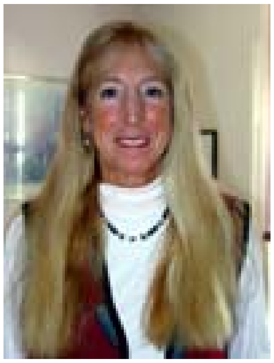
Powerful Patient #26, 2008 Week 20

Host: Joyce Graff, WebTalkRadio.net

Surviving Caregiver Stress

Joyce talks with Eve (not her real name) about her experience as a caregiver through her husband's chronic illness and death. She then talks with Dr. Sheryl Baker about Eve's experience, and about the changes that occur in the dynamics between the patient and the caregiver, and how we can all help the caregiver survive.


Sheryle Baker, Executive Director
Life Center of Tampa

1) ***About Our Guests***

Eve (not her real name) is the widow of a man who had von Hippel-Lindau disease, and a series of brain and kidney tumors that led him to a course of dialysis and eventually to his death. Eve graciously shares the pain of her experience so that we can learn from her experience.

Sheryle Baker, Ph.D., is Executive Director of Life Center of Tampa, Florida, a non-profit agency that provides counseling for victims of violent crime, and people who have lost loved ones, through chronic illness or sudden death. She a psychotherapist specializing in bereavement and traumatic loss and incident, Sheryle also studied and trained for over seven years with international authority on Death and Dying, Dr. Elisabeth Kubler-Ross. http://www.lifecenteroftampa.org/

2) ***About Caregiver Stress***

It is important to manage caregiver stress while you are going through the experience. If the patient is willing to negotiate the changes in roles and responsibilities that occur, that can help. Others around the caregiver can provide important support and outlets for stress.

For both the patient and the caregiver, there are a series of losses, culminating in the death of the loved one. Each of these losses must be grieved, and the grief worked through, or the stress turns outward (as anger) or inward (as bitterness and even illness).

Often when we are in a traumatic incident we muddle on through and seem to be doing fine. After the peak of the stress has passed, however, we crash. This "post-traumatic stress" can be devastating, and requires work to get through it.

3) ***About Grief***

Grief is a natural process to death and dying. It is not pathological in nature, but rather, is a necessary response to helping heal from the overwhelming sense of loss when a loved one dies.

Dr. Elisabeth Kubler-Ross did a great deal of research and work with people grieving a wide variety of losses and left an important body of work that has become the standard for understanding the grieving process. She divided the "stages" of grieving into the following:

Denial: "It can't be happening."
Anger: "Why me? It's not fair."
Bargaining: "Just let me live to see my children graduate."
Depression: "I'm so sad, why bother with anything?"
Acceptance: "It's going to be OK."

These are normal components of grieving any loss – loss of health, loss of function, loss of a loved one. These steps do not necessarily come in the order noted above, nor are all steps experienced by all people, though a person will always experience at least two. The important thing is to acknowledge the grief, and not get stuck in this process, but to work through it.

On a website dedicated to her memory there is a particularly helpful page about dealing with grief -- http://www.elisabethkublerross.com/pages/AboutGrief.html

4) ***Remember to Breathe***

Silly as it may sound, the best first aid for stress is breathing. You might want to ask a friend to learn the techniques with you, and remind you to breathe. This is something you can do anywhere – in person, on the phone, in the car, even in the sick room.

As demonstrated by Dr. Baker during this interview, the easiest way is simply to sit quietly. Listen to the sound of your breath. Breathe slowly in for a count of three, hold the breath for a count of three, and let the breath out slowly over a count of six.

There are some excellent books and audio programs to assist you in focusing on breathing and de-stress your mind and body:

- Andrew Weil, M.D., The Art and Science of Breathing http://www.drweil.com/drw/u/id/ART00521
- Andrew Weil, M.D., *Breathing: The Master Key to Self Healing* (book)
- Jon Kabat-Zinn, M.D., *Full Catastrophe Living, Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness* (book) and related audio programs
- Joan Z. Borysenko, Ph.D., *Minding the Body, Mending the Mind* (book) and related audio programs

5) ***Support Options for Caregivers***

Optimally, if the patient is willing to negotiate the changes in roles and responsibilities, the best option is to work out a new plan with your partner. Most of the time, though, this is not a possibility. The patient may be swamped with stresses of his or her own, and not able to think about the state of anyone outside him or herself. Or there may be very real modifications in the patient's thought processes – the result of the disease process or dementia. This is not always clear – the patient may be unaware of changes in the thought process, and may be highly resistant to such a suggestion. The caregiver has to acknowledge the reality, and enlist the help of someone who is more objective in the situation.

This could be a friend, a religious advisor, a mental health professional, a social worker. It might also be a support group in the local area, a telephone hotline, or a "virtual" support group on the internet.

Some good sources of support in your area:

- Ask the social work department at the hospital for a support group for caregivers. These are most frequently available around cancer or Alzheimer's, but both groups will welcome people dealing with similar diseases.
- Ask your religious advisor, or the Jewish Community Center or United Way
- Call the American Cancer Society or the Alzheimer's Association office nearest you. Both groups welcome people dealing with similar diseases.
    - American Cancer Society http://www.cancer.org, click on "In My Community"
    - Alzheimer's Association http://alz.org, click on "Find us Anywhere"

Some good sources of support on the internet:

Even if you can't leave the house or go far from the hospital room, you might be able to access the internet to find support. Hospitals usually have connectivity either from the patient's room or from a family lounge nearby.

- The support organization for the disease you are dealing with, like for example, the VHL Family Alliance http://www.vhl.org
- The Well Spouse Association http://www.wellspouse.org/
- Family Caregiver Support Network, http://www.caregiversupportnetwork.org
- Caregiver.com is a source of support and information for those caring for people with schizophrenia and other diseases. http://www.caregiver.com
- Family Caregiver Alliance, http://www.caregiver.org, click on :"groups" to find four online support groups for caregivers.