

6 Things Families with Aphasia Need to Know

“Aphasia and I have called a truce. There is no longer a war” —Melissa, wife of someone with severe aphasia

Many families with aphasia have similar experiences after their diagnosis. It’s likely ‘aphasia’ isn’t something you had ever heard of, but now your life revolves around it. Whether you’ve just recently had a loved one with this diagnosis or you’ve been dealing with it for years, here are five common issues you may share with other families with aphasia.

- **You will most likely need to do the research yourself.** Many families report being given little, if any, information or direction about what to do when they’re discharged from therapy. Many professionals aren’t even aware of intensive aphasia therapy. **Caregivers are left to their own devices to search for solutions, gather information, and try to make an informed decision about what to do next.** They often report feeling guilty that they didn’t know what to do. Work, family, and other activities are placed on a back burner while coping with this sudden change. As one caregiver put it “it’s like a bomb went off in our lives”.
- **Many professionals may tell you that there is no hope.** There are a variety of reasons for this, but almost everyone has been told that their loved one has ‘reached a therapy plateau’, while being given nothing to do about it. I’m here to tell you that **there is always hope if you’re willing to do the work.** Progress may be slow sometimes and faster other times, but **progress can always be made.**
- **You may not know anyone else with aphasia.** Even in more populated areas, many families report that they’ve never interacted with anyone else with aphasia. Seeing others with aphasia, regardless of the type or severity of aphasia, can be helpful. While direct comparison of progress isn’t recommended, seeing how someone else handles their aphasia can make a huge difference. Those clients with aphasia who are more outgoing and don’t care what people think can have a huge impact on those clients who are quieter or more nervous about interacting. There are few aphasia groups in the world, so many families meet friends when they come to The Aphasia Center in Florida. Online groups, such as [Aphasia Recovery Connection](#) on Facebook, are centered around support and social activities.

- **Your family may criticize everything you do without offering help.** Family members, especially those not living with you, may have good intentions but poor execution. Many caregivers report their loved one's family not understanding the depth of the aphasia. Other family members may tell the person with aphasia that they'll be all fixed in a few months, then criticize the caregiver for 'not doing enough'. It seems these family members are big on interfering but short on actually helping. **If you are doing all that you can, then that's all that you can do. You aren't single-handedly responsible for someone's recovery and you don't have a magic wand.** It may be helpful to talk to a therapist or other caregivers to help relieve the stress.
- **Your friends may shy away.** Younger people in their 20s-30s, in my experience, tend to retain some of these relationships better than other age groups. Many people don't know how to interact with their friend who now has aphasia, so they may stop socializing little by little. **This means that more of the socializing falls to the caregiver and immediate family.** Consider supporting your loved one's "free time" with their friends if they show interest and can safely be without you. Some friends just need a little help with what to do, some friends just do it.
- **Take breaks. You need them.** You can't be everything to everyone all the time. You will burn out without time to yourself. One caregiver who works has a camera in his living room and a phone next to his loved one, who sits in a recliner to watch tv and rest. A neighbor is available for any problems. While this will not be a solution for everyone, there are other options such as paid caregivers, friends or neighbors, aphasia programs, and more. **Your family with aphasia needs to understand that to be a more patient and loving caregiver, you need time to recharge and do things for yourself.**

Remember that aphasia recovery is a marathon, not a sprint. It takes hard work over time—there's not a magic pill, shot, or surgery that will replace this. So don't beat yourself up if you haven't "fixed" this. There are others out there just like you (see our [Caregiver Stories](#) or [ARC](#)) and it can and does get better.

A consultation with Dr. Bartels can be an easy way to get advice or recommendations if you need some help.