

Care Giving: Perspective from a Trench

Janet Ferree

PS-8420 Anti-Oppression, Pastoral Care, and Aging



“And do you take Goldie, to be your lawfully wedded primary caregiver?”

There is much information to be found on care-giving, care-givers, and self-care. There are twelve-step programs for care-givers and self-help manuals to prevent burn-out. Therapists are trained to help with stress associated with caring for another individual as well as protecting themselves from the strains of counseling. And the medical profession has conducted studies intended to shed light on areas that point to possible future medical needs of caregivers—especially the elderly who care for elderly—brought about by stress. But one under-represented area of study and service is the pastoral care of caregivers. How are caregivers seeing God in their lives, in the face of daily physical and mental turmoil, and how might a minister or clergy member offer emotional respite and comfort to those whose lives have been put under lock and key?

The term “care-giver” consists of two concepts, one rooted in idealism and the other reality. Especially around the holidays, magazines and newspapers display photos of happy, generous people helping others as pleas for financial assistance interweave with background stories designed to evoke pity on the victim and canonize the caregiver. Who could refuse donating money to a frail elderly Alzheimer’s patient, face fixed in an endearing pose, with her full-gown daughter doting on her in unaffected bliss while her grandchildren stand behind her in a bare but adequate room waiting to hold a festive family gathering—if they could afford food and a warm blanket for grandmother? Or the cancer patient whose wife remains by his side day-in and day-out without affordable respite care, tending to him in every sense of the word as his body slowly spirals downward out of control? While these scenes are accurate, they are likely to be fleeting moments escaping the timeline of perpetual home health care demands. Behind the scenes caregivers wrestle with issues of financial and emotional stability, along with the biggest dilemma of all: end of life issues.

Ideally, one would want to give—and be the recipient of—care that mirrors tenderness, affection, and compassion, whether independently wealthy or not. When a person is ill and/or dying they are faced with losing all they have—loved-ones included. The mental and emotional changes further decay the morale of the sick individual, making the situation utterly miserable. This is when patience and diligent love is most needed. And this is when reality can undermine the deepest emotional bonds between caregiver and receiver (I will refer to caregivers as CGs and care-receivers as CRs for the rest of this paper)—especially if it between a husband and wife. If one digs even slightly behind the stories mentioned above, a history emerges and the picture changes. Using myself as an example, I can tell you feelings regarding not just the care of a sick spouse, but the CG as well, are impacted by the necessity of full-time attention.

The View from a Trench

Never in my marriage did I really think about the, “...for better or worse, in sickness and in health” vow I made 29 years ago. Those were poetic lines, abstract concepts that either wouldn’t be an issue or were so far into the future that it still wouldn’t be an issue. At 26 years of age, being old is a theory, and being sick happens to other people. I was going to age actively and gracefully with my beloved until we were 100 years old. I was wrong. Twenty years later, cancer would strike my husband and I would become a caregiver.

Suddenly the responsibility for the emotional welfare of him and our teenage children fell to me. As they scattered to various colleges and established residences away from home I became responsible for their emotional support, the bills, the house and yard work, maintaining the cars, sorting out banking issues (too many accounts, not enough money in any of them), doing the taxes, etc. I also had to run to doctor appointments, try to keep family and friends in the picture,

make the house safe, work part-time and go to school full-time, and prepare myself and my children for my husband's death. When the cancer spread to his brain it became a matter of months before I would become a widow. Stark white fear gripped me. Decisions about life-support had to be considered, advanced directives needed to be signed, and wills had to be drawn-up. I had to locate the life insurance policy and change the way ownership of our home was filed to avoid huge taxes. Then it all went away; the cancer stopped. That's when the care-giving started in earnest.

When first confronted with the 24/7 status of caring for someone sick—whether in person or telepathically (one never fully shuts off)—the newness, the shock, the flash-bang of a suddenly descended reality can bring about an adrenaline rush that is remarkably therapeutic.¹ It insulated me from comprehending the strain I was under and created the energy I needed to continue. As the result of the treatment that spared his life, my husband is fully disabled with limited mobility, hearing loss, and mental diminishment. He can't work, or be left alone very long. And I am going crazy. Guilt hyperlinks everything I do and think. I warn the kids to do what they have to do to survive this, and to expect guilt-feeling no matter what they do, but to try to keep the damage down. In other words, be careful what you do or say...it will haunt you later. Good advice from newly acquired wisdom!

