Facing the Challenges of Being a Caregiver

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August 20, 2006 -- When a loved one is diagnosed with a very challenging physical condition such as Chiari or syringomyelia, a tremendous amount of our attention, love and concern naturally goes to the person who is suffering. At the same time that you are doing your best to comfort and help your family member adjust to the changes that are happening, you must deal with your own sadness for them and also for yourself and the life changes you are also going through. Caregivers can be so busy taking care of their loved one that they forget to think about themselves. Caregivers can feel guilty if they feel sad, depressed, or angry when someone else is sick.

This article is for you, the caregiver. I want to discuss some of the issues you face, starting at the time you hear your loved one's diagnosis. I will describe some of the typical feelings people go through as they try to adjust. They can include grief, fear, guilt and anger. If you understand the normal grief process, you can be easier on yourself as you go through it. You will also be able to identify danger signs and what to do about them.

If you have been caring for someone for a period of time, another important issue can come up-*caregiver burnout.* Often a caregiver can become not only burned out, but depressed. If you burn out, you aren't in good shape to take care of your spouse or child. I will talk about ways to cope and to find resources to help you.

Each devastating disease brings with it staggering demands on families. Some diseases lead fairly quickly to severe illness and death. Suddenly, a family member is gone. Others, like Chiari and syringomyelia, can present a lifetime of caregiving demands and emotional challenges to a family, but in many communities there aren't many resources to help. It is very important to realize the challenges involved in being a caregiver and what can be done to help make the load lighter.

The Adjustment Process

The first stage of the adjustment process, either after diagnosis or as someone's physical condition deteriorates is grief.

The grief you feel when you hear your loved one's diagnosis tends to be the beginning of a long process. You feel tremendous grief for your loved one and you do your best to help them deal with their emotional pain as well as their physical problems. At the same time, it is important to recognize that you are grieving for yourself too It is normal to feel those feelings. You not only feel tremendous sadness for your child or spouse, but also for the loss of the life you had before and of plans you had for the future. It may be very hard for you to allow yourself to grieve, and it may be very hard to find the time given all the other demands you are facing.

Where is the room for you? Everyone, including you, is focused on the person who is suffering physically. This is natural and normal. But if you are upset, others might feel, "why should you be grieving, this didn't happen to you?" Some will think you are selfish to have your own feelings. But it is important for everyone to understand that while the ill or disabled family member has the most to deal with, you are suffering too and need to go through your own feelings. If you and your mate can communicate, you will go through this process together. But frequently you can't talk easily about painful feelings, or your mate is suffering too much to listen to you Another family member, a friend or a professional can often help a lot.

Many years ago a Swiss doctor, Elizabeth Kubler-Ross, outlined the stages of grief. These stages apply to you, just as they apply to the person who is ill.

The first stage of grief is usually *shock and denia*l. You can't believe that this is happening to your family. You might think, "maybe it isn't true." Some people get stuck at this point and continue to deny that the problem is as serious as it is. It is very important that you recognize that the diagnosis IS true so that you can move forward. It is very hard to cope with something you deny, while to face it opens up new avenues for improving your situation and feeling better in time.

As the reality of the diagnosis sets in, *anger* can set in. Why is this happening to us? You might be angry at God, at doctors or even at your ill family member.

The third stage is *bargaining.* I have known people who have gone through a phase of thinking that if they do something differently, their mate or child will get better. A usually very rational friend of mine believed that his wife wouldn't die of cancer if he completed a crossword puzzle every day. You might feel that you are the cause of the illness somehow. This is particularly true if your child is diagnosed with Chiari. You might wish or pray that something bad would happen to you instead of your child. Of course, this only makes matters worse because you feel guilty as well as sad.

Depression is the fourth stage of grief, and the most challenging one when you are facing chronic illness. Depression can set in and stay. We know about people who lose a spouse or child and become depressed and can't seem to pull themselves out of it. But with chronic illness the challenges can be greater in some ways because there is no end to the situation. You are challenged to adapt to your changed life where your loved one's suffering doesn't end, but continues over the years. Caregivers are very susceptible to depression. I will talk about this in detail below.

Acceptance is the final stage. At this point, you have been able to let yourself feel the pain and sadness of your situation, but you have also been able to come to terms with it over time. You have heard the saying: "If life gives you lemons, make lemonade." Of course, this can be a lot easier said than done, but over time you want to accept the changes in your lives and find the good things to enjoy. If you have allowed yourself to grieve you can come out on the other side. If you deny your grief, it can fester. For men this can be more of a challenge than for women. Many men don't feel comfortable with emotions. Many have heard the words "Be a man." But emotions don't go away, instead they go underground and come out in other ways, particularly as anger.

