

The Aphasia Caregiver - Hero or Villain?

We often judge others by their actions, but judge ourselves by our intentions. We often see just one side of someone's behavior and judge them based upon that behavior. We have no idea why they did what they did, so we make up negative reasons. That person must just be heartless or a bad person. Maybe we think to ourselves, "**well, I would never do that**".

When we hear a young client's spouse has left him—we may be told it's because she didn't want to deal with his aphasia. I've heard that story before. I've heard the story where the young wife has taken all of the money from fundraising and spent it on herself. I've been told that clients are divorcing after they leave the facility. The first thing many people may think is "what a terrible person to abandon him just because he has aphasia". I've been guilty of it, too.

Then I've actually spoken with the 'terrible person' and realized that there's another side of the story. These people feel that they are in impossible situations now. Their relationships may have ended sooner or later without the aphasia. The aphasia and subsequent care, however, has pushed the issue to the forefront. Many people's relationships aren't cut out to stand the stress. Can I really fault a young woman with a toddler who feels that she needs to leave her husband? It's a sad situation all the way around. It can be hard to find the kind of support needed to keep it all together.

Each caregiver is very concerned about their loved one, wants the best for them and will work as hard as they can for them. However, the **caregiver is a person whose needs are often overshadowed by the needs of the person with aphasia**. Sometimes there are children involved who are suffering as well. Every single one of these caregivers doesn't want to look like the villain. Each is concerned about what will happen to their loved ones without them. While it's easy for me to tell them that they can't worry about what other people are going to think, the guilt makes their situation worse.

Many caregivers may feel overwhelmed, too stressed, exhausted and ready to give up. But they don't talk about it because they're afraid others will judge them to be horrible people.

I don't have any easy answers—you have to do what's best for you and your family. People are always going to judge you no matter what you do, so **having some sort of support network is critical**. There are always other caregivers out there who are feeling some of these same pressures. Remember that **no one is all bad**. Sometimes just saying these things out loud to another person helps relieve some of the pressure. Sometimes just writing it in an email to yourself helps. Find an anonymous online forum in which you can express your feelings without anyone knowing who

you are. You may still come to the same conclusion in the end, but have helped yourself manage your expectations by sharing them with others in the same boat.