

The Importance of Support **When** **Dealing with Chronic Illness**

Chronic illnesses have a devastating affect upon the victim, their family, and anyone close to them. For the most part, they are unable to perform many routine tasks, major ones like working for a living, all the way down to the simple task of pre-paring and/or eating meals.

Some illnesses, like the common cold, will only knock someone down for a short time, while other more serious illnesses like Alzheimer's, Cancer, Huntington's, and many others, make it necessary for someone to step up to the plate and become the caregiver for the victim. Caregiving can exist in many levels, with some caregivers only having to assist only with major chores, while others have to become like a parent/nurse/housekeeper combined for the person that they are helping.

Neither the victim nor the caregiver can accomplish the tasks at hand without the existence of a strong support system. The following pages will deal with the many levels of support, and will discuss what organizations, professionals, or individuals are usually involved in providing care for the victim.

Because the person that I am caregiver for is my wife, who is a victim of Huntington's Disease, most of the information I provide will center around that disease. However, the actual duties of the various caregivers will be pretty much the same. The primary caregiver will usually be a family member or close friend, and they will be instrumental in keeping all other aspects of caregiving in tune so that the patient gets the best assistance possible.

Personal Introduction

First, let me introduce myself and tell you a little about me, my wife Harriet, and her illness. My name is Winn White and I am a 70 year old man who has been married to my childhood sweetheart, Harriet, for over 47 years now.

When we married, we decided that we wanted to see the USA during our life together, so we have lived in Massachusetts (our home state), Florida, Arizona, Tennessee, and now Kentucky. We were both in the Air Force and were stationed in several places both here and abroad. We also have two grown daughters, three granddaughters, one step-granddaughter, one grandson, and a step-great granddaughter.

Over the years, I have suffered with COPD, diabetes, esophageal cancer, and have had a heart attack. Harriet has a genetic disorder called Huntington's Disease (HD), which she inherited from her mother, along with all four of her siblings.

It should be noted that all of these illnesses have the capability of being fatal, and without receiving good medical care as well as great home care from each other, neither of us would be here to tell our story, or to try and show others how to get the support they need when faced with such illnesses.

On the following pages we will deal with the many types of caregivers that make up a person with chronic illness's support system. Some will have purely professional relationships with the victim, and others will be more personal, usually being family members or close friends. All are important because they deal with a different aspect of the victim's condition, or of their daily life.

I will deal first with the primary caregiver, the person who has to maintain a good knowledge of the victim's condition, as well as of what the various caregivers are providing. I guess you could call him or her the "juggler" of the system because it is up to them to keep everything working together. Then, I will deal with the other people who help the victim cope, including medical professionals, support groups, friends, other family members, churches, and even the Internet.

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In order to avoid making any one caregiver seem more important than others, I will list them here alphabetically, as well as putting them in the chapters in alphabetic order. NO Support System works correctly without any of these levels. Each has a purpose, and they must work together to provide the right level of care and/or support.

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In this document I will be addressing issues and/or practices based on the needs of someone with Huntington’s Disease, because that is what Harriet has, and what I deal with for the most part. People who get seriously ill, or who care for someone who is, will need to gather information on whatever their condition is, and will need to get advice from medical professionals on what their specific needs will be. It is always best to get involved with a support group for their specific condition, and to get advice from their leaders.

THE PRIMARY CAREGIVER

Usually the primary caregiver will be a family member, or a very close friend, someone that the patient can trust with the knowledge of their illness or condition, as well as of their personal feelings. TRUST is a major issue. The primary should not be sharing any personal information unless the patient has asked them to, or at least has given permission to. For the most part, the patient will usually authorize the primary caregiver to provide information on daily problems, complaints, or changes in their condition with the patient's medical support team.

Because some conditions render the victim unable to really keep track of their own decline or progress, such as a victim of HD or Alzheimers, then the primary will tend to assist the victim in responding to the doctors' questions, and will often keep a log to assist in doing so.

Their duties may involve assisting with some of the following:

- Bathing
- Dressing
- Feeding
- Transporting, both by wheelchair, or in a vehicle
- Reading to them, especially mail
- Medicating

They should be given explicate instruction on many of these aspects by the medical team. Some of these duties will be quite simple at first, but as some of the more severe conditions progress the duties become more difficult. Unfortunately, some of the conditions will reach a point where the average caregiver can no longer handle their responsibilities, and professional help may be needed, and too often the day comes where the victim must be institutionalized.

Just to provide an example, as Harriet's primary it is my job to prepare all her meals, often having to puree the foods; to bathe and dress her; to assist her with her toilet habits, to transport her in her wheelchair, and in the car. Because her condition is severe, she can no longer walk at all. MOST illnesses will not become that severe, but HD tends to do so at some point. Her day is spent watching TV and napping. Unlike many HD victims, she has retained a good percentage of her intelligence. She can still add and subtract, and is still an awesome speller. This is rare at her stage of HD.

The most important thing to remember is that to the victim what you do for them is not as important as the fact that you are there for them. You become their anchor to normalcy.

As the primary caregiver, a person faces a great deal of stress, disappointment at times, exhaustion, and unfortunately will often feel that they are failing at their job. BUT, and this is important, remember that this happens to ALL caregivers, and cannot be escaped. There will be times when you have to get off by yourself, maybe go to a movie, maybe just for a walk. Keep in mind that your job is two fold. You are having to care for the victims needs, and at the same time must keep yourself healthy.

