



## A Caregiver's Journey with Loss

Some of you know exactly when your role as kin or friend changed to include activities that you now describe as caregiving. You remember when she had the stroke or when the accident occurred. Most of you, however, cannot cite a time or place because you drifted into the role of caregiver. Your family member's or friend's capacity to tend to all of her or his needs alone changed gradually. At some point during these changes, the disruptions to your everyday life reached the point where you described your altered daily routine to include caregiving. Whether your transition to being a caregiver was sudden or gradual, you now realize that life has changed in ways that are unwanted and unwelcome. Even though the circumstances and challenges that each of you face are unique and like no one else's, the experience of loss is common to you all.

Physical illness and impairment, advanced age and lessened capacity to perform routine tasks of daily living, cognitive and memory dysfunction, each in its own way sets into motion a series of losses. These events and changed circumstances disrupt one's daily routines, as well as expectations and plans for the future. The present and future that you imagined for this period of your life and relationship with the person for whom you care did not include caregiving or the uncertainty that surrounds a situation that you cannot ultimately control. You previously may have felt that you chose how to spend your days. You were the master of your household, schedule, and activities. Now your choices for daily activities are dictated more or

less by the limitations and needs of your loved one. Some of the losses that you experience in varying degrees from day to day include your autonomy, self-determination, and freedom.

Caregivers typically make these sacrifices willingly. Whether you are thrown or drift into the role of caregiver, you rise to the challenge, determined to do the best you can to support and comfort the one who depends on you now more than ever. Her or his needs become primary. Your needs become secondary. Putting the other person first is not only what you feel called upon to do; it is what you want to do because of your love or commitment. Whatever plans, desires, or hopes you had for yourself are placed on hold. By placing them 'on hold,' you are expressing a hope that health and strength will be restored and that you may reclaim your life and the blissful future you imagined. But, in the recesses of your heart and mind, you may fear or know that from now until your caregiving duties end, nothing will ever be the same again. Your journey in life has taken a detour and the road now travelled is filled with obstacles, potholes, and dead ends. The access ramp to the super highway of happiness has been permanently closed. Activities and milestones to which you looked forward seem perilously threatened now. That scenic Alaskan cruise, welcoming a grandchild or great grandchild into the family, celebrating academic graduations, strolling a beach hand-in-hand during your sunset years with the person who makes your life worth living, believing that mom or dad will be there for you always, and countless other dreams, expectations, and plans are now, at best, questionable and, at worse, gone forever. Add to your loss of daily freedom, lost plans, hopes, dreams, and desires that are not likely to be fulfilled.

There are other losses that can and should be named. Consider how your role in your relationship has changed. For example, he may have tended to home maintenance, managing the money, and conducting family business, but now he cannot and you must. She may have tended to the home, arranged social activities, and maintained communication with family, but now she cannot and you must. Your role has changed. You have assumed additional responsibilities on top of the demands of caregiving forced upon you by an illness or accident. Your former role is lost, and your new role is still evolving because you cannot fully foresee what more you will be called upon to do. The comfort and security you previously felt may be displaced now by anxiety or fear about your capacity to meet the challenges you face currently and in the future. Add role identity and role duties to the list of losses that caregivers endure.

Some losses seem less important, whereas others are more onerous. Consider possible losses of meaningful communication at some point during one's journey. Your loved one's ability to engage in conversation, share in decisions, remember and reflect upon past events may deteriorate or disappear. You may feel on your own, a sole decision-maker, abandoned to choose among options without the verbal consultation, wisdom, perspective and guidance of your loved one. You strive to make good choices even when you feel unprepared and ill-equipped. The demands to decide tend to increase in number and importance. You wish conversations had occurred in the past to guide and inform you in the present. Now it is too late. You long for a word that does not come. Conversely, your loved one's ability to comprehend and understand your thoughts and emotions may be lost. Communication is

multi-directional and multi-faceted. We take it for granted until it is gone. Then we realize how valued and meaningful it is.

Companionship is another loss familiar to caregivers. We tend to think that this loss occurs with death. On the contrary, companionship generally slips away incrementally as a loved one's condition deteriorates. She or he may be physically present, but the elements of companionship may recede one by one. Each shared activity and interest that filled your days with joy may slip away and each loss feels like a knife plunging deeper and deeper into your heart. Your journey may include a loss of physical and emotional intimacy, those elements of closeness that join two souls. As your loved one sustains a loss, a part of you is lost as well. Your wounded soul suffers as the fullness and wonderfulness of one who is so much a part of you is taken away a bit at a time. Add companionship to your list of losses.

There are countless other losses that we could mention. Loss of social and recreational activities, sense of control over life's events, employment, participation in faith communities, well-being, health, familial and filial relationships, finances, assumptions about the future, and many others that you would name if we asked you person by person. Even though these losses and others unnamed would be uniquely expressed in your situation, they all produce grief. Grief is what we feel when anything meaningful or valuable to us is threatened or lost. As Tim VanDuvendyk explains, grieving is that process of holding on and letting go. Caregiving, accordingly, is a journey in which loss and grief are familiar companions. Caregiving is a journey in which we strive to hold on but are forced to let go. It is a journey in which losses mount, grief intensifies, and the experience of grace seems hopelessly beyond reach.

