

BUILDING A SUPPORT SYSTEM

When someone becomes incapacitated enough to require assistance in their daily life, there are many facets that have to be considered. The following is a list of the most common levels of support that will be required.

1. **Familial Support:** Family members must learn to accept that the afflicted person is not the same person they used to be. They will have physical and even mental limitations that they didn't used to have. Other members of the family unit must be willing to pick up the slack, thereby lessening the stress that accompanies being disabled. If the affliction they have is progressive in nature, or is deemed to be terminal, then the workload for the other family members will continue to grow as the affliction gets worse. Great care must be taken in making sure that the afflicted family member doesn't feel that they are a burden.
2. **Friendship Support:** Unfortunately, once a person's ability to function normally, especially where social activities are concerned, over a period of time even the closest of friends have a tendency to drift away. Visits become further apart, and even phone calls become less frequent. Today, because of the many "social networks" like Facebook, one of the easiest ways to provide social interaction is to provide access to a computer, and to teach the person if necessary how to utilize such websites with caution.
3. **Religious Support:** If the person is one who has a strong involvement with a church, it is important that clergy, deacons, elders, etc. periodically visit them, and that they encourage members of said church to do so also. If they practice a faith that believes in taking communion, someone should be sure to bring it to their home. With people of strong faith, prayer is important, so they should have visits that include prayer, and should be notified when the congregation is praying for them.
4. **Medical Support:** Because of the way that most medical insurance plans are set up today, it is important that a person with a chronic illness have two physicians that understand their needs. *First*, they need a primary physician, who is aware of, and keeps up with all medical problems that the patient has, paying special attention to any drug interactions that may occur from the use of multiple medications. *Secondly*, they must have a specialist who has a thorough knowledge of the patient's chronic illness(s). These two physicians must have periodic contact with each other, in order to provide the best levels of medical advice and/or treatment.
5. **Support Groups:** Today most chronic conditions have support systems, which involve local support groups, where victims of such diseases and their caregivers can meet with others who share their concerns. These groups are usually run and monitored by an agent of an organization which keeps up with any new medications, treatments, or therapies that are available.
6. **Internet Support:** Fortunately today we have an information highway called the internet. There are many websites that provide the latest information concerning almost any disease or illness that people can get. Not all of this information should be accepted as gospel, but they provide info that can be brought to the attention of the patient's physician, caregiver, and/or support leaders.

DEALING WITH HUNTINGTON'S DISEASE

Those of us who either have Huntington's Disease (HD), or act as caregivers for someone who does, have many levels of support at our disposal.

Information and/or caregiver recommendations are handed down through channels to those dealing directly with HD. The HD victim will usually be under the care of a neurologist, hopefully one who is up to par on new treatments and medications for the disease.

They will also be under the care of a primary care physician, who should be watching for any drug interaction threats, as they are also involved with any other medical problems that the patient has, and of drugs being used to treat such problems.

The primary caregiver, usually a family member, is probably the patient's most important link to receiving their best treatment, and especially to coping with day-to-day living problems that are created by the disease. During the early stages of the illness, HD doesn't really manifest any real problems for the caregiver. Basically, at first they just monitor the illness's progress and make sure changes are passed on to the physicians. Anyone who decides to be a caregiver for an HD patient needs to realize that their job will become much more difficult as time goes on.

This person should keep up-to-date on all things that might improve their charge's lifestyle. Using the internet, they can visit many sites that deal with HD. A must is the HDSA (Huntington's Disease Society of America) site. This agency is responsible for the creation of local support groups all over the country. It is also responsible for many fund-raising events to assist with research on HD. The people who work for or with HDSA are dedicated to making sure that caregiver's and/or patients have access to the most recent developments in the treatment of the disease.

If the primary caregiver is the spouse of the person afflicted, they need to realize that their loved one will undergo changes that can be emotionally painful. Passion will be replaced in time with need of physical assistance with even the most personal activities. Marriage is built of many needs; some physical, some passionate, and some emotional. These needs are usually mutual, but when critical illnesses or injuries enter the picture, they can become extremely one-sided. Only the truest levels of love can survive this, often bringing to an end relationships that were considered indestructible. This is not intended to be a negative picture, but rather it is intended to prepare those entering the world of care giving for what lies ahead.

That said, let me use my own history as a spouse caregiver as an example of the changes we face, and need for understanding or acceptance. Without compassion; without understanding and/or acceptance; without true love, a relationship that is interrupted by chronic illness faces destruction.

When Harriet was diagnosed with HD, we researched the illness to be better prepared for what was to come. We discussed what lay ahead, and talked a lot about both her role as a person needing care, and my role as the one to provide it. We promised each other to be open concerning our feelings, whether negative or positive. She promised to let me know her concerns as she began losing abilities that she had all of her life; and I promised to stand by her no matter how depressed she became. It was imperative that she knows there is at least one constant in her life – my love.

