

No Way Out But In: Responding Positively to Chaos with Forgiveness and Grief

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The rapidity and volume of chaos for individuals using life-support devices can lead to lifestyles in which “crisis mode” becomes the norm. Our lifestyles often entail extremely ritualized self-care routines, highly limited mobility, occasional intense infections, steep medical bills, serious equipment malfunctions, voluminous healthcare paperwork, and the need for a reliable caregiver present at all times. Accordingly, most of us who are ventilator users or part of vent users’ teams become keenly interwoven with people, systems and machines.

Some matters, in time, grow predictable enough that plans can be established for responding to needs as swiftly and safely as possible. Certainly much can be done logistically to mitigate crises, and *Ventilator-Assisted Living* and other resources help us with that. However, I am happiest when I do more than prepare for or tend my body’s needs. Whether much is going awry or right, I restore my inner serenity and well-being each day by using prayer and meditation, by processing grief, and forgiving.

No day seems to pass without me using these mental resources. For example, with caregivers there can be an unending source of unpredictable inconsistency. In a four-week period recently, five caregivers (one fulltime, three parttime and one backup) experienced surgeries, both minor and major, intense abdominal pain, car problems, sick children, infections and viruses, food poisoning and a family funeral. One stole valuable items from my home. Another fractured her spine when thrown from her horse. This convergence of mishaps among my caregiving team left me with only my husband, who has a full-time job, to tend to me.

Those providing my care soon realize how very quickly a vent user’s health can deteriorate when their own health, transportation or communication problems, or even the needs of others who depend upon them, interfere with their ability to perform routine tasks. Even when caregivers care deeply, their problems become a vent user’s issue, too.

One of the most strenuous challenges accompanying chronic long-term disease is navigating human interconnections in healthful ways. It would be inappropriate for me to lash out at an employee for personal problems, even if those problems create grave situations for me.

Similarly, there is no solace in remaining riled when insurance companies and healthcare agencies or providers cannot resolve my problems as swiftly as I like or when their errors introduce hours of time I must spend calling, writing and re-addressing matters. Nor would it help me to harbor resentment toward God, nature, my parents or any factor I might blame for the genetic code that created me a body with limb girdle muscular dystrophy (LGMD).

However, having a debilitating disease and a need for life support from human and mechanical interfaces

present unending situations in which my life depends on how quickly I hone my coping skills and how well I can govern my own responses to unwelcome chaos.

Prayer, meditation, grief-processing and forgiveness are the best way I've found to counter the stress that emerges when my body has setbacks, machines malfunction, or unsettling events emerge in the lives of those upon whom I depend. I sustain myself with a reservoir of abiding peace by opening my day with prayers for my team and for the resources I need to do all that is mine to do. To keep myself fueled, I make time for mental relaxation exercises akin to those Adolf Ratzka describes in the Winter 2008, Vol. 22, No. 4, *Ventilator-Assisted Living*.

When disturbances arise, I use other forms of meditation, problem solving, deep rhythmic breaths, and self-reflection so my feelings align with my values of resilience, compassion and authentic cheer. The latter is where grief and forgiveness fit in.

The grief process begins automatically for any of us facing loss: we experience shock, anger, searching (most often to pinpoint a culpable source even if a scapegoat) and depression (whether mild or severe). Whether we recycle through those negotiations, thereby keeping ourselves incensed, or move ourselves forward into more empowering attitudes depends upon our willingness to try.

It is not automatic to remake one's self in a way that reasonably accounts for a past we cannot change and, thereafter, to invest in that new identity. It is a matter of choice. And mak-

ing that choice, for me, rests at the heart of forgiveness.

I prefer to integrate the final grief steps, or forgiveness, into each of my days because I think it best reflects my compassion for myself and others. I aim to abide by personal ideals of harmless, authentic, resourceful, cheerful and thankful thoughts, speech and behaviors.

Some days I am more consistent with this than others. At times I feel overwhelmed, and the process goes more slowly. But regardless of outer crises or discomforts and no matter the emotional anguish, I've not indefinitely lost my inner harmony and joy. Self-reflection, creative expression, meditation and prayer allow me to infuse my life with hope, purpose and vibrancy once again.

It becomes a self-sustaining cycle, because processing my grief and forgiving fully brings me solace and the clarity to see all the goodness and blessings in my life. Seeking and finding solace and optimism shore me up when the wearisome phases appear.

Sometimes there is no way out but in. That is, I turn inward when the going gets tough, and I dig down to find my own resilience, to make choices that maximize what's feasible in a given moment. No matter how impoverished my body, I feel rich because my mind, technology and other human beings continue working together to keep me going. At this I marvel. That fact is omnipresent, and for it I am grateful. ▲

Deshae E. Lott earned her PhD in English and Religious Studies from Texas A&M University more than a decade ago. Her publications and presentations deal primarily with disability or spirituality in America, and sometimes with both topics simultaneously.

Deshae currently teaches online English courses for Louisiana State University in Shreveport. She leads a non-profit organization whose participants weekly engage in spiritual studies including meditation, prayer, and inner purification techniques. You can learn more about Deshae at www.deshae.net.