

Caregiving with Sensitivity and Clarity

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While the word “elderly” refers simply to age, the word “elder” additionally suggests wisdom. Until my late thirties, I considered an elder to be someone over sixty and wise. Now I am over sixty and have been an elder caregiver for twenty-five years.

To share my profound journey as a caregiver and to support others on this journey, I have written a book, *The Art and Science of Caregiving: Stories of Inspiring Elders with an End-of-Life Guidebook*. I am deeply grateful to the elders ages sixty-two to ninety-nine who honored me with their intimate stories and inspired me to write about the transformative power, truth, and sacredness of the final stage of life.

A natural reciprocity exists between the living and the dying, and much wisdom is imparted by those nearing the end of life. In many traditional cultures around the world, elders are revered as teachers, spiritual guides, and a source of profound knowledge. If we are open to what they have to teach us, we can experience a more joyful life and peaceful passage.

In multi-generational households, the challenges inherent in aging and dying are apparent. Younger generations grow up seeing life as cyclical and perceive death as a natural part of being alive. They see how a critical illness or an accident can radically change their family’s routine. In homes where elders are actively included in daily life, younger generations learn from them. In so doing, the lives of elders are validated and upheld as they approach its conclusion. Direct exposure to death familiarizes younger people with natural processes and sensitizes them to the suffering of others.

When I began working as a hospice caregiver in 1991, I was saddened to discover that many people are frightened of death and are unprepared for it. This is primarily because they have had little direct contact with death. The tendency in our culture to remove death from our scope of awareness makes our experience vastly different from people in the world who see, smell, hear, and taste the impermanence of life on a regular basis. In India, the bodies of the dead are burned on funeral pyres on the banks of the Ganges. In Tibet, they are offered to vultures on mountaintops. The Day of the Dead rituals in Mexico honor and celebrate death with a spirit of lightheartedness, while people pay homage with reverence to their deceased loved ones. The tradition of wakes encourages and permits people to mourn with the body in an open casket for several days.

Many of you have had, or will one day have, a chance to help an elder and be present in their final weeks or moments of life. It is an invaluable opportunity to assist someone who is losing their capacity to function in the world and to assist in their preparation for passage. Over time, many of you will comfort and support a loved one through exceptional duress, while others will hold them in your arms as they die. Compassion is awakened and courage summoned in this way.

Caring for someone at the end of life is an act of love. Being a caregiver requires, and hopefully inspires, compassion for the challenges that people face when their health dramatically declines. Putting ourselves in the shoes of someone who has physical, mental, or emotional challenges may help us understand how difficult and humbling it is to deal with a body and mind that are not functioning as they used to. It can be distressing for an intelligent person to realize he is no longer able to have a simple conversation due to memory loss. It can be embarrassing for those who can't make it to the bathroom in time because their bladder or bowels are on a faster schedule than the rest of their body. During times of stress and discomfort, reassuring words can revive and nurture a disheartened spirit and rein in a frightened, wandering mind.

Elders with deteriorating physical and mental health require increased attention and assistance. However, it is important for them to feel independent and competent as they go about their daily lives. When an elderly person dealing with new limitations is not encouraged to do as much as they can on their own, they might regress into dependency, which may lead to mental and physical atrophy. Allowing an elder to perform functions with as little assistance as possible enables them to exercise the skills needed to continue doing these tasks.

Many older people take longer to get into gear mentally and/or physically. Being patient with their slow pace and letting them take the time they need to complete a task or resolve a problem fosters self-esteem and confidence. For many, daily life is arduous, and assistance is necessary and welcome. However, it is important to discern who welcomes help and who does not. Offering words when someone is fishing for them may ease frustration for some, but might not be welcomed by others.

If an elderly person is dealing with degenerating mental health, get to know the person they are now without calling attention to the faculties they are losing. Some elders feel as if they are losing bits and pieces of themselves every day as their ability to do things disappears. Do your best to refrain from comparing them to their former selves. They might be functioning at forty percent of their mental and physical capacity, but they are still one hundred percent human.

Unconditional love and compassion have a way of embracing people in their entirety. We all have feelings, views, personal preferences and a life history. Those who are critically ill are much more than their symptoms, disease and prognosis. Whether they have Parkinson's, Alzheimer's or cancer, and whether they will live for days, months or years, everyone merits respect and consideration. Life has many variables, and I have been surprised by the fortitude and apparent miracles that occur toward the end of life. Treating the dying tenderly as human beings, instead of minds and bodies that are shutting down, is a way to respect them in their dying process.

As a caregiver, we bring our personal belief system, values and aspirations to each situation. It is helpful to remember that each care receiver, as well as each person accompanying their process, deals with the challenges of aging and dying in their own way. This will result in different preferences and desires, for instance, between the care receiver and family members. However, it is important to defer to the wishes and natural process of the person who is dying.

For many centuries, Hindu sages and Tibetan Buddhist tulkus have taught that the level of joy experienced by a person at the time of passage may determine his or her next incarnation. The Dalai Lama confirms that one of the best ways to help people who are dying is to contribute to their joy so that they feel internally liberated. This is a primary focus of my work, as well as offering loving support. A caregiver's calm, steady presence can have a positive effect on those who are terrified as death draws near. The calmness of a caregiver's nervous system can have a calming effect on someone who is frightened. As a caregiver's nervous system grounds and stabilizes, the care receiver and those around them become more able and available to resonate with this 'calmness' and attune to it energetically.

End-of-life care often creates deeply loving and mutually beneficial relationships, in which two people learn from each other, give to each other, and receive from each other. The two are joined in a common purpose, one preparing for death, the other being attentive and supportive of the dying process. It is a privilege to witness someone move through their raw emotions and emerge from the depths of emotional pain to fully embrace the reality of their impending passage. Those who were emotionally prepared were better able to surrender to the dying process and depart with ease. I am grateful to have accompanied many peaceful passages, and to have witnessed the transformations that led to these graceful transitions.

It is a privilege and an honor to care for our elders and those who are dying. I wish you the blessings that this intimate experience can bring.

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