



An Area Agency on Aging

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Mission

To provide a comprehensive and coordinated system of services designed to promote the independence and dignity of older persons and their families in Muskegon, Oceana, and Ottawa – a mission compelling us to target older persons in greatest need but to advocate for all.



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Caregiving by Men: A Husband's Perspective

by Seth B. Goldsmith, Sc.D., J.D.

The formal diagnosis of ovarian cancer was confirmed after seven hours of surgery at Boston's Brigham and Women's Hospital. Prior to receiving that devastating news, we were in the land of possibilities, probabilities, and suspiciousness in large measure due to the inconclusiveness of blood tests, ultrasounds and CT scans.

For the next five and a half years, Sandra and I struggled with hope, disappointment, fifty hospital admissions, two other major surgeries, countless minor procedures, and two changes of physicians. And throughout these years, until her death, we had to function as a family, work, pay bills, go to school, be effective parents to our two teenage sons and assist our aging parents and a disabled sibling—in other words, live life. Additionally, for significant periods during those years, I became a caregiver.

In the ten years since Sandra's passing, I have been consulted by friends and family who are going through similar experiences. Most recently, a business colleague told me that his wife just had surgery for ovarian cancer, and I started sharing with him my observations about a husband or significant other's job when a loved one is stricken with cancer. Those conversations led me to prepare this article on ten steps for effective caregiving.

STEP #1 EDUCATE YOURSELF

Being an effective caregiver is a proactive job. It is imperative that the caregiver becomes an expert on the disease, particularly when the person with the disease is physically and emotionally drained from the diagnosis and treatment. This means reading the consumer-oriented literature from various relevant organizations, plus reading professional literature.

Some of this literature is available on the general search engines, but it is also useful to try the sites medical professionals use such as MEDLINE and MEDLARS.

Understanding these articles will be a new challenge. Initially many of them will, because of their technical nature, appear to be gibberish. However, within a few weeks of starting this self-education project the articles will start making some sense.

A final way to educate yourself is to attend professional meetings or at least obtain the professional meeting abstracts. The reason for this is also to identify, meet and talk with the cutting-edge researchers so that you will have resources for second or third opinions or perhaps to select a new physician.

STEP #2 BE ASSERTIVE (THIS IS TIME FOR SERIOUS CHUTZPAH)

Do not be a passive recipient of care. Ask questions, consider alternative approaches, and get second opinions. When someone you love is receiving care for a serious illness, they are often in a dependent and weakened state and the caregiver is the advocate. Effective advocacy is not about winning a popularity contest for most compliant patient, but rather always finding out what is in the best interests of the sick person.

Physician loyalty is good, but never put that ahead of the main objective; that is getting the best quality care for your loved one. For example, at one point we consulted

a highly regarded professor of gynecologic oncology who gave us advice which, if followed, would have shortened Sandra's life by 15 months. It was only by seeking a second and third opinion did we learn that he was simply ill informed about the therapy. In our situation, the second opinion was from an oncologist 400 miles away and the third from someone 1500 miles away. So, a willingness to go the extra mile, literally and figuratively, is an essential step in getting good care.

In another personal example of assertiveness, I am reminded of a Friday evening, when in response to my wife's severe pain, the oncologist ordered morphine for her which was later delivered by a home health nurse. Within sixty seconds of arriving at our house, the nurse had placed the box of syringes on the table, told me that I should use them as per the instructions inside the box and "have a nice weekend." I stopped her as she was reaching for the doorknob and asked if she would show me exactly how to use the preloaded single dose syringes (up until this point, I have been filling syringes from vials). She explained it was very simple: "Just open the container and use it." I demanded that we examine the new system more closely and it turned out that it was not all that simple. Indeed, the nurse eventually admitted that she could not understand the instructions in the box. Next, she called the home care pharmacist who also had to read the instructions and together they figured out the mechanism for using the system. Finally, over an hour later, the home care nurse was ready to train me on using this new system.

Assertiveness is also making phone calls to strangers, particularly researchers, who may be working on something you want to know about. I have done this numerous times and always found that a polite and honest conversation about a loved one's health will be well received.

STEP #3 UNDERSTAND THE THEORY OF DIFFUSION OF INNOVATION

The concept of diffusion of innovation is that new clinical treatments are not uniformly adapted throughout the health system. Typically, there are centers of innovation, early adopters of innovation, mid-term adopters and eventually late adopters of innovation.

Since time is both your best friend and worst enemy, it is imperative that caregivers be knowledgeable about what is being developed. Often years elapse between the first stages of research and the time of publication of research results. Consider the history of Taxol. Today Taxol is a first line drug for breast and ovarian cancer. Its long and complicated history began in 1962 when the first samples of the pacific yew tree bark and needles were collected. Twenty-two years later, in 1984, after an enormous amount of research, it began its first Phase I clinical trials to see if it was a useful drug. It took another nine years, until January 1993, before it was generally available for other than experimental purposes. It then took another period before it found its way out of the academic medical centers to the corner oncologist.

It is imperative to know that it may take several years merely to prepare an article for professional publication, have it go through the peer review process and then have it published. For the proactive caregiver, knowing what is on the horizon provides a leg up if it is necessary to go for some new medications or procedures that are not available in your community.