Care-giving, I soon learned, didn't end at absorbing two peoples financial and household responsibilities. Before long I had to make special arrangements for my husband to eat, put up grab bars all through the house to minimize his risk of falling, and get a hospital bed so he wouldn't struggle like a Bobbing Bird to get up. After wandering in a semi-awake state "talking"

¹ Jeanie Lerche Davis, Coping With Anxiety, 11 December 2009, available from <http://www.webmd.com/anxiety-panic/guide/coping-with-anxiety>; Internet; accessed 11 December 2009.

to an attorney about a trial case one night, I hid the guns (we was a police officer) in the event his next nocturnal living-room side-bar was preceded by a felony traffic stop on one of the kids. These changes gave entry for more: forced personal hygiene, spilled food, stumbling gait, and spontaneous vomiting, even in public places—restaurants being a favorite location. The physical hazards to my own body were increasing from holding-up 200 lbs of stubborn ex-marine/cop. My shoulders became weak, neck spasms plagued me, and depression set in. Wheelchairs and walkers arrived to make movement easier, yet offered their own hazards. Tossing a wheelchair up onto the bed of a pick-up, folding and unfolding a walker, and dismantling a scooter for transport all add time—and frustration/annoyance—to the simplest outing. Next to arrive was the toilet seat riser. It allows for easier positioning on the toilet, but bolts down so tightly that cleaning entails flossing between it and the bowl.

The list goes on, and each new gizmo and gadget designed to make life easier for my husband made mine more stressful. The white fear I experienced when I learned of his cancer and expected death came roaring back, only this time the fear addressed the reality that he *wasn't* going to die.

In a husband and wife caregiver situation the dynamics of marriage change. Established roles suddenly morph into parent/child or nurse/patient relationships. What used to be a marriage comes dangerously close to resembling a divorce, but without freedom to walk-away. When a spouse becomes ill, the CG spouse assumes all responsibilities, leaving little time for self-care. A San Jose Mercury News article interviewed a woman who candidly explained one of these major fallouts of care-giving: role changes. A vibrant and active wife suddenly found

herself in “care-giver mode”² and her love “changed from romantic to maternal.” It ended her marriage, but she remains her ex-husband’s aid and advocate. If this pattern becomes drawn-out for months or years the danger of infantilizing the CR mounts, mainly because it’s easier to do everything than struggle to allow the CR to do it his- or herself and spend time waiting for the task to be finished and/or cleaning-up afterwards. As a result, the CG is increasingly resentful, frustrated, exhausted, and lonely: vulnerable to finding emotional nurturing in the arms of another, and positioned for burn-out.

What About God?

Where do CGs place God in all of this? People who seek guidance and assistance from clergy and ministers may or may not come with solid beliefs about God. Illnesses and the giving-up of a one’s individuality are times when the existence of God gets called into question and the form God takes comes to the forefront. Notions of God revealed by CRs such as cancer patients can also be present among CGs, often times dredging-up images of God as protector, as Punisher, as Final Judgment.³ Thus, questions like, “What have I done wrong to deserve this? Why us? Can’t I pray it away? Why won’t God cure him/her?” become pivotal in the search for answers, validation, and relief. What then, in a pastoral setting, can be done to help a caregiver who has lost interest in caring and doubts all s/he has ever believed about God’s love?

Suggestions for Pastoral Counselors

In my experience, only the very devout and the very desperate seek spiritual guidance in times of crisis. When people have imperative needs to reason-out their beliefs about God it’s

² Bruce Newman, “Relearning How to Live: San Jose Non-profit Assists People Who Have Suffered Brain Injuries,” *San Jose Mercury News*, 12 December 2009, sec. A, p.10.

³ Jann Aldredge-Clanton, *Counseling People With Cancer* (Louisville: Westminster John Knox Press, 1998), 25.

important to get the full story that prompts the inquiry. But sometimes no specific reasoning is being sought. Sometime people might only need someone associated with church to lend an ear and make them feel less contemptible for having the feelings they do. As such, when a CG approaches a pastoral worker/counselor for advice or simply for someone safe with whom to speak, I offer the following suggestions:

1) Listen. A CG is sitting with you because s/he needs to talk/vent/share, and to have that framed by you within a religious context. They are using you as a confidant, someone whom they believe by virtue of being associated with a religion they trust, has “inside information” about God. According to Maya Hennessy, confidants are not afraid of emotions⁴ and as such can be trusted to hear everything without judging (Beware of facial expressions suggesting a negative response to the CG’s feelings).