You often do not talk about your losses, but you feel them. Your public face is one of stoic ‘grin and bear it’ perseverance or a fabled English ‘stiff upper lip.’ In your private moments, however, you cry out in anger, hurt, pain, frustration, fear, helplessness, and despair as tears flood your face in a futile attempt to wash away the losses being forced upon you. To paraphrase the words of the old spiritual, ‘nobody knows the trouble you see.’ There is a profound truth in this refrain, because nobody can ‘know’ the losses you sustain along your journey. How can they ‘know?’ They have not shared your intimacy and history with your loved one. Their lives and futures will not be affected as yours will be when the journey is complete. They do not, cannot, and will not have the same scars on their hearts that you will have. Although ‘nobody can know the trouble you see,’ that doesn’t mean that you should exclude others from your journey. The presence and support of others are lifelines that will help keep you afloat as storms of loss swirl around and threaten to overtake you.

I appreciate why caregivers brush aside the requests of family and friends to share their journeys. You are on a highly personal journey. Concerns for privacy, embarrassment, and pride may prompt you to kindly but firmly turn aside well-intentioned, repeated, and sincere offers to share your journey. You rationalize that others are too busy to take time to help carry your load. Moreover, you rationalize that they would or could not provide care as well as you. You convince yourself that your loved one only wants or will accept care from you. You anticipate that others will engage in what I refer to as a litany of ‘you should,’ that is, you should do this or that or you should not do this or that. From your perspective, this unsolicited and unwelcome advice seems easy for them to give. But, they do not walk in your shoes,

experience your losses, or bear your burdens the same as you. They cannot ‘know’ the trouble you see. And, you reason, if they cannot know, how can they help? How can they help your losses become easier to bear?

The truth is that they cannot mend your torn heart and soul. In many respects, you must heal on your own. This does not mean, however, that your consolation and recovery from loss should take place apart from the sustaining presence of family and friends. By inviting or permitting them to share your journey, they will make your losses easier to bear and your torturous journey easier to navigate. Admittedly, they may not always fulfill your expectations or needs. They may say things that you resent or do not comfort. But their well-intentioned words and compassionate efforts that fall short must not keep you from allowing them to sojourn with you.

When your journey as a caregiver is over and you reflect on all that happened, you will forget the bungled efforts and comments. They, like so much of your painful experiences, will fade from your memory. You will let these shortcomings go and remember or hold on to the security and comfort you felt because they cared enough to be with you, to share your journey, to bear your burdens, and by their presence say to you, to paraphrase my colleague Ron Sunderland, that what happens to you matters to them. The presence and support of family and friends give you comfort and are symbols of hope. However, you are the gatekeeper. You must allow them to come alongside you and share your journey. It is in your best interest now and in the future. Moreover, it is in the interest of the one for whom you care. As you care for yourself in this way, you will be equipped to provide better care for your loved one.

The presence of family and friends can be an important part of a healthy and hopeful response to your many losses. Your losses are real, incremental, far reaching, life altering, and unrecoverable. They cannot be minimized. Your sadness and emptiness or grief that fills the voids carved out by each loss is a normal and natural reaction. Grieving your losses, that process of holding on and letting go, can be hard work. It is not easy to let go of persons and things that enrich your life. But by holding onto your family and friends who share your journey, the process of letting go, your grief work that leads to healing, will be made easier. You must, for many reasons, resist the urge to go it alone, to secretly harbor your thoughts and fears, and to hide your grief from trustworthy, confidante family and friends.

Each caregiver's journey with loss is one-of-a-kind. Although no one but you can 'know the trouble you see,' that does not mean that you are destined to bear your losses in solitude, separated from the community of family and friends whose consoling presence can comfort, promote healing, and ease the burdens of your service as caregiver. Let me urge you to accept the offers of family and friends to be with you and assist you. When they say, 'let me know if I can do anything,' hear this as a sincere, genuine, and caring desire to share your journey and to do with and for you what will help you along the way.

You recall the biblical story of Job. He is described as a perfect and upright man who feared God and eschewed evil. He had a blessed life - health, wealth, wife, and children. But then, his children died, his wealth was stolen, and his body was covered with painful 'sore boils.' His losses were many and tragic. He became overwhelmed by losses beyond comprehension. His grief was great. What can we learn about loss from this ancient tragedy?

Upon learning of the evil that befell Job and that his suffering was great, three friends responded then as friends are disposed to do now. They left their places and went to be with Job to mourn with him and to comfort him. They entered into or shared his grief. They came and sat with him seven days and seven nights without saying a word. They were present. Job did not turn them away. He allowed them to sit with him and to demonstrate their solidarity with him in his despair and bewilderment. Caregivers should follow Job's example. You should accept and welcome the presence of family and friends during your encounters with loss. Presence, not words or actions, demonstrated that what happened to Job mattered to those who cared about him. The presence of others reminds you that there are persons and things to hold onto that also give meaning, value, joy, and purpose to life that are not being lost.

As caregivers, you cannot escape loss. You cannot escape the work of grief, that process of holding on and letting go, that leads to healing. You may choose to suffer alone. It is my prayer, however, that you respond to loss in a healthful and hopeful manner in the company of others, drawing upon their strength, and comforted by their presence.

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