



*Caring for Jefferson County Since 1985*

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## *CARE FOR THE CAREGIVER*

*“The things that matter most in our lives are not fantastic or grand. They are the moments when we touch one another, when we are there in the most attentive or caring way.”*

*-Jack Kornfield*



Dear Caregiver,

It takes courage to be a caregiver. Providing care for someone at the end of life can be emotionally and physically draining. You may feel stressed or alone. You may not know what to expect. We are here to support you and your loved one.

This section talks about ways to care for yourself so you can in turn take care of your loved one. It is important to keep in mind that your loved one can no longer do many everyday tasks and now depends on you for many more things. You might feel like it's easier to just take charge and make decisions. Your loved one will want to remain independent as long as possible. To help maintain their dignity it's important to always be patient and respectful.

The end of life Journey can be a very frustrating time for both you and your loved one. Your Hospice Team is here to help you through this journey!

Thank you for this opportunity!

Your Hospice Team



## **CARE FOR THE CAREGIVER**

When someone is caring for a loved one, that caregiver may ignore his or her own needs because of the needs of the patient. While this is understandable, it is important to realize that the caregiver must take care of himself or herself first in order to be able to appropriately care for the patient. Illness impacts the entire family, and it may be physically and emotionally draining for the caregiver in particular. It is important that you, the caregiver, take time for yourself, as well as take care of yourself. Try to remember that you are only one person and cannot do everything.

Even if you are a person who never asks for help, this may be the time that you have to make an exception and seek the help you need to take care of yourself and the patient. Remember that your friends and the patient's friends really do want to help, but are often respectful of your privacy so will hesitate to help without at least some opening from you that this will be acceptable.

What would be most helpful to you? A dinner brought in, cleaning the kitchen or bathroom, weeding the garden, picking up groceries, or simply sitting with the patient for an hour or two so you have some time to yourself? Only you will know what you'll find helpful, so think about this and work with the Hospice of Jefferson County Staff to identify those who can best help you.

If you have family members, friends, neighbors and church members who are willing to help out then you could make out a list of people willing to help around-the-clock when it becomes necessary. While you might want to be the only person caring for the patient, this is not realistic when the patient needs care around the clock. If you have the financial resources, you may wish to hire help when necessary. The Hospice of Jefferson County Team could offer suggestions on when this might be appropriate. If there are several people caring for the patient, it is often helpful to keep notes of the patient care in a communication book or journal for other caregivers to read so they will know what has been done prior to their 'shift'.

Remember that the patient is often worried about you also, even if it does not seem that way to you. If you take care of yourself, this may be the best thing that you can do to comfort the patient. It is certainly the best thing that you can do to help you to be able to continue to care for the patient.

What helps you to cope when stressed: listening to music, walking, praying, having lunch with friends, journaling, watching television? The activities that help you to cope need to become a regular part of your day. Caring for someone who is ill is very rewarding, but

also very stressful. If you do not have outlets to deal with this stress, it may cause you to be short with the patient or to become ill.

**If you need to feel guilty about caring for yourself then feel guilty, but DO care for yourself! To be able to take care of another, you must first take care of yourself!**

Tips on taking care of yourself:

- Get enough rest, perhaps nap during the day. Conserve your energy.
- Exercise. Even a short walk helps sleep and gives energy.
- Eat well. Choose a variety of foods from the five basic food groups. Drink plenty of water.
- Reduce stress. Think about what has helped in the past.
- Take breaks. Relax and think of other things.
- Pay attention to what your body is telling you. Is it tired, stressed, tense?
- Nurture your spiritual side. Pursue those things that are uplifting to you.
- Pamper yourself, especially on difficult days. Be patient and considerate of yourself.
- Avoid unrealistic expectations of yourself.
- Allow others to help you.
- Set limits. It's ok to say "no" sometimes.
- Recognize your needs and limitations.

Tips on helping loved ones:

- Allow them to talk. Listen without judgment and with only occasional comment.
- Acknowledge and validate their feelings and let them express their feelings in many ways.
- Avoid taking any negative feelings personally.
- Let them have control over their situation as much as possible.
- Include them in decision making and discussions.
- Let them do as much as they want to and have the energy for, no matter how slow, painful or difficult it seems to you.
- Don't underestimate their pain, symptoms and fear, they are real and valid.
- Avoid judging.
- Talk about subjects you used to discuss together, the times you shared.
- Laugh.

# CAREGIVER BURNOUT

By Dr. M. Ross Seligson

Being able to cope with the strains and stresses of being a Caregiver is part of the art of Caregiving. In order to remain healthy so that we can continue to be Caregivers, we must be able to see our own limitations and learn to care for ourselves as well as others.

It is important for all of us to make the effort to recognize the signs of burnout, in order to do this we must be honest and willing to hear feedback from those around us. This is especially important for those caring for family or friends. Too often Caregivers who are not closely associated with the healthcare profession get overlooked and lost in the commotion of medical emergencies and procedures. Otherwise close friends begin to grow distant, and eventually the Caregiver is alone without a support structure. We must allow those who do care for us, who are interested enough to say something, to tell us about our behavior, a noticed decrease in energy or mood changes.