2) Inquire. I advise not re-phrasing what the person says to you in an attempt to show them you hear them. This can undermine the discussion if the person knows anything about counseling strategies. The CG needs you as a religious person responding to them, not someone working from a professional model of interaction. Ask this particular question—possibly at the end of the session--with the option for the CG to refrain from responding: *Is there anything you want to say that you simply can't say to anyone else out of fear of being misunderstood and condemned?* Don't flinch if the CG says s/he wished the loved-one would die. This is a feeling that resides in every CG I have known and is rarely voiced because of the fear, pain, anguish, guilt, and assorted other impaling emotions that happen to the CG as well as the unprepared hearer. CGs need to be able to voice this feeling, and it always comes wrapped in guilt. Personal experience has taught me that what is really being said is the CG wants his or her life back. The CR is no

⁴ Maya Hennessy, *If Only I'd Had This Caregiving Book* (Bloomington: AuthorHouse, 2006), 47.

longer the person he or she used to be; quite often a phantom has taken-up residence where Mom once resided. The CG is left caring for a stranger—and not always a nice one. One woman, caring for her 6’4” firefighter-husband with a brain tumor, found herself running from him as he pursued her through the house with a butcher knife. She lived in constant fear and didn’t want to risk the life and safety of others to stay with him so she could leave. Guilt and finances prevented her from seeking institutional care. When she cleared the home of all sharp objects, he found a hammer.

When someone says she wishes her husband would die it can result from the agony of watching a loved-one suffer, from the fatigue of caring both physically and emotionally for an adult, and the desire to move on with life. The former spouse/parent is gone. Often the CG and family has already grieved the loss but are forced to remain in care-giver limbo—and the emotional and psychological damage from living a suspended life can be paralleled with indentured servitude. Feelings of hopelessness and mourning one’s lost future are common.

3) Invite laughter when appropriate. Humor is therapeutic. Encourage the CG to laugh as often as comfort allows. For instance, after listening to my concerns, a nun offered to take my husband for a walk along the cliffs of Big Sur, knowing he stumbles often. Another example on the dark side is my grown daughter, smiling at my frustration and anger from being a CG for her father, saying, “Pine-sol, Mommy. Put some in his coffee.” It has since become the family “code” that breaks the mood and brings smiles. The humor comes from the ridiculousness of such comments, not from any harm being wished. From a medical perspective, WebMD says, *“Humor therapy is also valuable as a preventive measure for the caregivers of people with chronic diseases. Caregivers are at high risk of becoming sick themselves, and humor therapy*

*can help release the stress that comes from being a caregiver. Caregivers and those they care for can practice humor therapy together, and they both are likely to have better health as a result.”*⁵

4) Ask: *How do you see God in all of this? Do you feel you are being punished? Are you losing faith? What do you see in terms of an afterlife?* Church can be a strong force that some may see as the brandishing of theological weapons. As a counselor/confidant, peel away the layers of human-developed dogma about God and work from scriptures and images that reinforce love and cohesiveness among all aspects of life; when the human individual is abstracted away from the greater creation-picture, feelings of possible death can be more alienating and hoped for an afterlife can fade. CG thoughts that bring about self-condemnation by virtue of believing God’s will is being played out to the detriment of the CG is not healthy for anyone—the Church included. This is where the Twelve Step Program⁶ for care-givers can be helpful. It gives clear guidelines for steering thoughts about God away from the negative and towards relief of emotional burdens. Where the CG may speak of indecisiveness towards the use or removal of life support, try to dialogue about what s/he believes about life after death, and if making a decision about removing life support in any way impacts these beliefs.

5) Don’t baby or placate the caregiver. By the time s/he approaches someone for religious and spiritual advice it is either at the very beginning of the care experience and is overwhelmed, or when s/he is at wit’s end and wants to run away from it. Exhibiting pity or overflowing streams of concern at these times are often not helpful. They can be quite the opposite. Overwhelming emotions need to be met with kindness and calm strength, not thick and syrupy endearment. Don’t try to get them to like or want to continue taking care of a loved one—it isn’t usually

⁵ WebMD, Humor Therapy-Topic Overview, 27 June 2007. Available from <http://www.webmd.com/balance/tc/humor-therapy-topic-overview>. Accessed 11 December 2009.

