

The Heartbreak (And Hard Work) Of Family Caregiving...

Pamela D. Wilson

(Good morning, Providernation. November is Alzheimer's Awareness Month. Today, guest columnist Pamela D. Wilson takes us through the heartbreak and hard work of family caregivers.)

The heartbreak associated with losing a loved one to Alzheimer's disease is indescribable. One day, an adult child holds the hand of a parent; the parent asks, "Do I know you?" and the child's heart (no matter what age) breaks into thousands of tiny pieces, never to be repaired. A spouse experiencing a similar moment may feel the sting of rejection or the absence of appreciation after a lifelong marriage of commitment and caring for a husband or wife experiencing memory loss.

How are spouses, children, relatives, and friends of someone with Alzheimer's disease supposed to be a spouse, a child, a relative, or a friend, when the individual with the diagnosis no longer recognizes them? Does this lack of recognition seduce family members to hold on more tightly with the hope that one day a loved one may show a glimmer of recollection? Do family members feel disconnected and less committed to continue to visit a loved one who no longer remembers or feels connected to them? Does this lack of recognition of marriage by a spouse with memory loss raise the option for the healthy spouse to pursue a companion or even another lifelong partner?

I am commonly asked by caregivers of persons with dementia or Alzheimer's disease if their experiences are unusual. I respond that with a diagnosis of memory loss there is no usual, meaning that each journey is unlike another and that there is no crystal ball to predict the future. This uncertainty is the component that results in stress and anxiety for families because many feel they have no control over the situation and delay making a plan for care.

Planning Crucial

The planning component is critical for persons diagnosed with memory loss especially if the memory loss is diagnosed early, if the individual is aware of the diagnosis, and is able to express wishes and desires in writing to family and to a spouse. This is the time to appoint a medical and financial power of attorney, to finalize a living will, and to establish a will or a trust. This is also the time to have "what if" discussions with family. What if the time comes that a husband or wife can no longer provide care at home? What if a care community becomes a necessity? In what type of community would the individual with memory loss choose to live? Are there financial resources to pay for care or is Medicaid a likely payer? What are the wishes for burial or cremation?

These practical questions should be a priority, in addition to the more difficult discussions of creating memories today so that when memory does fail, the family has something tangible by which to remember a loved one: photographs, family recipes, discussion about the family tree, my wishes for what happens when I don't recognize my wife, brother, sister or children. Denial and delay of these discussions—not talking or thinking about end of life—permits family members to avoid these all important but difficult conversations that result in conflict later as the disease progresses.

My husband wants me to take him skiing and point him in the direction of a steep cliff. I hear other individuals say,



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“put me somewhere and go on with your life.” Those who love the outdoors desire to go camping and have an adventure from which they don’t return. One might wonder how sincere these statements are and if there truly was a change in situation would the request change to desiring care rather than desiring to quickly end an unpleasant situation.

Have ‘The Talk’ Now

The conversation of what do I want for myself (and my spouse), especially for individuals with memory loss, is important and should be held early before memory loss or a chronic or terminal disease advances, held when logic rather than when emotion or guilt become entrenched and change the conversation. I recommend placing these wishes in writing as children and other family members typically place guilt on a spouse or the responsible caregiver for making decisions they may disagree with yet decisions that represent the wishes of the care receiver. How many times after a loved one passes away do families argue over cremation or burial, service or no service, and last wishes—more often than families might imagine.

If you were the person diagnosed with dementia or Alzheimer’s, what type of life would you wish for your spouse if you knew that there will be a time when the marriage relationship focuses solely on care tasks related to the advancement of the disease? Tasks like incontinence care, feeding, and constant one-on-one companionship. What if your care needs required that your spouse identify others—in home caregivers or a care community—to provide hands-on care because your spouse alone cannot provide the level of care and support that you require? What happens to the marriage when you are no longer able to recognize your spouse or to find the words to carry on a meaningful conversation? A marriage where your spouse grieves your loss as your memory slips away day by day and is isolated in the role of caregiver and lonely because of the responsibility and duty of care?

What would you want for your spouse? The dilemma of a community caring for a spouse with dementia or Alzheimer’s is rarely discussed. Marriage is supposed to be forever. Many spouses in a marriage affected by dementia or Alzheimer’s disease feel guilty if they seek out companionship and loudly hear from others that they should remain dedicated to their marriage regardless of the condition of the spouse diagnosed with memory loss. This, like the prediction of what will happen as the result of a diagnosis of memory loss, is an unusual situation with no usual. There are no right or wrong answers, only actions.

When Love Hurts

Seeking companionship or love outside the marriage isn’t the same thing as abandoning your loved one. I have personally witnessed the challenges of this situation for the caregiver spouse who is committed to a loved one yet emotionally and physically exhausted from being a 24/7 caregiver and having no social life. I have also witnessed the loneliness and isolation of a spouse caring for a loved one with dementia or Alzheimer’s disease, who then becomes as ill as the spouse for whom care is provided.

Research affirms the benefits of continued social activity and connection for caregivers; this includes marital caregivers. How might society address the challenge of the healthy spouse caring for a spouse with a diagnosis of memory loss with no recollection of the marriage? Should the legal profession begin including direction in medical power of attorney or other marital agreements regarding “at the time I need significant care, I wish for my own care x, y, z, and I wish for my spouse a, b, c?”

Just like the concept of a life review to create an ethical will that shares values, blessings, life’s lessons, hopes and dreams, and love and forgiveness, do we need a specialty legal document surrounding marriage and caregiving when there is no spousal recognition or when care requires long term placement that risks elimination of all marital savings and finances?

A Broader Discussion

Alzheimer’s disease appears daily in the press; it is a dreaded diagnosis. Caregiving, while well publicized, is not a

subject of awareness until the need arises and one becomes a caregiver. Care relationships are filled with denial and avoidance of planning. Society avoids the subjects of illness and death.

Might we be better prepared for caregiving and aging if there were more discussion of the process of aging in the community; whether in churches, medical offices, or community groups? Might we be better prepared for responding to the challenges that result from caregiving and how these affect family relationships, including marriages, if this was part of a school curriculum or workplace support program? Might these broader discussions—if discussed earlier in life—have a positive impact on daily health and retirement planning so that when caregiving becomes a reality there are fewer crises and more focus on making memories?

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