 - Vision and touch
 - Thinking
 - Perception/awareness
 - Safety and insight
 - Impulse control (stopping oneself)
 - Attention
 - Emotional lability

Left side of the brain:

- Helps:
 - Communicate
 - Analyze
 - Compute
 - Problem solve
 - Plan and organize
- Stroke can cause problems with:
 - Communication
 - Movement
 - Vision and touch
 - Thinking
 - Behavior
 - Emotional lability
 - Lack of interest/depression
 - Low motivation

Brainstem:

- Controls alertness, basic bodily functions and consciousness
- Can result in weakness in tongue, mouth or throat, effecting swallow
- Can often result in decrease in motor control and coordination, balance and muscle weakness/paralysis
- Can result in double vision, coordination of eye movements, ability to open or close eyes

Neuroplasticity:

- Neuroplasticity: the ability of the **brain to form and reorganize** synaptic connections, especially in response to **learning or experiences including following an injury**
 - Occurs after stroke or brain injury to compensate for lost function
 - Influenced by your environment and actions taken by that person
 - Recovery can be over a lifetime
 - Relearn skills, they may not be the same but your brain is capable

Common interventions:

- All interventions have **specific** criteria for their use. Not every patient is appropriate for interventions such as tPA (clot busting medication) or a mechanical thrombectomy
- Medications: Thrombolytics
 - Alteplase: used for ischemic strokes (clots)
 - Can be used for those who are within 4.5 hours of stroke symptom onset, or “last known well”
- Mechanical Thrombectomy
 - Removal of large blood clots
 - Also known as a “stent retriever”
 - Can be used for those who are within a 6 hour window of time from stroke symptom onset or “last known well”

How can you reduce your risk of stroke?

- Don't smoke
- Reduce cholesterol
- Reduce sodium intake
- Control high blood pressure
- Be physically active
- Control diabetes

The Emotional Impact of Stroke: A Sense of Loss

- After someone experiences a stroke and loses function in some way, shape or form, it can be followed by a grieving period. Grieving the loss of independence, the loss of your sense of self, your life roles, etc.
- What does grieving look like?

Stages of grief



- Kübler-Ross Stages of Grief
- Everyone processes grief in different way, at different speeds and some don't go through all stages
- Listening and recognizing where someone is at in the stages of grieving can help you to effectively provide the support they need at that time

Continued:

- As someone is coming more into acceptance of their “new normal”, they may be asking more questions on how to adapt to their life now
- If someone is angry, they may just feel the need to vent their anger to someone and it is important for you to listen and validate how they are feeling, not telling them they shouldn't feel that way, or they are wrong, etc

Wellness



- **Spiritual**
 - Process of understanding beliefs, values and ethics to guide your life
- **Emotional**
 - Managing stress levels, staying caught up on work, getting sufficient sleep, asking for help/seeking counseling for yourself
- **Intellectual**
 - Staying curious and engaged in learning new things
 - Reading for pleasure, awareness of social and political issues, etc

Continued:

- Physical
 - Exercise, nutrition, sleeping, managing stress, preventative medical and dental care
- Social
 - Having a strong social network to provide you support and guidance when you are stressed
- Environmental
 - Taking care of your global environment and personal surroundings
 - De-cluttering, recycling, volunteering to clean-up
- Financial
 - Take steps to live within your financial means and planning for your financial future.

Caregivers:

- If caregivers are present, you can ask if the survivor is ok with their caregiver joining the call as well
- Caregivers can provide valuable feedback on survivor performance and adaptation especially if survivor has any deficits with insight.
- This would also provide an opportunity to ensure the wellbeing of caregiver.

Caregiver burnout

- Caregiver burnout is a real thing and it is valuable to “check in” with caregiver during call and see how they are feeling
 - Caregiver burnout is defined by the Cleveland Clinic as: “Caregiver burnout is a state of physical, emotional and mental exhaustion. It may be accompanied by a change in attitude, from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able, physically or financially.”
- Symptoms can be, but not limited to: withdrawal from friends & family, loss of interest in activities previously perceived as enjoyable, overall feeling of being down, hopeless or helpless, change in sleep patterns, getting sick more often, irritability.