STEP #4 RECOGNIZE FEAR, ANGER AND FRUSTRATION

Anyone who has a diagnosis of cancer is fearful and often angry. Why me? Is a common question. Some people with cancer also blame others; "If there wasn't



January's Website

www.caregiverslibrary.org

Quotes

"To read a poem in January is as lovely as to go for a walk in June."

Jean Paul

"The magic in new beginnings is truly the most powerful of them all."

Josiyah Martin

"This is a new year. A new beginning. And things will change."

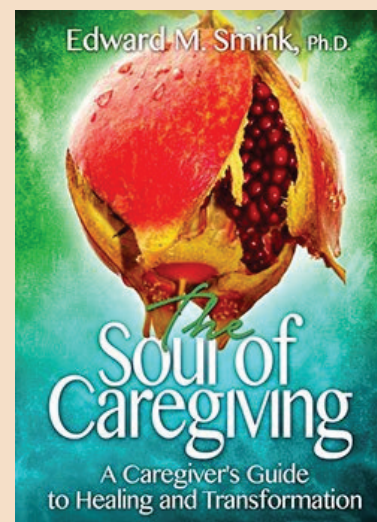
Taylor Swift

This Month's Book

Soul of Caregiving

by Edward M. Smink, Ph.D.

Who are the caregivers? We all are, for at the heart of being human is the capacity to care, to reach out to others and explore the relationships we build. The Soul of Caregiving is about us.



Communicating with Someone with Dementia

There are four basic things you can do to make it easier to communicate with a person with dementia.

- 1. Avoid distractions.** Speak to the person in a room that is quiet. Turn off the TV and radio. Stop any other tasks you are doing and focus your attention on the conversation.
- 2. Use non-verbal cues.** Make eye contact with your loved one, and smile. This is very important. It can help put them at ease. Facial expressions and tone of voice can help communicate messages if it is hard for your loved one to understand sentences.
- 3. Simple messages.** Talk about one thing at a time. Use short sentences and give directions one step at a time. Give your loved one specific options like “would you like a cup of coffee or tea?”
- 4. Listen actively.** If you don’t understand what your loved one said, politely let them know. You can also repeat back what you understood and ask them if it is correct.

Other strategies to keep in mind are:

- **Always use names.** Introduce yourself when talking to a loved one with dementia. For example, “Hi Mom, it’s me, Ben”. Avoid using pronouns like he, she, or they. Instead, use names when telling stories.
- **Start conversations.** You may notice that your loved one is talking less. Start a conversation with them about a topic that you would both like to discuss.
- **Try not to argue.** If the person says something you don’t agree with or isn’t true, you can let it go. If you constantly correct them, you likely will not have a good conversation. It can be helpful to try to find the meaning or message behind what your loved one said, instead of focusing on the facts.

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so much stress in my life, I wouldn’t now be sick.” My experiences suggest that all you can do is validate that fear or anger. Trying to be logical or scientific does nothing but add fuel to the fear or anger. If possible, some type of therapy, particularly support groups for the entire family, should be considered.

In most instances, the caregiver is equally fearful and angry. While it is clearly useful to share these emotions with therapists and in a caregiver support group, one should be more circumspect in sharing it with the victim. Frankly, they have enough on their plate dealing with their own issues. As another friend put it simply, “The caregiver has to be the rock, the foundation of the family, and who needs a crumbling foundation?”

STEP #5 FORGET STATISTICS

There is only one statistic that counts, whether you are alive or dead! Articles and physicians like to talk of survival rates, but these numbers are not relevant since one’s only concern is not the cohort’s survival but rather the individual’s survival. So even if the five-year survival rate for ovarian cancer is 15 percent, what difference does it make if you are not one of the survivors?

STEP #6 STAY STRONG EMOTIONALLY AND PHYSICALLY

Being a caregiver is tough work. Most of us find that we still have to do our outside jobs and we’ve picked up a full-time inside job. Obviously when Sandra was feeling well, the job was undemanding. On the other hand, there were times, particularly in the last 18 months, when being a caregiver was exhausting and frustrating work. It is also hard work to be someone else’s advocate, but we must always remember that our advocacy may indeed make the difference between life and death!

Under no circumstances should you be a hermit. For me, as for many men, work became an important social outlet. Initially I was afraid to tell people what I was going through, but as I opened to a few colleagues, I found them to be an enormous source of support for which I will be eternally grateful.

Finally, being physically healthy is as important as emotional health. I don’t need to spend much time on what we all know: eating right and exercise. Unfortunately for me, I would find solace in “comfort food” and be too tired to exercise. My only advice is fight for your own health—it is critical for you and your family.

STEP #7 EXPLORE ALTERNATIVE AND COMPLEMENTARY APPROACHES

The history of Taxol is truly a story of alternative medicine. After all, what was the search that found Taxol about but examining thousands of plants to see if one of them might yield a possible answer? So, there is much we do not yet know and a great deal of alternative and complementary medicine that may be helpful or at least comforting.

