

How Did I Become a Caregiver?

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Most of you are here today because you have reached a point in your relationship with another person that you realize, perhaps reluctantly, that you are now a caregiver in addition to whatever other role you have with the person for whom you care.

I'd like to invite you to take a moment and engage in what philosophers call a thought experiment.

Think back about the events in your life that have brought you to this conference?

Try to remember what changed along your journey that irreversibly altered how you see yourself in relation to the person for whom you care now? Whereas before you were a spouse, child, sibling, or friend, at what point did caregiver become part of your self-image.

Now, as uncomfortable or as painful as it may be, try to imagine how you would feel if you were not able to give the care to your loved one that she or he needs.

Though none of you would want to happen what has brought you to this place, all of you are committed, to paraphrase the late Tammy Wynette, to stand by your husband, wife, mother, father, brother, sister, grandparent, partner, or friend. That person for whom you care deeply is no longer totally able to tend to all of his or her

needs, and you are determined to compensate for those losses the best you can. You may not want to or can't bring yourself to imagine what lies ahead because at some level of your soul you fear that your loved is on a course that will ultimately go beyond your control and end in a separation that is too painful to contemplate.

Even though you resent the intrusion of the disease or condition of your loved one that has altered your dreams and expectations, you know that you don't want to be anywhere else, you want to do your best, expend your energy, demonstrate the depth and strength of your love, and meet the challenges of today and tomorrow with compassion and courage.

Hear me now and take to heart my counsel which will be repeated in many of the workshops throughout the day: you must, first and foremost, despite your instincts to the contrary, take care of yourself.

I suspect for many of you, your knee jerk reaction to my admonition may be along the following lines.

Oh, Dr. Shelp, I'll tend to myself when he or she no longer needs me.

Sickness and health, those were contingencies in our marriage that I vowed to face with fidelity and love. It is my duty to care for him or her and I don't want to impose on anyone to do what I want and am obligated to do. I keep my word.

My mother or father gave me life, sacrificed for me in countless ways, now I reciprocally owe it to her or him to provide the care that is needed.

These all are realistic and expected explanations of why you are doing what you do, but they are not reasons to not take care of yourself first. These types of excuses

and the complex and strong feelings that underlie them do not invalidate or refute the necessity of caring for yourself as a prerequisite or condition for caring for your loved one with the sensitivity, patience, compassion, tirelessness, and devotion that you desire.

The fact that you are here suggests that you realize at some level that you need information, resources, and insight in order to be the caregiver that you have pledged yourself to be.

Today is planned to be a time of renewal, education, affirmation, and empowerment for you. It is a time for you to realize that you are not alone, that countless others in this community and across this nation, are on a similar journey, and that all of us involved in this day want you to succeed as a caregiver, which includes a priority to and practices of caring for yourself.

Being here is one way to care for yourself. Exercising discipline in how you spend your time so as to include time with friends is another way to care for yourself. Maintaining contact and conversation with family and friends can secure those vital links to others that can overcome the social isolation that many caregivers experience. You can confide in trustworthy friends what is happening in your life, how you feel about it, and how you are responding to this unwanted challenge in your relationship. You can renew your spirit by continuing to draw upon the symbols, rites, and resources of your faith or spiritual beliefs. You can experience respite, a break from your caregiving work, by entrusting the care of your loved one to others for periods of time in which you engage in other activities that will help you face the challenges in the days

ahead. You can call upon the resources of agencies and programs for information and assistance, and you will realize that people care about and support you in your role. You can strive to not be consumed by the negative aspects of what is happening by being open to and discovering the blessings in caregiving and the opportunities within these travails to draw closer to your loved one. You can accept with gratitude the expressions of concern, support, and offers of assistance from friends and family as tangible declarations of their solidarity with you and affection for your loved one. You can find communion and encouragement in support groups for caregivers where you can learn that you are not the only person in the world going through this. Interfaith CarePartners and partner congregations here in the Woodlands will be starting several support groups that you are invited to attend. They are called Common Ground: Caregiver Conversations and if you want to learn more about this opportunity, see me or Becky Campbell at our table in the exhibit area.

