

HD Survival – “It’s All About Support”

I have been around the world of HD for many years. My wife’s mother was diagnosed with it back in the 1980’s, and passed in 1994. My wife and at least 3 of her siblings were also found to be positive. One of her nephews, Lee Degenhardt, is a member here. Harriet herself had the HD gene go active in 1998, at which time she was advised that she would probably be gone in ten years. BUT, thanks to the drug Xenazine, she is still here, and that drug did cause some reversal of some of the symptoms.

I have been fairly active in HD support groups over the years, both online and at local groups here in KY. I spend a lot of time preaching on the importance of support, at all levels. Survival for people with HD, as well as for the caregivers, is “ALL ABOUT SUPPORT”.

Level One: Familial Support. It is imperative that family members, especially immediate family, learn all they can about HD, and learn what they can do to help the person who has the HD cope with the daily trials that come with be afflicted. They will be faced with watching a loved one go through the various stages of the illness. I have had to watch my wife of 47 years go from being one of the most intelligent people I knew to being a person who at times cannot remember her name. Together, we have watched two of her siblings expire, with some of there offspring now showing signs of having the disease.

Level Two: Medical Support. Back when Harriet was diagnosed there really wasn’t a great deal of knowledge about how to treat HD. There were no really effective medications, causing life expectations to be short term. Then a company called Lundbeck developed the drug Xenazine, which was prescribed in a step-up program, beginning with one tablet in the morning, followed a month later by one in the morning and one at night, then two in the Am and one at night, and finally two in the Am and two at night. In Harriet’s case, when she went to one in the AM and one at night, she became a zombie, so they left her at one and one, which is where she still is after almost two years. It is important that a person with HD has a neurologist who specializes in HD and/or movement disorders, someone who keeps up with the latest advancements in treatments.

Level Three: Friendships. Hopefully, the person with HD will be able maintain some level of friendship outside of immediate family. We live in an apartment complex that has several residents who are at some level disabled, and we all tend to lean a little on each other for moral support. The old saying that “NO MAN IS AN ISLAND” is nowhere more true than in a home where someone has a heavy disability.

Level Four: Local Support Groups. In most parts of the USA you will find a fairly strong support group for HD within a 30 mile radius. These groups are extremely important, not only to the HD victim, but also to family members and caregivers. HDSA (the Huntington’s Disease Society of America) usually oversees the activities of such groups, includes guest speakers, shows films, passes

out updated info, assists new members, or people who have just been diagnosed, with finding good doctors, and gathering information on the different stages as the person with the HD progresses.

Level Five: Online Support. The information highway, known as the internet, has become a valuable tool in finding information about HD, just as it is with most chronic conditions. Social networks such as Facebook will have many groups. Just for an example, on Facebook there is a very active support group for HD call “The Good, the Bad, and the Ugly”. I personally belong to five different groups, just on Facebook. Organizations like HDSA also have websites where you can see the latest developments in treatments and/or support for almost any disease or condition, including HD.

So, every facet of dealing with chronic illnesses like HD involves one key ingredient...**SUPPORT!**