



Having Hope in Hard Times

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August 21 and 28, 2010

Dante, the 14th century Italian poet, completed his epic work, **The Divine Comedy**, in 1314, shortly before his death in 1321 at age 56. Written in the first person, it tells of the poet's allegorical journey through the realm of the afterlife, Hell, Purgatory, and Paradise, as conceived by medieval Roman Catholic theology. I suspect the opening line in **Inferno** or Hell describes us at some point along our journey as caregiver. Dante writes, "Midway upon the journey of our life / I found myself within a forest dark, . . ."

Your 'dark forest' may be the experience of the devastating effects of dementia, the dependent aftermath of a stroke, the shadows of macular degeneration, the physical weakness of a long life, the consuming effects of cancer, or the impairments of arthritis, diabetes, or other condition, to name only a few. The worry, fatigue, grief, isolation, frustration, anger, and fear of your 'forest dark,' at times, may cause you to feel that you have passed through the portal to Hell above which, in Dante's imagination, these words are inscribed, "Abandon hope, all ye who enter here."

Indeed, as caregivers, there may be times in which you feel hopeless in the face of the unrelenting challenges you face and the demands placed upon you. There surely are times in which you question your capacity to continue in your role and to provide the quality of love and support you are determined to give. In those moments when you feel most weak and overwhelmed, you may feel that your situation is not only desperate, it is hopeless. Your life

and world are spinning out of control and you feel powerless to alter its course. You feel tired, defeated, and alone. You can see no future better than today. The 'journey of your life' is at a point you never wanted to reach, a point at which you feel like a victim of a cruel fate, impotent to defeat malevolent forces tossing you to and fro, and, perhaps most damning of all, unable to find meaning in your daily experience or hope for tomorrow. Maybe Dante was correct to describe such a situation as Hell, a place where or state in which we are without hope.

Fortunately, the times that caregivers feel truly hopeless are few, because when we have no hope for tomorrow, we cannot go on. The very fact that you continue in your loving service to another is proof that you are not hopeless. You may be exhausted, confused, uncertain, fearful, enraged, or broken, but you are not without hope. At some level of consciousness, you cling to hopes that there is purpose, value, and meaning in your daily service. At some level of consciousness you cling to hopes that life still has value. At some level of consciousness you affirm that tomorrow is worth seeking. At some level of consciousness hope exercises its power to sustain you despite the trials in your lives. It does not free us from the hardships of today, but in hope we are open to the possibilities of a better tomorrow and to the prospect, perhaps in retrospect, to be grateful for this experience of caregiving, though we may not be able to recognize or affirm the inherent blessings in our current distress.

About 500 years after Dante, the German writer Goethe (1749-1832) remarked, "In all things it is better to hope than to despair." I suspect that Goethe's insight is the testimony of most people facing some adversity for which a solution is not readily apparent. Goethe's insight may be especially pertinent to caregivers. The capacity to hope, an implicit protest

against one's current harsh reality, and to look beyond one's current situation to a better day surely is one means by which we humans persevere through threats, disappointments, and losses. Hope, in a sense, proclaims our desire and determination to endure a painful present and to emerge from a darkness that encroaches upon us into a new bright day filled with promise and joy.

Hope for caregivers and the persons for whom we care are complex and multifaceted phenomena not easily analyzed, interpreted, or understood. Yet, hope is a condition for and defining characteristic of human existence. I think it is true that of all creatures, humans alone hope because only humans appear able to anticipate the future. Hope, it is said, is the "power that gives us the power to step . . ." into an uncertain future, shape it, and infuse it with meaning.

For caregivers, hope can be expressed in the trust placed in medical personnel and others to change things for the better by easing or removing the burdens of the person for whom we care. At best, we hope for a cure or, at least, unimpaired living. Our desire is that the knowledge, skills, and resources of others will triumph - our loved one and our lives together will be restored to a prior peaceful state.

