

Caregiver Strategies

As families attempt to make good decisions throughout their journeys with Huntington's Disease, denial can cause all kinds of conflicts and complications. As we know, there is the lack of awareness of symptoms that is caused by the disease itself, but in addition there's the denial that we and others use as a psychological defense mechanism. Denial by caregivers, other family members and even professionals causes its own share of difficulties.

Here are some strategies that I have developed from my own experiences and from those of others who have walked ahead of me on the journey which can reduce the problems caused by denial and help with good decision making for a better quality of life.

1) Nobody's Perfect – It's a Journey.

Don't grade yourself and take away points every time you get cranky or have to struggle to find a solution to a problem. Caregiving is a journey, you will always have challenges along the way and you will learn and grow as a person.

2) Start as you mean to go on.

The patterns of coping, of interacting with each other, of dealing with symptoms that you establish early on will be hard to change later.

We caregivers are often given the advice to 'pick your battles.' While that is certainly useful advice, I feel that it should be paired with the advice to start how you mean to go on. We can adjust and adjust to HD until we're not meeting our own needs and not accomplishing things we need to be doing for the whole family. It's an insidious process. As you make changes in your life, ask yourself, am I going to be comfortable with this pattern indefinitely?

3) Prioritize your goals.

We all know what we want but we have to consider what we don't want and are afraid might happen. Talk to your loved one early on about both values and priorities. How important is independence vs. safety, for example? Maintaining a stable home for young children vs. caring for affected family members in the home for the course of the disease? A frank discussion early on can help with difficult decision making as the disease progresses.

4) Try to stay off the Huntington's Disease roller coaster.

One particularly challenging thing about Huntington's Disease is that it seems like everything is going along smoothly for awhile and then suddenly it changes. You adapt to the disease, you restructure the environment, you work with the doctor to find the right medications then suddenly there's a crisis or an abrupt decline. Set boundaries, establish bottom lines, develop routines, and get the help you need (counseling, medication, support) so that you are not always anxiously 'waiting for the other shoe to drop' but can cope when changes and crises do occur.

5) Remember that every good day with HD is a victory.

Given all the challenges we face as caregivers and all the challenges people face with the disease, it's good to remember that every good day with HD is a victory.

6) Learn all you can about the disease – knowledge is power.

Read, ask questions, and learn about the disease so you can work with your loved one and the doctor on managing the symptoms. Understand the cause of behavioral symptoms so you can remove some stressors from the environment and improve communication.

7) Plan for the future.

Discuss the difficult issues, tackle the practical tasks that are needed as early as possible. After a positive test or diagnosis for HD, some families try to put aside thoughts and conversations about HD until it is 'necessary.' The downside to this is that when you are ready to pick up and discuss some things that need to be discussed – is it time to go out on disability from work, are there symptoms that would respond to medication, etc. – the person with the disease may not want to do so. End of life issues such as wills and advanced directives are always easier to resolve when one is healthy and that includes both the person with HD and the caregiver.

8) Be comfortable talking about the disease

Don't let it become a taboo subject. We need to talk about it as we would anything that affects our lives. You can use humor in discussing it. Difficult discussions about the future can be prefaced with the phrase, "If the cure isn't here by then...." we leave, he'll want to go back and check again.

9) Take care of legal issues.

When you first visit the doctor with your loved one, ask him to sign a form allowing the doctor to discuss his medical condition with you and/or your adult children. In this way, you can avoid any HIPAA law complications.

At some point in the disease progression, you as the caregiver may need to have legal authority to act for an individual because they are legally or mentally incapacitated. People with the disease can decide on a future guardian in many states by having their attorney draw up a 'springing power of attorney' that goes into affect only when they are incapacitated. Advanced directives regarding end of life care can be drawn up as well.

10) Become an advocate for your loved one.

Becoming a successful advocate is an important part of coping as a caregiver for two reasons. First, once you know that you can do this, you feel empowered and that's important when dealing with a disease that makes us all feel powerless initially. Second and most important, we will know that we've done our best for our loved ones.

Apply for benefits, find resources, and be able explain the disease to others – family members, friends, and those in charge of benefits to help make life easier for the person with HD.

11) Keep on top of the paperwork.

Start a file as soon as possible. Here are some examples of things you might need. Birth certificates, marriage certificates, divorce decrees, insurance policies, and the HD gene test results are some of the commonly requested documents. Keep a copy of the person's resume because dates and places of employment will be needed. Grab a copy of the doctor's professional card for address and phone number and keep a record of doctor visits.

Make a copy of every form that you fill out before you mail it. You will see this form or similar ones again and again and it will save time to be able to just copy your previous responses. Also, if a benefit is denied, it will be helpful to see what you wrote. Perhaps they've overlooked information that you've provided or misinterpreted something or it may be that you haven't explained something fully.

12) Keep a notebook.

Get a notebook. When locating resources and dealing with people who control benefits, I have found it to be very valuable to get a notebook and write everything down. Name, organization, date, time, phone number, what I asked them, what they said, whether any follow up is planned. If someone can't help me I always ask if they can suggest someone who can. Take lots of notes. You may think you'll remember what you need to know but it quickly gets overwhelming if you don't write it down.

13) Find support.

Treasure the family and friends that offer support and friendship as well the new friends who will become your extended family. There will likely be some family and friends who will be unable to offer us the support we need. It is sad but we cannot afford to waste our energy worrying or being angry about it.

There are a number of sources of support from groups run by HDSA chapters to Internet chatrooms, bulletin boards, and email discussion groups.

14) Understand the stages of caregiving.

The stages of HD are widely publicized but we caregivers also go through our own stages. They are not necessarily the same for everyone, but it seems clear that we see what we are ready to see and accept what we are ready to accept and not until we have finished the work of one stage are we ready to move onto another.

In this first stage, we need to come to terms with our loved one having the disease. This can be a roller coaster while we wonder if certain things are symptoms, decide they are just stress-related for awhile and then become concerned all over again or while we can clearly see symptoms that should be treated while our loved ones insist that everything is fine.

I call the second stage 'battle mode.' There is much to be done during this stage such as finding the right medication and creating a less stressful environment. The two of you are fighting this disease together and you're determined to have the best quality of life possible while you wait for the cure.

As the disease progresses, caregivers begin to realize that they aren't fighting the disease along side of their loved one but need to become the executive personality. Caregivers are at risk for depression if they aren't clear about having moved into this third stage and if they do not acknowledge their feelings of anger towards the disease and grief for the losses.

15) Look back on your journey so far

No one is perfect, including us caregivers. Grading ourselves is not helpful but we do need to reflect on our experiences so we can continue to move forward. I've borrowed an idea from Ann Curry, co-anchor of the Today Show. Her father told her that it's good to periodically take stock of how far she's come in her life by asking three questions – Have you loved enough? Have you done your best? When you had a chance to do good, did you take it?

- Marsha L. Miller, Ph.D.