In our personal journey, we never stopped the traditional medical treatments, but did go regularly to a Chinese physician who specialized in herbal medicines. Additionally, Sandra spent a week at Deepak Chopra's Ayurveda Medicine center, regularly meditated and periodically had massages. Obviously, it is impossible to know whether any of this helped her physiologically, but I can attest to the fact that she felt it was emotionally important to her.

STEP #8 TAKE CARE OF THE PAPERWORK, WILLS, FUNERALS, ETC.

This is heavy lifting. Perhaps this is the attorney in me, but I urge all families to put their "business" houses in order. This means preparing wills and trusts if necessary and arranging all manner of end stage issues such as deciding who will be the health care proxy, what are the requests for heroic interventions and DNR orders, decisions on custody of children (in worst case scenarios) and finally funeral arrangements.

When death occurs, the last thing in the world you want to be doing is rushing off to a mortuary and listening to a funeral director discuss the 20 options for caskets, liners, limos, services, etc. Take care of this rotten business at a more opportune time and then forget about it!

STEP #9 BE OPTIMISTIC/COMMIT TO THE FUTURE

There is absolutely no value in pessimism. It brings both you and your loved one into an unhelpful and paralyzing place. Many of us who are faced with these enormous challenges have found it helpful to take concrete actions that indicate this commitment. For example, I have seen people buy new cars, take long postponed trips, purchase new houses and, in our own case, finally, after more than a decade of vacillation, build a huge and beautiful addition to our 100-year-old home.

STEP #10 FIND A SPIRITUAL FOCUS

A saying that came out of World War II and most recently applied to Hurricane Katrina was "there are no atheists in foxholes or hurricanes." The obvious point is that when we are faced with deadly situations, we are likely to look for support or solace in a higher spiritual order. In my own case, this trust in a higher spiritual power provided a measure of solace, a focus for prayer and an avenue for my rage.

While life may not always be fair, the crisis generated by a serious illness does indeed provide the caregiver with extraordinary and very real opportunities to demonstrate love. The demonstration of love for another will provide a lifetime of rewards for everyone, but in order to maximize its benefits, the caregiver must learn how to be effective for themselves and their loved one. My hope is that this article is a step (or perhaps ten steps) in that direction. ❖

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Is it okay to lie to your loved one?

Conflicts may happen when a person with dementia believes something that the caregiver knows is not accurate. As dementia progresses, it is common for a person with dementia to ask questions about parents or spouses who have died. It is also common for people to talk about work, even if they have been retired for many years. These topics can come up many times a day, and each time caregivers are faced with a dilemma: is it okay to lie to their loved one to avoid arguments?

Telling the truth is an important value, but there are times when telling the truth causes more problems and has little benefit.

When you are responding to a loved one, you should consider the short-term and long-term effects of telling the truth versus not telling the truth. You should also consider what your loved one would want to experience.

Challenging Conversations Strategies

One option is to respond to feelings or emotions instead of facts. Remind yourself that even if the facts aren't real, the feelings that your loved one has are real. If your loved one is asking to see someone or go somewhere, it is often because they have an unmet physical or emotional need.

Another option is to redirect the conversation. To do this, you can start to talk to your loved one about a similar topic or an unrelated topic. If your loved one is worried about getting to work on time, you can ask them to tell you what their job is like.

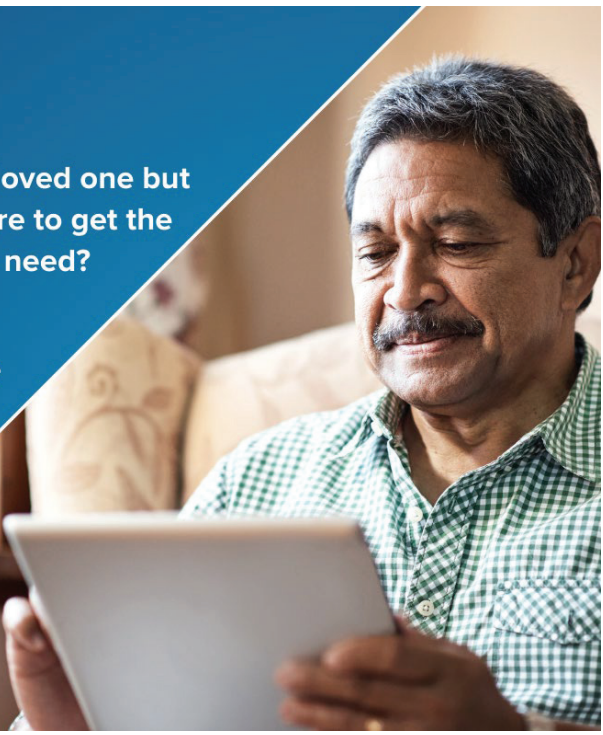
A third option is to use distraction. Try to get your loved one to focus on another conversation or activity. For instance, you could tell them that they need to have a snack before they go out, point out something you see outside the window, or get them to engage in a fun activity. ❖



Caring for your loved one but don't know where to get the information you need?

Start with this free caregiving resource

Free caregiving resource!



Practical advice to care for your loved one.

Trualta's Caregiver Portal shows you how to manage aging at home

Sign up for free!

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