Helping a child who is diagnosed

If your child has been diagnosed, you may be able to go through this grief process with your spouse. While this is very sad and painful, there is something comforting about sharing your feelings with someone and going through hard times together. Sometimes though, a spouse will get stuck in denial or anger. You may need to help them understand that it is normal for them to have feelings too.

Children who are diagnosed are going to go through their own feelings as they adjust to their condition. It makes a huge difference to a child if they feel supported and taken care of by a competent parent, but this doesn't not mean you should pretend that you don't feel anything, or that what is happening isn't a big deal. Children tend to have great intuition and can pick up on how you feel. They need to know they can express themselves and grieve too. Children who can't talk about feelings can sometimes draw pictures or make up stories with their animals, There are books they can read that portray kids facing challenges and dealing with them successfully.

Each child is different, as we all know. If you are confused about how to help them with your child's emotions, talk to your child's doctor or someone else you trust who knows your child. You want to make sure that your child doesn't feel isolated in what they are going through. You want to be open to how they feel without pushing them on one hand or denying on the other.

Facing emotional or mental health issues

Depression

Grief passes. Depression doesn't. It can settle in like a black cloud that affects everything. Depression can make even the best day seem bad. Any small problem becomes a large one. I know a woman who had cancer and said, "I've been depressed and I've had cancer. Depression is worse!" Because caregivers tend to have a high rate of depression, it is very important to be able to recognize it. You also want to be able to assess whether your mate or child is depressed. Symptoms:

1. Your mood is down much of the time and doesn't improve like it used to.
2. You sleep too much or too little.
3. You gain weight or you don't feel like eating.
4. You feel irritable a lot.
5. You cry easily and don't know why.
6. You have trouble concentrating.
7. You feel hopeless.
8. You lose interest in activities that used to be fun or interesting.

If you feel suicidal, this is a huge warning sign of serious depression. You, or someone close to you, must take action and call your doctor

Anxiety

Some people get anxious rather than depressed. Others get both. Anxiety tends to appear as:

1. Physical symptoms such as shaky hands, feelings of inner tension, racing heart, cold/clammy hands, dry mouth, light headedness, "lump in throat".
2. You feel "on edge".
3. You have difficulty concentrating
4. You have trouble falling asleep or wake up a lot
5. You feel irritable.

What to do about depression and anxiety

Many people don't want to acknowledge that these are serious problems, or think they will "just go away". Anxiety and depression are common, and these conditions can have a huge effect on the quality of your life. You may have suffered from these problems before illness appeared in your loved one. If not, the emotional pain of seeing someone ill or disabled, plus the stresses of care giving, can bring on anxiety or depression. *See a doctor or mental health professional.* Many communities have low-fee mental health services if money/insurance is an issue. You may be offered medication and/or counseling. Don't be ashamed that you have these problems. You will feel a lot better if you accept the help that is offered.

If you absolutely can't bring yourself to get help or can't find anything you can afford, but you have access to a computer-USE IT. There is a tremendous amount of information and support on these topics on the internet. Just type in "depression" or "anxiety" and you will get all kinds of information. Here are several sites: www.pyschologyinfo.com. Another is: www.depression.com

If you have other emotional or mental health issues, the same advice applies: don't be ashamed to get help.

Fear, Guilt, Resentment and Anger

Fear, guilt, resentment and anger are common feelings that people often face when a loved one is ill or disabled. I will describe each one and what you can do to feel better.

Fear

Living with fear for your spouse or child (or family member) can be overwhelming. "What will happen to them? What will happen to us? How will we handle finances? How can I cope with the stress? What about my own health? Every new symptom can bring more fear for you. How can I manage with this new problem? I can't stand to see my family member in pain. I can't handle their fear. I'm already too scared."

The first step is to acknowledge your fear. It is normal to feel fear, but you don't want to be possessed by it. After acknowledging the feeling, ask yourself, "What can I do to relieve the fear?" For some people this means getting more information about Chiari/Syringomyelia. A good place to start is this website. You can go to doctor's appointments with your loved one and ask questions. For other people more information creates more fear and you need to respect that. Each person is different.

Fear can become a handicap. If there is nothing you can think of to relieve your fear, try to acknowledge it, then let it go as best you can. The feeling will come back, but again, try to tell yourself that there is nothing to be gained by dwelling on fear. Denying it doesn't work very well at all, because you start to behave in ways that confuse the people around you. If you experience fear, again, acknowledge it and try to let it go when it comes up if you can.

