

WHAT IS A CAREGIVER???

A CAREGIVER IS someone who cares enough about a friend or family member to put their normal activities aside and dedicate themselves to assisting that person in any way that they can.

A CAREGIVER IS someone who researches whatever illness or disability their friend or loved one has in order to understand how it will effect that person, and to better understand how they can best help them

A CAREGIVER IS someone who learns from medical professionals, family members, and other friends of the afflicted person, what the needs of the afflicted person are, what their interests are, and who can be reached easily if assistance is needed.

A CAREGIVER IS someone who understands that the afflicted person can become angry, sad, confused, or depressed with little or no warning. It is especially important that they recognize depression quickly, and that they know what steps to take to protect the afflicted person from self harm.

A CAREGIVER IS someone who is willing to find entertainment to keep the afflicted person's attention, whether it mean watching TV shows, playing games, reading, or just visiting. With illnesses like HD, Alzheimer's, and other illnesses that affect the mental abilities of those who have them, this may mean having to play extremely simple games that are designed for small children.

A CAREGIVER needs to understand that the afflicted person may not remember how to acknowledge their gratitude for what is done for them, but they can be assured that they as a caregiver will become very important part of their life.

A CAREGIVER must maintain a great deal of patience when dealing with the afflicted person, as well as with their friends and family members. Catastrophic illnesses and conditions tend to upset the normal activities of everyone involved, and at times they may unknowingly exhibit hostile traits, especially verbally. Keep in mind that it isn't really them talking or acting out, but rather it is the life style that has been forced upon them.

Let's take a minute and look at what a caregiver can expect as time goes on while caring for someone who has a progressive illness, such as HD. To do this I will speak in fair detail as to what I have experienced on my journey through caring for Harriet. You need to know that Harriet and I have been married for 47 years. We have gone through college **together**, have served in the Air Force **together**, and have raised two daughters **together**. The operative word there is "**together.**" Being a caregiver is just one more step in the long journey through life together. Survival in the world of Huntington's Disease cannot be handled alone. As the disease progresses, the role of the caregiver becomes more constant and far more difficult.

As a side note, I don't want people to think that Harriet's and my life hasn't been a one-way support program. Back when she was healthy, I had stage 4 esophageal Cancer, and she never gave up on me, never left me, and was my major line of support throughout our journey. Support is a two-way street. Both the person receiving the support, as well as the one giving it, require a great deal of encouragement. In a strong support system, the parties involved learn to lean on each other.

Let's travel back to where our HD journey began. In the 1980's we found out that Harriet's mother had this strange disease called Huntington's Disease (HD) and that any children borne by her had a 50-50 chance of inheriting it. It was recommended that Harriet and her 4 siblings get tested. The four that we know got tested, Harriet and her two sisters plus one brother all tested positive. Her other brother to our knowledge never did.

Harriet and I were told that she probably had ten years left, and they recommended that our girls be tested. Our older daughter was tested and was negative, and our other daughter decided that meant she had it and didn't want the test. One of Harriet's sisters couldn't handle it and took her life, something that is common in the HD world. The other sister is still alive. One of her brothers has passed on, and the other that wasn't tested is still alive to our knowledge.

When we were told that it would be ten years before I would lose Harriet, they didn't know that some awesome drugs would come along and help to slow the progression down. It has now been almost 20 years since the diagnosis.

So, now we have set the stage. Let me get us back to the caregiver's role, and what they can expect as the disease progresses, with emphasis on what their role will be throughout. Let me insure you it won't get easier, but just knowing that you make a difference makes it very rewarding.

IN THE BEGINNING

When we first learned about Harriet's condition, and came face to face with the knowledge that it denotes a very bleak future, we began getting any tracts, books, or magazine articles that we could find on HD and similar diseases. Some painted a horrific picture, but some (the ones we concentrated on) gave suggestions on how to face the different stages, and how to control some of the symptoms to some degree. We learned what activities to refrain from because the disease itself is so tiring as it progresses. We learned what HDSA was, and what role it would play as time went by. We found out that it was important that we know that not every neurologist really knew that much about HD, that we needed to be sure that whoever we choose was knowledgeable with *movement disorders*. The way it was explained to us was simply that HD is like having both Parkinson's disease (a movement disorder) and Alzheimer's (a mental impairment) at the same time.

The person who becomes a caregiver for someone with these types of diseases needs to understand that the actual person with the disease in many ways escapes a lot of the problems involved, because of the brain's loss of comprehension. The caregiver, however, is fully aware, and can easily become overwhelmed. Watching someone you care about, who is mentally and physically strong, lose their strength and agility, and at the same time losing their mental comprehension, is tough. Be prepared for some mental stress and depression, and be ready to get a doctor to give you some mild anti-depressants.

In order to be aware of what level of progression the person being care for is at, it is advisable that the caregiver ask some questions each day, simple questions like "what is my name?", "what day is it?", "how many children do you have?" Be aware that sometimes, on a bad day, you may be shocked by the answers you get. Harriet has two daughters, Norma and Brenda, and five grandchildren. Yet, on a bad day, everybody is "Brenda." People tend to think that this must be her favorite, but in reality Brenda was our most mischievous, so her name got use a lot more.

People with diseases such as HD live in a relatively dark world and can become extremely depressed. This is why interaction is important. They need to be aware that people care. They need to be included in daily activities, whether its is just watching TV, or even playing games. We found two fairly simple games that we can talk Harriet through, which helps to make her feel included and/or wanted.

The most difficult thing about dealing with people like Harriet, when you have known them or been with them for the better part of their life, is watching the negative progression. Harriet went through both high school and the honor role or dean's list. She doesn't even know what a grade of B or below looks like. She served in the Air Force, was a sergeant, and was the administrative assistant to her squadron commander. She worked for large companies like Walt Disney World, where she appeared to be just a clerk in a souvenir shop, but also had another role, as the one that those of us who were in Security at WDW took bags of items that had been shoplifted to so that she could determine the extent of the crime. This was because she knew the price on almost anything that we might have confiscated from the criminal.

It is very important that a caregiver is aware of their charge's background, as it gives them something to talk about. Too many times a person taking care of someone who is handicapped thinks that the most important part of their job is cleaning, dispensing meds, or bathing them. BUT, if I had to pick the most important thing #1 would be companionship and/or verbal interaction.

UPDATE: On January 6, 2017, Harriet asked me for a kiss while laying on a hospital bed in our living room. I knew this wasn't a good sign, but gave her the kiss, after which she closed her eyes and went home to God. She had fought a good fight, had stayed with us until she just couldn't take any more, and will always be remembered for her love for those around her.