The Heart of the Caregiver

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A Caregiver’s Journey

“To become a caregiver is to lose oneself - to live in the silent shadow of infirmity or disease ... it is in acknowledging this difficult task that you - the caregiver - are awarded your angel's wings.” (From my book, From Fear to Faith, A Caregiver’s Journey, endorsed by Hospice International) [1].

“I speak not of death and dying, but of life and living, each and every moment, with dignity, respect and faith, till the last breath.”

Joy

What was your experience like as a caregiver for your husband?

In 1998, just two months after retiring to Florida, my husband was diagnosed with a terminal disease. The words “6 months to live” changed our lives forever. No longer were we beginning a new life as carefree retirees; we were beginning a life that held spiritual, emotional and physical challenges. Our children were all quite a distance away and so I was the main caregiver. And it was a difficult fact to face, but no one really makes friends when death lingers at the doorstep. There were very few people who came to help, and those who did were truly Angels with their compassion and kindness. But for the most part, this care giving journey was one of alone-ness. Looking back, however, the solitude was a key component in allowing me to truly experience the role of caregiver. It was that “burning at the fire,” so to speak, that has brought me to where I am today - a passionate caregiver advocate.

Were you prepared for the difficult challenges and what did you learn?

There is truly no way to prepare to be a caregiver. The challenges arise so unexpectedly. Immediately one becomes a nurse, a social worker, a chaplain. My husband turned to me for spiritual strength and emotional counseling when in reality, I needed that for myself. I was unsure of myself in ministering to his physical needs, but learned a sense of humor is a basic pre-requisite for all caregivers. One cannot survive without it. I also discovered that if I could come from a place of Love, always tending to his needs with a Spirit of Love, I could not make a mistake. Love does conquer all!

I thought my husband's terminal illness was “all about him,” but I learned the process of dying is, indeed, a family affair. I learned about Family Dynamics and the different ways in which our 7 children dealt with the diagnosis and their father's deteriorating condition. It was important to tune in to their individual personalities, belief systems, and level of understanding about the process of his illness and subsequent death. On a personal level, the discovery that I was stronger than anticipated was a welcome surprise. I came to believe I could do anything!

Faith was also a key component to the success of this journey. Through daily affirmations, it became possible to keep my mind and heart centered on the spiritual path instead of on the physical path. Each morning, I would state my intentions for the day, even if they were as simple as “I will live in the moment,” or “Every thought and word today will be filled with compassion.” Those intentions provided guidelines for me because the physical loss, day by day, was too difficult to handle otherwise. They kept me centered on the “job” at hand.

I learned to be forgiving - of myself - each and every day - for my shortcomings and lapses of faith. It was necessary, as well, to be forgiving of my husband. He didn’t choose to be ill, and yet it is normal for the caregiver to harbor some resentment, disappointment and abandonment when a spouse, in particular, has caused their dreams to vanish under the cloud of disability, financial strain, emotional and spiritual challenges, and the unfathomable acceptance of death as inevitable.

I learned to live in the moment, not grieving for the past and not dreading the future - not giving any power to the imagination of “what if’s.” No one can predict the future, so living one day at a time - one moment at a time - was a good plan.

I learned it takes courage to be a caregiver - to stretch oneself emotionally, spiritually and physically. When my body ached from the lifting of his withered body, and I thought I could not lift him one more time, I called out for courage and strength. My life became a constant prayer - always asking, begging, pleading, for just one more moment of courage.

You describe five «cities» of transition through which people travel during any time of loss. Can you briefly describe each of those and

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why they are important in the process?

The "5 Cities" are Disbelief, Despair, Acceptance, Farewell and Triumph. When the doctor told us my husband had 6 months to live, I fell into that first city - the City of Disbelief. It truly is dark, cold and lonely. I felt the air literally leave my lungs and I grabbed my chest, feeling as though it was I who would die at any moment! I lived in that city for several weeks unable to process the words. They were too huge, too unbelievable. Looking back, it is important to live in that city for a while. It gives the body, mind and spirit time to recover from the shock of the diagnosis and time to create an inward plan for the outward journey. By that I mean, it gives the soul and spirit time to heal from the shock so one might live in the physical world - that of caregiving.