If you are fearful, your loved one with Chiari/Syringomyelia, probably is too. Can you talk about it and support each other constructively?

Guilt

Often, especially if your child is diagnosed, you will feel something called "survivor guilt". This guilt is the feeling that whatever happened to the other person should have happened to you instead. In some cases you think it would almost be easier for you to suffer than to have your loved one suffer. Other times, you think you <u>deserve</u> to be the one to suffer.

Things get even more complicated if you have an ill spouse who feels resentful that they have the problem and you don't. How can any of your problems possibly measure up to what they are going through? How can you be happy if they aren't? Why should they do a household chore that is difficult when it is so much easier for you? Your loved one may not understand that you are running night and day either to work and then home to responsibilities, or home all day helping them. Since their situation is worse then yours you can't complain. This can lead to:

Resentment

No one wants to feel resentment. You certainly don't feel proud of yourself for feeling this way, yet you get tired of having to do so much, being worried, being sad. You want to feel better, but that makes you feel guilty all over again. Resentment can sneak out in sarcastic remarks, conflict over minor day-to-day issues. You didn't want your loved one to suffer from Chiari/Syringomyelia, but you didn't want this to happen to you either. Since you know that you aren't "supposed" to feel resentment, you deny that it exists. But your first step must be to admit your feelings to <u>yourself</u>. Otherwise, resentment can lead to:

Anger

One of the most difficult emotions for a caregiver is anger. How can you be angry at someone who is ill? Yet you feel it and the feeling can be very legitimate. While you have every right to feel angry at times, how do you express it? Do you hold feelings in and then have an angry outburst? One of the most important things about anger is recognizing what you are feeling. If you know you are angry, you can think about how to handle it. If you don't know, it can pop out in very nasty ways.

Sometimes you can have a very painful and legitimate reason for anger. Your spouse/family member has essentially abandoned you emotionally. They are preoccupied with their health and problems, they are in pain or stressed and you discover you no longer have a mate you can talk to like you used to. People who are sick or in pain often "regress". This means they can no longer function as the loving, competent adults they were before, but can act more like a child. They usually can't help it. They have physical challenges, plus all the emotions they have to deal with. Pain makes it very hard to focus on anything else. While this situation can make you angry, it can be very hard to admi because it seems selfish. But if you acknowledge your anger to yourself, you can start to find ways to cope with it better.

What you can do about your painful feelings

First, recognize that all of your feelings are normal. *The challenge is what to do about them*. Can you talk about your feelings with your spouse or family member? If you know that you aren't the best communicator, things are even more challenging than before. Sometimes, though, you can get closer to your mate in sharing the challenges of illness/disability if the two of you can talk about it and go through it together. They may be suffering the most, but you are probably suffering the second most. They can feel guilty about "putting you through this" so it can be hard to talk.

If you are the parent and your child is ill, can you discuss your feelings with your spouse? Can they talk to you? Some people clam up, which can be very difficult.

What if you can't talk about your feelings or your partner can't listen anymore? You need help! Who CAN you talk to? Do you have other family members, friends, members of your church or synagogue? If you do, try to open up to a few people.

Some caregivers can't talk about feelings, but you need to start by being honest with yourself. Acknowledging a feeling is not a weakness. *Honesty with yourself is powerful.* Instead of being at the mercy of feelings you can't identify or that you deny you have, you can decide on the best way to proceed, so that you will eventually feel better.

Why some family members or friends can't be supportive

Anytime a family has to face serious illness or death, you will find that some people just can't be supportive. Others can burnout over time. One of the most devastating things for a family to discover is that some family members and friends simply can't be there emotionally or sometimes any other way either.

Illness brings out the best in people and the worst in people. Some people you didn't think were that close will suddenly come forward. Some will abandon you completely.

Why? Frequently the problem is fear. If a serious illness can happen to you or your family, it can happen to them. Some people can't face this. Some people feel overwhelmed in their own lives and see your problems as an additional burden they can't handle. Others simply can't put themselves into another person's shoes. They will either resent your needs or deny they exist.

It is extremely hard to be forgiving to these people, especially if you thought they were close to you. If you are a spiritual person, you may be able to use your religion or faith to help you with your feelings and deal with forgiveness. In any case, when this happens it is a big challenge to work on acceptance and/or forgiveness. Anyone who has dealt will illness and/or death in their family can tell you the same thing. Some people simply can't come through for you, painful as it is. You need to focus on those who can come through. Sometimes, these are strangers. I have a friend whose family pretty much abandoned her when her son needed a kidney transplant. Who came through? A woman who read about the son's condition in the local newspaper. She donated her kidney and the families have become close friends.