⁶ Samples, Pat, et.al. *Self-Care for Caregivers: A Twelve Step Approach*, (Center City: Hazelden, 1991)

something that can be opted out of, anyway. Suggesting ways to make it pleasant or “holy” will only leave a person feeling more guilt, possibly placing a wedge between the CG and God.

6) Ask: *Would you be interested in either speaking to a parishioner who is experiencing the same situation as you, or would you be comfortable having someone new to care-giving look to you for insights and advice?* Sometimes when those who suffer use their experience to help others it is empowering, giving back some strength, some control, and a sense of purpose. It can be helpful in gaining a new perspective on one’s own dilemma by stepping away as sufferer and recognizing all the strategies, techniques, and skills that have been acquired, thus constructing a bridge from vulnerability to enhanced personal strength. There is also safety among CGs. One woman with whom I was having lunch said as a matter of normal conversation, “I wish he would die and be done with it.” She then set her fork down and looked at me, saying I was the only person she could say this to because she knows I understand. Scenes like this can offer far better release from anxiety and guilt than professional counseling sessions and should be encouraged.

7) *How is the CGs health?* It has been shown that CGs run a substantial risk for health-related issues associated with the physical tasks and personal neglect that accompany caring for another person for prolonged periods of time. One study on women caregivers supports the conclusion that care-giving is a women’s health issue.⁷ Further studies have demonstrated the necessity for a medical/professional way to assess the stress on individuals associated with care-giving and an example of such an assessment can be seen in the Modified Caregiver Strain Index.⁸ The Index offers a series of question relating to changes in the CGs life ranging from sleep disturbance to financial strain to feeling overwhelmed and each is given a rating of “yes,” “sometimes,” or “no”

⁷ Judith Wuest et al., “The Effects of Past Relationship and Obligation on Health and Health Promotion in Women Caregivers of Adult Family Members,” *Advances in Nursing Science*, (2007): 206-20.

⁸ Lisa L. Onega, “Why Assess for Strain in Family Caregivers? *American Journal of Nursing*, 108 (2008) 64-69.

and each answered is given a numerical weight. The purpose for such studies is to establish a baseline from which to identify and monitor areas of great stress that can result in the CGs health compromise. When CGs are aware of such studies it can give validation to any physical symptoms they may be experiencing and might prompt closer medical tracking of themselves.

8) *Offer practical advice.* Chances are the CG is doing what s/he can to find private time but it usually isn't enough. But it's important to gently remind them to take time daily for themselves. Suggest using the CR's nap time to do what brings them pleasure, *not housework*. Perhaps a box or trunk can hold activities that renew the spirit and give a sense of creating. I learned to make soap as a way to feel not only in control of something, but to create something new and useful in the face of human disease and disability. Watch happy movies with upbeat endings. Take a class in something you've always been interested in—even if it's on-line. Have coffee with “normal” people. Buy clay and clutter the windowsill with odd little objects that can absorb your stress. And if the CG is really good to themselves they might consider a massage on a regular basis, a trip to the nail salon (men, too!) or a pedicure where the feet are massaged. It's imperative to have something of personal interest to draw the mind away from illness and disability. The CG must climb back on top of his or her life and take control, even if it means shifting the importance of their relationship with the CR to themselves. After all, if the CG is destroyed the CR is in trouble. Think of a life guard—s/he must stay far enough away from, or be positioned in back of, a drowning person so as to avoid being pulled under water and drowned along with the victim. The cold hard fact is, if the CG is destroyed along with the CR, two lives have fallen instead of just one and the remaining family is left to endure the fallout.

9) One final area to discuss is the CG's feeling about end-of-life issues. In addition to wondering who will be left to take care of the CG when s/he requires care, s/he may be faced with having to

remove—or refusing to remove—life support from the CR and needs to examine her or his feeling and attitude towards it and how those feelings may conflict with those of other family members and individual religious views. In this situation I advise that unless the pastoral counselor has some expertise in the matter, it is best to listen and discuss the options the CG brings up in hopes of leading him/her to clarity within their own mind, although the CG might be referred to their primary care provider for information on palliative and hospice care which can assist in tough decision making.

