



The Living Losses of Life-Changing Illness

by Elizabeth Landrum, Ph.D

Relishing predictability, we humans cling to familiar patterns. It's often chance, not choice, that throws us off course, forcing us to reorder our lives. When one comes face to face with a progressive, life-limiting or chronic illness, loss and its counterpart, grief, become significant and challenging. The inevitable changes imposed by illness involve an array of losses: social, financial, physical, loss of normal activities, plans and dreams, familiar aspects of oneself or partner, shared roles and responsibilities, freedoms, ... changes in almost every relationship, in self-image, lifestyle, priorities and comfort. Often, one's fundamental or cherished beliefs must be altered. Grief and loss in many forms will always accompany the person living with serious illness as well as their caregivers and loved ones.

Caregivers of those with degenerative or terminal illness experience an unrelenting sense of loss as they live through the constant adjustments that come with the illness's progression. They grieve the losses occurring in their own lives as well as in the life of the person who is ill. Looking back, they may find constant reminders of what has been and is no longer. These illness-related ("ambiguous") losses may be deeply felt, yet are often not understood. The emotional consequences are not the same as depression, not something to be "fixed". This grief is continually evolving, taking a significant toll.

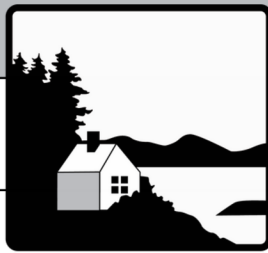
During decline from dementias, ambiguous losses are usually experienced in stair-step progression as a person is physically present but different, less able to be emotionally or mentally available. The experience of a chronic illness is also invariably one of an accumulation of losses, the depth and breadth of which depend on the severity of the illness and the limitations it imposes.

The resulting grief process involves moving back and forth between coping with loss-related stressors and the stress of remaking and managing life to accommodate changes.

Anticipatory grief is future-oriented. Looking forward, one often encounters uncertainty, fear and dread about facing the changes to come. People living with or next to certain illnesses are likely to feel a profound loss of a felt sense of control and predictability, especially when illness's progression and/or eventual resolution are uncertain. They live with questions about what's next, what will be taken from them, what they will never be able to experience, and how long any phase of the illness might last. Planning almost anything can be difficult to impossible.

Grieving styles vary, and are likely to involve a spiraling process, possibly including sadness, anger, guilt, frustration, distractibility, numbness, sleeplessness, anxiety, disorientation, fear. Some people become more active or agitated; others might be immobilized. No matter how compassionate and caring, one can easily feel inadequate, or resentful about what's been stolen or what's required to manage life. Loss of energy usually accompanies the constant grind of ongoing illness or decline.

When the feelings created by these ongoing grief processes are not understood or acknowledged, they compound the stress, confusion and loneliness that accompany illness. Denial of grief is natural, yet it can diminish one's quality of life. What helps is to name the experience, to feel one's feelings honestly and without judgment, and to share them with someone who listens well and understands.



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INTRODUCTION

by Megan Havner, CSM

Making a good match between a client and volunteer is one of the biggest highlights of my job. I want our clients to feel comfortable, safe and supported. I also want our volunteers to feel the same as well as to feel that their efforts are appreciated. Allan, Terry, Perry and Diana are just two pairs of many with LIHHS. I'm so glad that we're able to offer this service to the community. Our clients' information is kept confidential - when approached about sharing their stories with the Lopez community, both Diana and Terry gave an enthusiastic "yes!"

DIANA & PERRY

A note from Megan - *Last fall, I met our client Diana, whose first volunteer was heading off island for the winter. At the same time, one of our board members, Perry, became a volunteer. My gut feeling was that they would be a good fit - both women are inquisitive and sharp. After the first couple of visits, I was pleased to hear that the two of them had hit it off!*

Our good fortune to participate in this program is that it nourishes the unfolding of long-lasting friendships at a critical time in the lives of two people. In Perry's case, as a board member of LIHHS, she longed to experience a relationship with a client. In my case, I realized I was emotionally isolated in spite of having Ed, a dear and supportive spouse, and kind friends as well here in our delightful Hamlet community. Perry, confined to a wheelchair for over a decade, wanted good accessibility and shared interests found in friendship. I hoped as well for a meaningful friendship. What a perfect match for each of us!