Sometimes hope is expressed as a negative, as in 'I hope the diagnosis is not cancer, Alzheimer's, diabetes, or other feared and ominous condition' for which there is no cure or the treatments are difficult to endure. At other times, hope is expressed as a positive, as in 'I hope that this drug or treatment works for her' or 'I hope that I have strength for another day.'

However expressed, hope should not be confused with fantasy or a make-believe reality. Hope is related to what is possible, not what is impossible. Hope is misplaced if its object is impossible. Accordingly, escaping death is not something for which we can hope because finitude is an inescapable condition of life. When we hope for what is impossible, we engage in fantasy or in delusion. Moreover, when we hope for what is not possible, we are on a certain course to disappointment and despair. In the end, our hopes will be in vain and our despair may be even more intense.

In situations of bodily weakness and threat, hope for restoration should be informed by and grounded in the capacity of medical science and clinical skill to alter temporarily the destructive effects of disease and bodily malfunction. We can deny and defy reality, of course, and believe that anything is possible; but hope properly can be directed only toward that which is reasonably believed to be possible within our time and place. Hope is not a baseless optimism that a threat will disappear when every sign and evidence suggests that it will not. Hope does not deny a threat. Nor does hope reconcile us to evil or agony. Rather, hope enables us to face adversity and, as a caregiver, live through it. Hope enables us to persevere and ultimately to claim victory.

I can hear your objections now. ‘What do you mean ‘victory’? My loved one will only get worse. Our lives will never be like they were before. The future we imagined together has been taken from us. What is the victory to be claimed? For what can we hope?’

Let me suggest that even in those moments when you feel hopeless, even when despair seemingly overwhelms you, and even when losses come quickly and severely, you are not

without hope. I know this sounds contradictory, but let me explain. If you are truly without hope, if you truly have no desire to care for your loved one moment more, if you truly think there is no value, good, or blessing in your caregiving or your relationship together as it is today with all of its distortions, you would not continue in the role of caregiver or continue to tend to her or his needs. The very fact that you stay the course and sacrificially do the best you can is a profound declaration of hope.

When we are overtaken by a season of woe and confronted with the nature of the human condition with its limits, vulnerability, and finitude, it is hope that empowers us to adjust and to stay the course. Hope counters despair. Hope declares that all is not lost even as our journey in life becomes more troubled and threatened. Hope allows us to see beyond the current reality and points us to a future of new possibilities. Hope helps us to find meaning in life, even during those painful and heartbreaking moments that seem to have no end. Hope, accordingly, is transformative. It enables us to re-image and re-interpret the present within a broader, richer narrative of our lives and our relationships with others that includes exhilarating mountaintop episodes of unspeakable joy even as we wander in a valley of darkness and uncertainty. Hope counters our tendency to reduce our relationship with our loved one to the current travail and its potential to block, as the late Paul Harvey would say, ‘the rest of the story’ of our lives together. These are some ways in which hope can transform ‘times like these’ into meaningful times, renew our depleted spirits, refresh our tired bodies, sweeten our sour moods, and remind us of the reasons for our intimate and unbreakable bond with the one

for whom we care. Remembering better days can be consoling because it makes it possible for us to have hope, even as we grieve the turbulent waves of loss that presently wash over us.

Our memory of better days causes us to hope for better tomorrows. Our bond with the one for whom we care and all of the experiences that have made it so strong that we do not turn away when the going gets tough prompts us to hope for better days ahead. In hope, we are able to transcend the current situation, to look backward in gratitude and forward in anticipation while not denying the difficulties of the present. The fact that the bond between you and your loved one holds strong and is sustained by hope is a victory to be claimed and celebrated as you pass through your ‘forest dark.’

Other victories await discovery by those who have eyes to see and ears to hear. There are experiences, conversations, moments, expressions, manner of touching, and silent times from which blessings emerge that comfort now and will console at a later time. In these moments, you are reminded that the side of your weakened loved one is where you want to be. These moments may be unlike any others in your history. They are unique because you have never been in this exact situation before. For these reasons and others, these moments are to be seized and cherished. Some victories may be evident now and others apparent only in the future as you look back and remember some aspect of this time that brings you satisfaction, peace, and even gratitude. These victories are possible. They are appropriate objects for hope.