These and other strategies may be required to sustain and refresh you so that you can care for your loved one. A disease or condition may be consuming your loved one. It would be an even greater tragedy if that disease or condition has a victory in consuming you too. You cannot control the outcome of the disease or condition that affects your loved one. You must entrust those interventions to medical personnel. You can, however, control how the disease or condition affects you, and you can strive with your loved one to secure and preserve throughout this journey those experiences, activities, and emotions that are most important to you.

All of your workshop leaders will provide you with information and tools that will assist you. Most, if not all, workshop leaders have been where you are. They have been caregivers and they understand your successes and disappointments, hope and despair, strengths and weaknesses, enthusiasm and fatigue, faith and doubt.

Our goal for this day as planners and presenters is to trumpet to you as powerfully as we can that you are not alone and you do not have to meet the challenges of caregiving by yourself, on your own, without a place or people to turn where you will feel the empathic embrace of others that will sustain you for your journey. Look around. You are people who may differ in many ways, but there is one feature that you share, one role that you all have in life, one commitment that binds you to another and together, and one journey into an uncertain future that you didn't ask for but lovingly accept. Each of you is one of a multitude of people who are caregivers.

Think about that term – caregiver. The role and work that you have assumed is morally noble and morally honorable. You do not seek a pedestal or praise. You seek only to serve and comfort as you and your loved one seek purpose and peace in your travail. And on behalf of those for whom you care, let me say as sincerely and profoundly as I can, thank you!

Several years ago in a training session, we were asked by the workshop leader to think of one word that described our experience as a caregiver. After a few minutes of quiet reflection, and some soft shedding of tears on the part of some, the leader divided a blackboard in half with headings of the words negative and positive. Then as we went around the room, reported our word, and told why we chose that word, it was written

on the board as a negative or positive experience. You can participate in this exercise now in your mind. What is your word that describes your experience until now?

As you might expect, a variety of words were reported. Negative words like exhausting, depleting, painful, angry, frustrating, hopeless, alone, duty, burden, fearful, and others were commonly spoken. There were fewer positive words spoken like blessing, grateful, closeness, growth, redeeming, joyful, and a few more.

I suspect you are wondering what my word was. It was satisfied. Satisfied didn't mean that I had escaped many of the list of negative experiences and feeling during the course of my service as a caregiver. And, it didn't mean that I experienced all of the positive experiences in the same way as other speakers did. But, on balance and in retrospect, I was satisfied or at peace with myself and my performance. I was satisfied that I had done the best I could in the circumstances. In the role of caregiver, I was not perfect. I made decisions and did things as I looked back and wished that I had chosen or performed differently. But in those moments, with the information and options that were available, I did the best I could. As I looked back at those times now seen as shortcomings, I forgave myself. The ability to forgive oneself and others is critical to stay the course as a caregiver and to reach that point where caregiving is a positive experience. I was satisfied without having been perfect. Looking back and even at the time, I was grateful for the special opportunity to care, love, and support each of my parents during their days of need.

Our hope for today is that you will gather some information, resources, skills, and wisdom that will help you be a caregiver that discovers the positive aspects of these

alternately trying and joyful days. Our hope is that you will both today and in a future day when the title caregiver no longer applies be able to look back on this experience, to remember and reflect upon all that you have done well and where you have fallen short, and say with gratitude and satisfaction, I did the best I could and that was good enough. My loved one expected nothing more of me. I expected nothing less of me. I cared for her or him and I cared for myself so that I could give my loved one the very best of me for as long as I was needed. You are not supermen and superwomen. You are loving people who are responding to one of life's many set backs. All you can do and all that is expected of you is to do the best you can.

I pray that God will bless and sustain you and your loved ones through these challenging days. It is my prayer that this day, in contrast to the days clouded by hurt, loss, fear, and fatigue, will be for you a day to be refreshed, revived, equipped, and affirmed. Seize it. Savor it. Allow all that you experience to lift your spirits, empower you, nourish you, and sustain you. You are not alone. There are people, programs, and agencies eager to assist and support you as you care for your loved one and care for yourself. Accept these offers of support as gifts to be treasured and used today and for as long as you need them.

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