The second city, the City of Despair, is equally as cold and lonely; however, this is where one cries out for mercy, understanding, and allows the spirit to express the emotions. When my 6-year old grandson, Joshua, was diagnosed with cancer, my daughter kept allowing the spirit to express the emotions. When my 6-year old grandson, Joshua, was diagnosed with cancer, my daughter kept asking "Why?" She expressed her Disbelief - then her Despair. I allowed her to speak, to have that avenue of expression, to hear her speak the words that were taking up so much space in her heart. It is healthy to acknowledge these feelings, to hear one speak of those feelings to a safe "audience." In my daughter's situation, I was her safe audience. She needed understanding, not platitudes.

The third city is the City of Acceptance. It is warm and golden in that city because we have "given up the fight," so to speak. When all the tests and procedures to help "save" my husband were completed, we realized our energies would be better spent living with what we had rather than longing for what we didn't have. We didn't just give up - we simply re-directed our energies to the present moment, acknowledging the gifts we saw all around us.

The City of Farewell is the fourth city. With our parents, we often see a Farewell to their ability to care for themselves. If we are caring for someone who is handicapped, it's a Farewell to the life we envisioned for them - a healthy, vibrant life. In a relationship, it is a Farewell to what could have been. When we change jobs, move to a new neighborhood or state, it's a Farewell to all we have known. There are many different types of Farewells, but it's a city we live in. Once we acknowledge that we are in the City of Farewell, we can bend and sway with the changes rather than fighting them.

For me, the City of Farewell loomed before me for 2 years. (My husband's "6-month diagnosis" lasted 2 years). I often moved back and forth between the "cities," often visiting once again the City of Disbelief and Despair - and always knowing it was the City of Acceptance where I longed to be. Those 2 years gave me time to adjust mentally and spiritually, to prepare in some small way, for what I knew was inevitable.

The last City is the City of Triumph and it is a blessing to see it looming in the future. It is indistinguishable at first. The caregiver often cannot imagine any type of Triumph. In reality, each day of caregiving is a Triumph; each little success, each stepping stone, an exercise in spiritual growth. It takes paying attention or to use my favorite word, Awareness, of what is, and not a longing for what might have been.
this long goodbye?

That's called Anticipatory Grief - a lingering sense of loss during which time the caregiver rehearses the death scene and the possible consequences afterwards. The positive side of Anticipatory Grief is that it allows time to resolve issues and to say a proper goodbye. For me, I was able to give the children time with their father during which they could complete any unfinished business - “words left unsaid.” I wanted them to have the very best experience during a very difficult time. They told me afterwards this provided them with proper closure. They felt they had said and done everything they could to create a healthy goodbye.

In terms of professional caregivers in the institutional setting, how can they be best trained to compassionately and effectively care for their patients?

I have spent the last 11 years affirming and validating, nurturing and inspiring the caregiver. This includes the professional caregiver as well as the family caregiver. Professional staff who serve the sick, elderly, handicapped, and especially those at the end of life, are a certain breed of compassionate caregivers, but their cup can run empty. To fill their cups, I suggest practicing a “disassociation” from the grief of the families. However, for a compassionate person, that is so difficult. Recently, at a conference for over 1,000 hospice volunteers in Cleveland, Ohio, I related the story of how my husband, as he lay dying, told me he was in love with another woman! You can imagine my Disbelief and Despair! Even then he had a mischievous smile on his face. Then he told me he was in love with the hospice volunteer who had served our needs so beautifully and compassionately. It was all good - I was in love with her as well - her kind heart, her magnificent and generous spirit.

Often it is difficult to remain distanced from the emotions of the families. I would say to be effective in their position, to best serve the needs of the patients and their families, it is important to remain balanced - to be aware of the danger of being overly involved - and to find the courage to step back and become a little selfish about one’s own spiritual and emotional welfare. It’s all about paying attention to our own needs.

Endorsement

“This book is a tasteful collection of poems, prayers and meditations that I think would be useful to any caregiver dealing with end-of-life issues. It is very much in the spirit of palliative care—where you may be unable to add days to the life, you add life (and meaning) to the days. Reading how one couple achieved this would be both comforting and inspirational to others in a similar situation.”

Roger Woodruff
Director of Palliative Care, Hospice International

References