Burnout isn't like a cold. You don't always notice it when you are in its clutches. Very much like Post Traumatic Stress Syndrome, the symptoms of burnout can begin surfacing months after a traumatic episode. The following are symptoms we might notice in ourselves, or others might say they see in us. Think about what is being said, and consider the possibility of burnout.

- Feelings of depression.
- A sense of ongoing and constant fatigue.
- Decreasing interest in work.
- Decrease in work production.
- Withdrawal from social contacts.
- Increase in use of stimulants and alcohol.
- Increasing fear of death.
- Change in eating patterns.
- Feelings of helplessness.

Strategies to ward off or cope with burnout are important. To counteract burnout, the following specific strategies are recommended

- Participate in a support network.
- Consult with professionals to explore burnout issues.
- Attend a support group to receive feedback and coping strategies.
- Vary the focus of caregiving responsibilities if possible (rotate responsibilities with family members).
- Exercise daily and maintain a healthy diet.
- Establish "quiet time" for meditation.
- Get a weekly massage
- Stay involved in hobbies.

By acknowledging the reality that being a Caregiver is filled with stress and anxiety, and understanding the potential for burnout, Caregivers can be forewarned and guard against this debilitating condition. As much as it is said, it can still not be said too often, the best way to be an effective Caregiver is to take care of yourself.

*This article was provided by caregiver.com.*



# Caregiving 101

By Michael Plontz

A family member has just been diagnosed with an illness that will eventually require round-the-clock care. Of course you want to be the one giving that care. This decision is usually made without hesitation; of course we want to be our loved one's caregiver. Who else could take better care of them? However, when the reality of your decision sinks in, your head will be swimming with uncertainty, anxiety, and maybe even fear. Certainly you will have many questions. Welcome to Caregiving 101, a primer for first-time caregivers.

First of all, arm yourself with knowledge. An old maxim states that "Knowledge is power," and it's true. Knowledge will empower you to take the best care of your loved one and yourself. Learn all that you can about your loved one's condition, illness or disease. There are local branches of national organizations like the Alzheimer's Association and the Cancer Society all over the country. Use them as a tool to find out all about your loved one's present condition and what the future may hold for both of you.

Another reason to learn is to take better care of your loved one. You may educate yourself through health care manuals, books and videos. The Internet is also a good source of information, but navigate carefully through that material because not all of it is valid. Also, ask lots of questions of your health care professionals. They are the best people to show you proper techniques like transferring, lifting and bathing. When you learn all that you can, you will be more confident in your caregiving abilities.

Caregiving can be an isolating experience, so it's helpful to talk to others who are, or have been, in your shoes. You will feel that you are a part of a growing community of caregivers. You may also learn about options and community resources that you were not aware of from other caregivers. These people can also help with difficult decisions concerning your loved one. Determining your responsibilities will probably be one of the first things you struggle with, so talk to others who've been there before.

You must remember to take regular breaks from your caregiving responsibilities. You can't be good to someone else if you're not good to yourself. Use your relatives. They can help in several ways—financially, socially, and as respite support. If relatives are unavailable or do not exist, try community services like a volunteer group at your local church. Try and follow these guidelines for caregiving breaks: take half-an-hour a day to practice yoga, meditation, needlepoint, reading, etc.; spend a couple of hours a week away from the house at the mall, coffeehouse, library, etc.; monthly you should have an evening out with friends, go to a play or concert, etc.; on a yearly basis you should go on a well-planned (and well-deserved) vacation. These guidelines will help in avoiding "caregiver burnout."

Your community most likely has organizations about which you never gave a second thought until now. These may include, but are not limited to, Meals on Wheels, day care centers, and home care agencies. If applicable, contact your local Area Agency on Aging for a list of services and organizations. Your local medical supply store may have gadgets and devices to enhance your loved one's abilities, at the same time making your life a little easier. You might also inquire about local, state or federal programs that might provide financial aid for you and your loved one. As needs increase, so do costs. Understanding which programs can help and what you can afford, will allow you to plan for the future.

One way to deal with the emotional roller coaster you may experience is to get your feelings down on paper. Some journal entries might address the following subjects: How do you feel now? What are your fears and/or concerns? What outcomes would you like? What losses have you noticed so far? What changes in your relationship with your loved one have caused you to feel sad? What changes have given you comfort? Journaling is a healthy way to put your feelings "out there" and to possibly alleviate some of the anger, frustration and helplessness you may be feeling.

Caregiving need not be a lonely and emotionally debilitating experience. According to the latest statistics on caregiving for the National Family Caregivers Association, nearly half of the U. S. population has a chronic condition. From that number 41 million are limited in their daily activities while 12 million are unable to live independently or even leave the house. One can deduce from these numbers that there are millions of family caregivers out there. So keep in mind that you are not alone, and best of luck to you and your loved one.

*This article was provided by caregiver.com.*