The Ongoing Losses
When Living with Dementia

Roseville Alzheimer’s & Dementia
Community Action Team

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The Guest House

This being human is a guest house. Every morning a new arrival.

A joy, a depression, a meanness, some momentary awareness comes as an unexpected visitor.

Welcome and entertain them all! Even if they're a crowd of sorrows, who violently sweep your house empty of its furniture, still, treat each guest honorably. He may be clearing you out for some new delight.

The dark thought, the shame, the malice, meet them at the door laughing, and invite them in.

Be grateful for whoever comes, because each has been sent as a guide from beyond.

Jelaluddin Rumi
(my use of bold print – Ted Bowman)
From *Dear Alzheimer’s: A Caregiver’s Diary & Poems*

My husband and I have been living with Alzheimer’s for more years than we know, probably ten…I read everything I can get my hands on.

There is no getting over Alzheimer’s. No moving on. Each of us who cares for a person with Alzheimer’s has to find ways to copy; these are unique to the individual. Whether the loved one is at home or in a nursing facility, caregiving does not end. It becomes part of the self.

Abe is still Abe. His hands are as warm now as they were when I met him nearly three decades ago. His eyes still twinkle. But he is disconnecting, and my heart breaks every day.

A magazine article asks: What’s the best thing to happen to you this week?

Seeing Abe enjoy activities and people at the Assisted Living Facility
Watching him smile at other residences as they walk by
Listening to him say hello to man across the way
Watching him shake someone’s hand
Seeing him with a group of staff and residents at a nurse’s baby shower
Hearing him say he’s having a good time

I have read in a number of places that a woman’s married to a man with Alzheimer’s is living a widow’s life. In the two and half years since my husband’s diagnosis, I have not felt a sense of widowhood, but last night at a social function I did feel I am living the life of an almost widow. Here at the table were a handful of couples, each while engaged with everyone in the group as I was also, were also happily engaged with each other.

An almost widow is not a widow. The relationship that used to be has taken a different form, but wherever I go, Abe and his illness are there with me.

How People Survive Adversity

Characteristics

1. Almost without exception those who survive a tragedy give credit to one person who stood by them, supported them, and gave them a sense of hope.

2. Those who survive a tragedy understand the magnitude of that which they have lost.

3. Those who survive a tragedy have learned to transcend their guilt.

4. If you want to survive a crisis, you need a reason to live.


Dehumanization of loss

Repeated experiences of unacknowledged and unmourned loss contribute to the dehumanization of loss...It’s one thing to lose something that was important to you, but it is far worse when no one in your universe recognizes that you lost it. The failure to acknowledge another’s loss is to deny that person’s humanity.

Slightly adapted by Ted Bowman from *concepts of Ken Hardy*
LOSS Refers To
Being Deprived of Or Ceasing
To Have Something
That One Formerly Possessed
Or to Which One Was Attached

GRIEF Is a Whole Body
Response To Loss:
Emotional
Cognitive
Spiritual
Visceral

Losses can include
Past, Present and Future Stories

The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.
(Rachel Naomi Remen)
Ambiguous Loss

Losses that are unclear, confusing, and for which outcomes are unknown

Psychologically Present and Physically Absent

Physically Present and Psychologically Absent

Dialectical Interventions

When working therapeutically with families facing ambiguous loss, the both/and approach is essential. In the absence of clear information, we cannot say, for example, that a person is dead or not dead, or here or not here. With both/and thinking, people can understand more easily that a loved one on a respirator, but brain dead, is both gone and not gone, or that a person with Alzheimer’s disease is both here and not here. Such situations call for dialectical interventions… Whatever your clinical discipline, I recommend the both/and approach for finding meaning, as there may be no other way to gain the resilience needed to deal with ambiguous loss.

The Intersection of Joy and Grief: Honoring Each

Either / or ways of seeing and responding to events and feelings can compromise both the either and the or. At all seasons of life, there are intersecting experiences of joy and grief. Rather than push one away, a both / and approach acknowledges overlaps of feelings and experiences. The challenge is find ways of honestly honoring one’s joy and one’s grief.
Ted Bowman

Joy and Grief

There is joy experienced as a real quality in the world - not as a state resulting from an appraisal of my situation in the world.

...joy as a seemingly real quality of this lived world can invade us even in pain and periods of deep grief. It does not seem to be the case that joy and grief can occur simultaneously, but they can occur alternately; that is, the pervasive emotion may be grief, and yet joy can slip in momentarily. So it may happen that even in the deepest grief, filled with guilt and sorrow and regret and despair, I may still see and feel joy there-in-the-world, trembling at my fingertips. Turning from a graveside or leaving the hospital after holding a dying hand, joy may burst through like a rainbow over tears. Grief is not thereby lessened; indeed, it often intensified.

STRETCHED

SOME PRACTICAL SUGGESTIONS

SELF-CARE (Respite, Sleep, Good Food, Body Care, Exercise)

ROUTINESLY ENGAGE IN NURTURING ACTIVITIES (Music, Nature, Things Of Beauty)

ESCAPE (Books, Hobbies, Friends Who Don’t Talk About Caregiving)

RECOGNITION (Cultivate Friends And Professionals Who Give You Feedback)

TALK ABOUT IT/BE HEARD

ASK FOR HELP

MULTIPLY CHOICES (Be Creative, Seek Creative Options)

MAKE INFORMED DECISIONS WITH THE BEST INFORMATION THAT YOU HAVE AT THAT TIME AND THEN DON’T SECOND GUESS YOURSELF

ENGAGE IN SPIRITUAL PRACTICES

SAY NO TO SOME THINGS SO THAT YOU CAN SAY YES TO OTHERS

MAINTAIN THE VALUE-BASED REASONS FOR WHAT YOU DO

CHALLENGE YOUR NEGATIVE BELIEFS AND ASSUMPTIONS

PARTICIPATE IN COMMUNITY ACTIVITIES

PLAN AHEAD (Advanced Directives Of All Kinds)

Prepared by Ted Bowman, from many sources