Care for the Counselor

For the pastoral counselor, I recommend a book entitled *The Resilient Practitioner*.⁹ It offers practical strategies for avoiding burn-out yourself. The chapters discuss the importance of self-preservation (which may also be helpful for the CG seeking your help), the balance of self/other care, and the need for laughter and the importance of self-renewal. Since this type of counseling is itself *care-giving*, you as pastoral counselor, professional or not, are now a CG and subject to many of the same stresses as those living with the direct physical care of a loved one. Without proper balance—which is much easier in theory than in practice—the counselor can fall out of control and into the trenches him- or herself. It can become more difficult when a parishioner is a “pew-friend,” or neighbor and thus the boundaries may blur, making it difficult to remain removed from the CG far enough to be helpful. This can strain the strength and kindness needed to help the CG make sense of the situation in a theological framework, and can spill over into *your* private life. The temptation (and tendency) to disengage from those with problems outside of what you must confront becomes powerful. I have one friend and one cousin who’s phone

⁹ Skovholt, Thomas M., *The Resilient Practitioner* (Needham Heights: Allyn and Bacon, 2001).

calls I hide from because I cannot deal with more misfortune—which is a signal that I am burning-out and should reread this book.

On a Positive Note

Being a care-giver has had its rewards. By releasing my stranglehold and ownership on family and the medical profession, I can see the hands of God keeping my feet dry in the trench. I've learned I can't make my husband be how he used to be so I quit trying; Now I must learn to appreciate the man I have in his place. My faith in God has soared in spite of my resentment of the situation, and I've learned to reflect on the bigger picture during the one or two quiet moments I have each week, and thank God for what *is* rather than be angry for the loss of what was and what will never be.

On the practical side, I've learned to change the oil in the cars and purchase a car without getting taken advantage of by virtue of my gender; I am an ace with finances, managing to put three children plus myself through college, pay the mortgage and stay out of debt by paying cash for everything; I can balance time like a professional and squeeze in work, school, study, prepare three meals, housework, get the dog to the vet, bathe my husband, and spend quiet time with him before I collapse into bed; I can hire a contractor and secure a good deal, put on a wedding for my daughter, and personally assist converting the garage into useful space; I can sheetrock, tape, and texture walls; I can use my husband's *reach-extender* to remove a water-drenched dead rat gift-offering by my bed at 4:00 a.m. during a storm and flick it outside—though I did force my husband to wake-up and listen to me panic. And after all of this, I can remain a Mass Coordinator at my parish without wondering (very often) if there is a God.

But the most positive outcome so far is that I have complete trust in God that this ordeal serves some purpose, even if my husband and I aren't the ones who directly benefit. In a pastoral setting, because of being in a high-visibility position during the Mass, I am approached by parishioners who share their stories—often times at the medical clinic where I work. My church connection has enabled me to assist other cancer patients and their families find their faith and face the reality of their situation. It has given me a platform from which I can share the most coveted of feelings in a safe and understood environment. And when I offer my husband's story of miraculous recovery, it not only inspires hope and, to be honest—dread for the caregiver but gives him/her a story of optimism to take home to their loved-ones, providing at least a few minutes of lightness and relief from an otherwise muddy existence within the trenches of care-giving.

Bibliography

Aldredge-Clanton, Jann, *Counseling People With Cancer*, Louisville: Westminster Press, 1998.

Davis, Jeanie Lerche, *Coping With Anxiety*, 11 December 2009, available from <http://www.webmd.com/anxiety-panic/guide/coping-with-anxiety>; Internet; accessed 11 December 2009.

Hennessey, Maya, *If Only I'd Had This Caregiving Book*, Bloomington: AuthorHouse, 2006.

Newman, Bruce, "Relearning How to Live: San Jose Non-profit Assists People Who Have Suffered Brain Injuries," *San Jose Mercury News*, 12 December 2009, sec. A, p.10.

Onega, Lisa, "Why Assess for Strain in Family Caregivers?" *American Journal of Nursing*, 108 (2008) 64-69.

Samples, Pat and Diane Larsen, *Self-Care for Caregivers: A Twelve Step Approach*, Center City: Hazelsen, 1991.

Skovholt, Thomas M., *The Resilient Practitioner*, Needham Heights: Allyn and Bacon, 2001.

WebMD, Humor Therapy-Topic Overview, 27 June 2007. Available from: <http://www.webmd.com/balance/tc/humor-therapy-topic-overview>. Accessed 11 December 2009.

Wuest, Judith, et al., The Effects of Past Relationship and Obligation on Health and Health Promotion in Women Caregivers of Adult Family Members, *Advances in Nursing Science*, (2007): 206-20.