Harriet and I escape a lot of the stress and the tension, because we laugh a lot, both at ourselves and at the disease. She has maintained her sense of humor which makes a huge difference. Some victims cannot do this, and with many of the patients that suffer with neurological illnesses like HD, they can become very angry, and even a little hostile. At those times the caregiver must keep in mind that it isn't them talking or throwing tantrums; **IT IS THE DISEASE!** I try to remember the good times and forget the bad. Harriet and I married "for better or worse", and we have seen a lot of the better and unfortunately because of her illness we have also seen some of the worse. Dealing with illnesses that have mental issues requires two main things...**PATIENCE** and **MORE PATIENCE**. Ultimately, having the person still with you makes it all worth it.

NOTE: Most cities, counties, or states now have agencies that can send assistance to the home to allow the caregiver to go shopping, and often they also do housework while watching the patient. We have a girl that comes in twice a week, who bathes Harriet, does light housekeeping, and fortunately does my least favorite job...the laundry. All of this takes a great deal of pressure off of me. A state agency pays for this for which I am very thankful. When we lived in Florida, there was an agency there that did the same. It is important that a caregiver take advantage of any assistance they can get.

There will be more references to the primary caregiver as we deal with the other members of the support system because the primary will have a lot of interaction with the others.

FAMILIAL SUPPORT

Chronic illnesses don't only impact the victim and/or the primary caregiver. They also affect the all members of the victim's household. It is imperative that all family members get a strong knowledge of whatever disease the victim has, how it affects them mentally or physically, and what their role is in helping take care of the victim. They need to know how they can help the primary caregiver, as well as the victim. It has been proven time and time again that families that work together on the caregiving better maintain familial harmony than those where there is no harmony or cooperation.

Without interrupting their educational needs, younger children can handle some of the lighter workload, such as dishwashing, helping serve meals, and doing laundry. This shouldn't be an imposition because it is a normal chore load for children anyway. Older children can probably help with moving the victim in their wheelchair, helping them dress, etc. Family unity becomes a strong bonding agent for a family which could otherwise become disjointed. I have observed that children who are allowed to help their mom or dad with these issues are more sympathetic to the needs of the victim, and at the same time gain a feeling of belonging and having pride in themselves.

FRIENDSHIP SUPPORT

It is often difficult for a victim's friends, especially their best friend, to accept their new limitations. Usually, at least for a time, they want to help somehow, but aren't sure what they can or should do. It is up to both the victim and the primary caregiver to sit down and explain what the victim is going through, and how they can help. They need to know their role, as well as their limitations in helping. Both the primary and the victim need to accept that even the strongest friendship can slowly disintegrate as the condition continues to stand in the way of previous activities.

INTERNET SUPPORT

In today's world, there is no better place to gain knowledge on anything than on the "information highway", the internet. The various caregivers, family, friends, and professionals, can look up information on the victim's illness, on new treatments that are available, on support groups in their area, and on just about all aspects of caregiving. I personally visit several online support groups for Harriet's illness, HD; and for caregivers. I have probably learned

more there than from books, or from the doctors, especially when it comes to adjusting to her mental decline caused by the disease. Support groups are there just for that....**SUPPORT!**

MEDICAL SUPPORT

Medical plans today make it imperative to have two active physicians when you are dealing with a chronic illness.

First, you must have a primary physician, one who handles all routine medical needs, such as physicals, medications control, routine illnesses like a cold, and weight control.

Then, you must have a specialist that knows everything available about the disease that is considered a “chronic” illness. Basically, to put it in simple terms, a chronic illness is one that probably will not go away. It may, or may not, be able to be controlled. The specialist needs to be one that keeps up with all the latest treatments and available medications for the particular disease. The primary must keep track of any known interactions between routine illnesses and the chronic ones, especially where medicines are concerned. Keep in mind that some people develop more than one chronic condition, which may mean that there could be several different specialists involved. On top of the different physicians, the pharmacist is another important part of any treatments for illnesses. They are most apt to catch the possibility of interactions between different meds that are prescribed by the different doctors. With some conditions, there can also be several different therapists involved in the treatments.

The main thing to remember is that there is one person who is in the middle of all of this, the one who needs to keep track of all treatments and meds, the **PRIMARY CAREGIVER**.

RELIGIOUS SUPPORT

One of the biggest questions that tends to come up is how important is the church in providing support for someone with a chronic illness. This is a tough one, because it really depends on the victims personal convictions. To someone who never goes to church, it may not be important at all. To the casual churchgoer, who attends a weekly service but doesn't get involved in activities it may be important, and it may not. To someone who is extremely

active in the church, or is in a position of authority there it will most likely be very important.

For this writer, it is very important. Prayer has helped keep me here to take care of Harriet. I was sent home to die with stage four cancer thirteen years ago. A lot of people prayed for me daily, and the cancer disappeared, so to me the church needs to be in my support system.

Do I believe that God has to be involved? That isn't for me to say. Each person has to make that decision based on their own faith. I believe that God left me here to take care of Harriet, so for me it is very important. I do believe that if a person is an avid churchgoer, their preachers, deacons, etc. have an obligation to visit them and give them heavy emotional support.

SUPPORT GROUPS

Almost any chronic illness that exists today has support groups throughout the country. Are these important? In my mind they are one of the most important suppliers of support. Harriet and I attend an HD support group in Louisville whenever we can, depending on her condition. These groups are most important because others with the same illnesses can share their experiences, their problems, and new treatments that they are getting.

In my mind it is imperative that both the victim and the caregivers attend these meetings. Sharing experiences is probably one of the best ways of learning more about a person's condition.

A SIDE NOTE

Harriet has one other source of support, something that is always with her, always a source of comfort, and NO IT ISN'T ME. She has a 15 pound support dog named IZZY who is always on her lap or sleeping next to her pillow. Fortunately most states, especially KY, allow these dogs anywhere.