When family and friends burnout

Anytime you are dealing with a chronic problem, even the most well-meaning people can burnout. At those times you need additional help. Some churches offer pastoral counseling. Many communities offer low-fee counseling. Online support groups can be great, including www.caregiving.org

Caregiver burnout and what you can do

Caregiver burnout can be a devastating problem. If you are burning out, it probably means that your child or family member has been sick/disabled for a long time and isn't feeling well themselves. Just because someone may be in worse shape than you doesn't mean you don't need help.

Here are some signs of caregiver burnout:

1. Grief that doesn't get better, anxiety or depression as described above.
2. Chronic exhaustion. You look and feel tired most of the time.
3. Anger and resentment are getting you down.
4. You feel burdened all the time.
5. You get sick a lot more than you used to.
6. You withdraw from family and friends.

If you are burning out, do not ignore it! If you burnout completely you won't be able to care for or help your loved one. You are important too!

When you are burned out, you are often too tired to do the things that can make your life better. Is there anyone, anywhere you can talk to? Your spouse, a family member, friend, church member, doctor, etc. Have they made recommendations that you have ignored? YOU MUST TAKE ACTION. You can't do this alone. Any support is better than no support. Can you ask people to come in and give you a break? If not, there are communities that offer some kind of respite care services. Ask you doctor or call the hospital social worker.

- Take a vacation, even if only for an occasional weekend. Can you stay with a family member or friend and get totally away from caregiving while someone else steps in? Some people feel too guilty to take a break, or think they can't leave an ill person. But if you aren't strong you can't go on and nobody benefits. Are there respite care services in your community? Check with the Office of Patient Services at your local hospital for advice.
- Get the mental health treatment you need. See your doctor. You will also feel a lot better if you can get some personal counseling. It can really help to have an objective outsider listen to your problems and feelings.
- Call somebody even if it is hard to do. If you have no one, go online. Any message board for caregivers for people with chronic illness or spinal cord injuries is likely to offer some help.

If you have a church or spiritual community, ask for help.

Does your local hospital offer support groups for caregivers, or have a referral list of places that do?

- Domestic help - You hate to "burden" a family member or friend. But could they do a regular chore for you? If you belong to a church or other organization, can someone there organize a team to help, ie. cook a meal, shop, do an errand, drive to a doctor's visit, come in for a few hours?
- Get more information on chiari or syringomyelia if you feel it would help. This newsletter is a great resource, as is the website. Some people don't want to think about a painful topic anymore, and avoid information. Do what works for you.

- Find something you can do that brings you happiness. Spend time in nature, play sports or exercise, enjoy music or art, start or continue any hobby that sounds like fun. Several of my clients have enrolled in painting classes. It wasn't easy to find time to do it, but eventually they did. Just because someone is ill doesn't mean you don't deserve some fun or happiness.
- Ask yourself: "Is there anything I can do to make my day a little bit nicer?" If your answer to this is "no", you might be too depressed to care. Again, if that is the case, *call a doctor and make an appointment***.** Get a physical if needed. Tell the doctor you think you are depressed. If you can't afford a doctor, find out about the nearest community clinic.
- Some families can afford to pay for outside help but don't do it. If you are fortunate enough to be in this situation, think realistically. Are you doing too much when you could get some relief.? Do you feel guilty about asking for help?

Each of us has burdens and gifts in life. When someone is chronically ill the burdens can feel insurmountable. But you aren't alone. When all else fails, the modern world has brought us the internet. Information, caring, advice, support is a click away. When we have people to share our burdens with we realize we aren't alone. If we like to escape those burdens rather than talk about them, there are people, information and groups for that too. You can even play solitaire online!

Looking at the positive side

First of all, recognize your gifts. A crisis can defeat us or can force us to develop into people we never knew we could be. If we face our problems we can find ways to make things better-at least a little bit. If we deny them, they can only get worse. If you are overwhelmed, do just ONE THING a day to try to make things better. It will make a difference in your life. A caregiver I know tries to take a few minutes to think about the good things that happened each day.

Finally, don't forget that there are reasons for hope. Medical science is advancing day by day.

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[Ed. Note: The opinions expressed above are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Anyone with a medical problem is strongly encouraged to seek professional medical care.]