

Caregivers as Advocates



The word “Advocacy” can mean many things but, in general, it simply means to take action. It involves speaking or acting on behalf of yourself or others. As you try to navigate through the recovery process from TBI for your loved one, you will often feel like no one is speaking up for your loved one. Initially, that person might have to become you, as you then work with you loved one to learn to advocate for themselves as well.

Self Advocacy - Taking action to advance and represent your own interests

Peer Advocacy - Taking action to represent the rights and interests of someone other than yourself!

Why Is It Important For You To Advocate?

- No one else can tell your or your loved one’s story
- No one else knows what you or your loved one needs more than you
- YOU are the expert on you and your loved one



Did You Know?

The thought of speaking up and asking questions might make you nervous or anxious. But, if you do not speak up for your loved one or for yourself, you are effectively screaming loudly for everyone to hear that everything is OK just the way it is.

In order to make your advocacy efforts effective you should:

1. Break down the problem
2. Educate yourself
3. Identify your rights
4. Develop a solution (goal) and strategy to address your problem



Be realistic about your expectations. Learning how to negotiate a compromise is often a very important component to effective advocacy. Also, do NOT be afraid to ask others to help!

Advocacy Plan - Step by Step



Step 1: Problem Analysis

Questions to Ask Yourself

- **What is the problem or issue?** If there is more than one, identify the one most important to you.
- **What is my goal?** Try to keep this to one clearly worded sentence.
- **What facts to I know?** Write these down to organize your thoughts.

Step 2: Information Gathering

Questions to Ask Yourself

- **What additional facts or information might I need regarding this problem?** Identify your rights in the situation
- **How can I go about gathering this information?** When possible, surround yourself with friends, family professionals, and other advocates to help you navigate the system and collect the information you need.
- **Who is the decision-maker I need to influence to solve this problem?** If you are not sure who has the authority to make the decision...ask!
- **Are there other people who can help me?** Consider your AHIF Resource Coordinator.



Step 3: Solution Analysis

Questions to Ask Yourself

- **What are some possible solutions to this problem? (Be specific)**
- **What are some barriers to these solutions?** Is the decision-maker following some policy that does not allow them to meet your request or adopt your solution?
- **What do I expect the decision-maker to say or do?** Do you have an emotional need, such as needing someone to apologize, or is it a concrete need?
- **Consider these methods for approaching the decision-maker:**
 - ◇ Making phone calls
 - ◇ Holding an informal meeting
 - ◇ Writing a letter of complaint
 - ◇ Filing a formal complaint



Still need someone to help advocate for you?

If you are feeling overwhelmed, reach out to your AHIF Resource Coordinator.