Almost instantly, we developed a strong bond. We discovered a wealth of golden threads that we used to weave a tapestry of connectedness. It began as she described the accident that landed her in a wheelchair and altered her life forever while I had a less dramatic event of a stroke. From there we proceeded to find geographical links in our respective worlds—she had been a vet in Sausalito, and I had children and grandchildren in San Francisco and Berkeley; she also lived in Vermont for a time near where I spent childhood summers with my grandmother. In addition, Perry loves to bake sweets and I love to eat them. Recently, she has also been able to bring her dear service dog, Vector. We also share a passion for reading and discussing books, movies and podcasts; we discuss health challenges, doctors and meds; and in this election season, political topics frequently burst forth. Never a dull moment when Perry comes to visit me!

There is such a stream of stories that we have swapped back and forth, built on small kindnesses and memories. My Scottish grandmother often told me that "summer friends will melt away like summer snow, but winter friends are friends forever." Last week when we chatted about this article, Perry commented that since we share similar interests, "we've become true friends." As I close this essay, an image I have is one spoken by Michelle Obama that "by chance we met. By choice we became friends."

TERRY & ALLAN

A note from Megan - *Shortly after I started this job, Allan reached out and shared that he and his client Terry would be happy to have me join one of their visits. I was welcomed into Terry and Capper's home, and was struck by the strong bond between them. Allan's calming, engaged presence put Terry at ease and they felt like lifelong friends - something that I wanted to foster in all of our client and volunteer partnerships.*

Terry: I was very ill when we reached out to LIHHS. I was waiting for an operation that was six months away and had a catheter. They wanted to put me in a facility. Instead, my lovely wife Capper sprung me and took me home. We got a caregiver who taught Capper how to care for me, but could not stay permanently.

The next day, faced with my care, Capper reached out. Allan Tamm started coming on Thursdays for several hours to help us. I was not too sure about Allan but we conversed, went for walks and began to become friendly. Allan also helped me around the farm. He helped me around the farm, and eventually we would go to town, buy pizza, and walk toward the harbor and talk. We began to be friends.

I was a stonemason, used to being strong and a singer songwriter used to singing and playing guitar. After my operation, although successful, I could do neither. Allan and I began to play guitar with Steve Ruge. Relearning guitar is difficult for me, and my voice was lost. We meet once a week and all of this is improving.

I can only say I am glad to know Allan. He is a good man, caring and patient. We have become friends which can be difficult for men. I am healing, and singing. Thank you.

Allen: About 30 years ago, I volunteered to do respite care for a coworker whose husband was dying from AIDS. He was unable to speak, but while caring for him I had a sense of the preciousness of each moment and how much it meant to him.

In recent years I've been serving home support clients, and that's rewarding, too. Initially my visits with Terry were limited to helping with tasks and errands, but over time they've become more social. Accompanying him on exercise walks is one of the ways we've had time to talk and get to know each other better. We are even practicing guitar together, recovering something we both had lost. The thoughtfulness of both Terry and Capper is a key element to the relationship, and I'm a lucky guy to be their volunteer and friend.





WHAT'S NEW AT LIHHS

Creaky Yoga: LIHHS has partnered with Creaky Yoga. For more information about their offerings, visit their website at creakyyoga.org

LIHHS Online: You can now access our DME catalogue and our book library online at lihhs.org.

Emergency Flight Program : Thanks to your generous donations during Give Lopez 2024, we have been able to partner with the Lopez Fire Department to develop resources and provide limited funds to Lopez residents who need to return home after emergencies. Stay tuned as this program rolls out soon.

UPCOMING EVENTS

Living Well on Lopez: Living Losses, *presented by Elizabeth Landrum and Nancy Ewert*

*Nov 9th, 10 am
Grace Hall*

Jingle Bell Celebration

Sponsorships available now, tickets for sale in the fall.
Contact office to sponsor

*December 7th
Community Center*



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