Has this been easy? Definitely not. I have had to watch a woman who was extremely strong physically and mentally go through the transition to being almost completely dependent upon me. I

have watched the physical part of our relationship diminish greatly, replaced by a common need for emotional support. I have had people recommend a nursing home for Harriet, but I could never do that. Forty-six years ago we promised to remain true to each other "in sickness or health", "for better or worse", "richer or poorer", "UNTIL DEATH DO US PART!" We both took these vows seriously. When I had stage 4 cancer, she was there for me. Now, I am there for her. Can one person do this alone? NO! That is why back at the beginning of this writing I listed the many levels of support that will be needed.

I have had the support of doctors, preachers, friends, and especially family. I have had organizations like HDSA providing me with up-to-date information on HD, and on new treatments, etc. Harriet and I have been members of, and have even run, support groups that concentrate on support needs. . I have frequented HD websites on the internet, and have kept in contact with people we have met that share our plight. All these things together, combine to make my job as caregiver easier. I believe that medical science is on the brink of finding a cure for this disease, and for other diseases that affect the mind, and I pray daily that this happens before we lose the battle. However, if it doesn't, I also believe that those of us that have fought the battle need to continue helping others learn to cope.

DETERIORATION

Let's talk a little about the physical and mental deterioration that will take place in the person being cared for. It is important that a caregiver be aware of what lies ahead so that they can be prepared to make necessary changes in daily routines and so they will be prepared for the increased responsibility that will fall upon them. The following are the most traumatic things that will take place.

One of the early changes that will take place is the involuntary movements and/or sounds that the person will exhibit. The sounds can include chirping noises, grunts, groans, or even words, all being uttered with no apparent meaning or purpose. The movements can be minor, like a mild jerking of the hands or feet, or can be dramatic like violent jerking of the head, or kicking motions. If the movements are pronounced, it can become necessary to move anything that is breakable or that can hurt the person out of the reach of the person.

You may also begin to hear words being uttered that don't go together or make sense, often causing the person to get frustrated because you can't figure out what they want or need. Sadly, this can cause the person to stop trying to tell you what the need, and often conversation tends to disappear. This is especially hard on couples who have always been very conversational in their relationship, like Harriet and me.

Also, because of the involuntary movements, and sounds, the person can lose needed sleep, and will appear tired all the time. Basically, an HD patient tends to either sleep a lot, or barely at all. There are times when Harriet gets so tired, and takes such deep naps that I have to get close to make sure she is still breathing.

Eating becomes a real nightmare. The HD victim will eventually begin having problems chewing and/or swallowing food. Because of this, in order to avoid choking, it often becomes necessary to puree their food. Liquefying food with a high speed blender, or a Magic Bullet, becomes the norm

when preparing lunches.

For a while, we followed the advice of a doctor to have a stomach tube installed and feed Harriet commercial liquid high protein drinks. She didn't like this because there is no taste sensation involved. Later on, once she was put on Xenazine, she went back to foods, but we did have to liquefy them. This made it so she could taste what she ate, but could also swallow the food without choking. We will talk about Xenazine more later on.

As time goes on, walking becomes more difficult, and eventually many HD victims end up in a wheelchair. When that happens, ***it is important that a therapist comes to the home and teaches both the caregiver and the HD patient how to make transfers safely from the chair to things like the bed, and the toilet.*** The more the HD patient can do, the easier the job is for the caregiver, and the less likely they are to take a fall.

It is necessary that people realize that the job of caregiver isn't easy at all. There is a lot of frustration involved. There is often disappointment. And, worst of all, if the patient is a loved one, there is the fact that you are watching them deteriorate. ***It is very common for a caregiver to develop levels of depression.*** If this happens, you may need to talk to a doctor about antidepressants. If you find yourself tearing up watching sad movies, it may be an early sign of depression.

To help people understand better what lies ahead in the world of caregiving for an HD patient, I am going to take you through the various stages that Harriet and I experienced as the illness went through these stages and slowly took over our lives. Our purpose here is not to depress anyone, but rather to prepare them and hopefully to help them accept and understand their role. One of the main reasons that so many caregivers end up giving up is that nobody ever prepared them for the future. Hopefully, the following pages will make it easier to face what lies ahead.

EARLY REALIZATION

Way back when Harriet's mom came down with HD, we were told by her doctor that each child had a 50% chance of also having it. It was recommended that they all had a gene test to determine whether the HD gene was present. They all opted to do this, and unfortunately all five were found to have the gene. Harriet was the oldest of the five, so we expected to be the first couple that would have to deal with this. But, in the world of Huntington's nothing is carved in stone, and she ended up being the last of the five to have it manifest itself. Harriet and I did a huge amount of research on the disease, in the hopes of being able to take her through the various stages with as little discomfort as possible.