What if survivor is making suicidal comments or threatening to hurt themselves or others?

- **Report to program coordinator immediately or proper authority if necessary**
- HIPPA does not prevent you from reporting this to authorities.
- National Suicide Hotline #988 (call or text)
- Depression Hotline #988 (call or text)
- All states have an Adult Protective Services agency. Placing a call to report a concern for a vulnerable adult can result in local police agencies making a well check in a short amount of time
- You can tell the person about your concerns and feeling the need to report it, but you are not required to tell them this

Communication During Visits:

Effective communication strategies

- Use open-ended statements or questions to facilitate answers more than just a yes or no
 - How did _____
 - Tell me about _____
 - Please describe for me _____
- Make sure to allow processing time for person to respond to your question/statement
 - “Silence is golden”
- Use positive statements vs negative statements
 - “I remember feeling that way” vs “You shouldn’t feel that way”
 - “You seem down today, did something happen?” vs “You’re just having a bad day”

Continued:

- Non-verbals
 - Includes our posture, gestures, facial expressions and/or body movements
 - Also includes tone of voice, pitch and volume as well as rate of speech
 - Be aware of your non-verbals but also be attentive to the person's non-verbals
 - Eye contact is important
- Active listening
 - Restating what the other person is saying provides reassurance to them that you are in fact listening to them and what they are saying is valuable
 - “What I hear you saying is _____”
 - “Tell me more about _____”
 - “I’m sensing _____”
 - Use the 80/20 rule: other person speaking 80% of the time, peer volunteer 20% of the time

Cultural Diversity

- Definition of culture: the customary beliefs, social forms, and material traits of a racial, religious, or social group (Merriam-Webster Dictionary)
- Definition of diversity: an instance of being composed of different elements or qualities including but not limited to:
 - Age
 - Ethnicity
 - Gender
 - Religion
 - Country of origin
- Be careful to not make assumptions about someone based off of differences that may be inaccurate
- Don't be afraid to ask for clarification

Communication Barriers After Stroke

What is Aphasia?

- Loss of ability, to varying degrees, of a person's ability to understand or express speech
 - Expressive aphasia: difficulty expressing self through speech or writing
 - Receptive aphasia: difficulty understanding speech or writing
 - Dysarthria: weakness in muscles for coordinating speech, making getting words out correctly difficult

Communicating with someone with cognitive or speech difficulties:

- Do not be afraid to say you didn't understand what they said
 - Repeat back to them what you did understand, and to clarify what you couldn't understand
 - Apologize
 - Try asking yes/no questions if finding words is difficult for them
- Avoid speaking loudly/yelling unless person is hearing impaired

Continued:

- Remove distractions ie busy areas or turning off tv
- Use multiple choice or limit choices
- Ask if they have any tools to help with communication ie letter board
- Make sure to include person in conversation and speak directly to them even if using someone else to assist in conversation or an interpreter
- Stay focused on the message they are trying to convey, not how it's being delivered

Setting boundaries:

- Do not give medical advice
- Do not breach confidentiality
- Do not visit to survivor's home, even if they request it
- Don't be afraid to ask for help if
 - You feel uncomfortable
 - You think person is at risk
 - You are unsure of the answer(s) to their questions or concerns
- Don't feel guilty if you say no

F.A.S.T. Recognizing a Stroke

- **F**ace drooping
- **A**rm weakness
- **S**peech difficulty
- **T**ime to call 9-1-1
 - Time is brain, every second counts!
 - Stroke warning signs:
 - Sudden severe headache with no known cause
 - Sudden weakness or numbness of face, arm or leg especially on only one side of the body
 - Sudden vision changes
 - Sudden difficulty with walking, including dizziness, loss of balance or loss of coordination
 - Sudden difficulty speaking or understanding what others are saying