As we plunge deeper into our ‘forest dark’ and the last days of our earthly journey with our loved one, the objects of our hopes may become more concrete and immediate. My colleague Stephen Post has written extensively about the moral challenges related to

Alzheimer's disease. His wise counsel with respect to hope is applicable to any person with a condition that is ultimately terminal and those who attend to her or him. Post suggests that we can hope for our loved one to be free from pain and given comfort care as life slips away. We can hope for symptom management to promote the best quality of life possible as she or he defines it and the quality of life for us together. We can hope for the grace to accept that dependence on others is a natural and inevitable aspect of human life and love, and that we can entrust ourselves to others who will not forsake us (Stephen Post, **The Moral Challenge of Alzheimer's Disease: Ethical Issues from Diagnosis to Dying**, p. 125; Ps. 71, "When our strength fails us . . . do not forsake us"). We can hope that from these days experiences will be shared that will emerge as blessed memories to console and warm our hearts with gratitude; memories that will triumph over and heal the wounds that now cut so deep and hurt so much.

If it is true that 'where there is life, there is hope,' then it seems similarly true that when we are in a caregiving role, we are people who must hope. Hope is something we do. The objects of hope may be many and unique to particular people and situations, but those objects for which we hope must be within the realm of possibility, as I said earlier. But hope is more than what we do in good times and bad. Hope, more broadly, is a style of living that proclaims that this moment also has meaning and value despite the alarms, dangers, anxiety, and grief within it. It is this style of hopeful, confident living that believes in a better tomorrow that makes the hardships of today bearable. Perhaps Vaclav Havel, the Czech playwright who became President of Czechoslovakia, got it right when he said, "Hope is not the conviction that

something will turn out well, but the certainty that something makes sense, regardless of how it turns out.”

The Psalmist millennia ago reached a similar conclusion as he anguished over the fidelity of God as God’s chosen people were in exile. Like you, Israel was in a hard place where, as Roger Lovette writes, “it’s nearly impossible to sing the Lord’s song. This is a place called hopelessness – a region of enormous pain” (“Reflections on the Lectionary, Sunday, June 27, Psalm 77,” **Christian Century**, June 15, 2010, p. 21). Perhaps we can identify with the Psalmist’s lament toward God: “Has God’s steadfast love ceased forever? Are God’s promises at an end?” Has God forgotten to be gracious (Ps. 77: 9)? Has God abandoned a chosen people?

In answer, the Psalmist does what I have suggested to you, he remembers how God acted in their history. He invokes the names of Jacob, Joseph, Moses and Aaron. He refers to the nation’s exodus from bondage. Because of these mighty deeds and memories, the Psalmist offers a different interpretation of the hardships of exile. It is not the end of a relationship. It is but one moment in a longer, richer, meaningful narrative of relationship between God and a chosen people. His message to Israel is “Trust in God’s care even when you cannot understand [God’s] . . . movements in history” (Pat Graham, “Psalm 77: A Study in Faith and History,” **Restoration Quarterly** 18.3 [1975], 158). The past gives context and meaning to the present and, for the Psalmist, reason to hope for the future despite the desolation of exile. Memory and hope are inextricably bound. Memory and hope have power to give meaning to your period of exile as they did for Israel.

‘Having hope in hard times’ is what caregivers do day-in and day-out as you journey through a season of woe. Hope is not a possession. We do not own hope. Hope is an orientation, a perspective, a disposition, a way of being, and a way of living. It is, among other things, a capacity and openness to find meaning in story and song, gentle touch, understanding word, or endearing glance of those for whom we care. In company with them and others, it is my prayer that the ‘forest dark’ you and your loved one are in is hope-filled, a hope-full-ness for what is possible – the discovery of meaning and purpose that makes each day worth living now and that will make these days in memory a time for thanksgiving and a source of peace.

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