

The Ongoing Losses When Living with Dementia

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Overview of Content

- **Self-awareness – essential starting point**
- **Stories of dementia**
- **Losses, including shattered dreams**
- **Chronic sorrow – ongoing grief**
- **Resiliency promotion**
- **Reasonable hope**

- **Reflections about the day**



Essentially, the only instrument we bring to the helping process is ourselves. Hence, the more self aware we are the more present we can be in the helping exchange.

Paraphrased from comments by Virginia Satir

Self Awareness

The expectation that we can be immersed in stressful work daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.

The expectation that we can leave stresses in our personal lives and not bring them to other parts is also unrealistic.

The way we deal with distress and loss shapes our capacity to be present to life more than anything else.

The Guest House

**This being human is a guesthouse.
Every morning is new arrival.**

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

Welcome and entertain them all!

Beginning lines of a poem by Rumi



Signs of Quality Care

Human presence

Empathy

Empathizing with yourself

Respect

Authenticity

Flexibility

Mutual participation

Clarity about role and boundaries

Communication skills

Caring

Adapted from work of Dale Larson

**Change
Change
Change**

**Is A Time When
Predictability Breaks Down**

**Our Predictable Ways
Of Thinking About And Doing Things
Are Interrupted By Change**

Change Results

In Uncertainty



Change And Transition

It isn't the changes that do you in, it's the transitions. Change is not the same as transition. *Change* is situational: the new technology, the new procedure, the new worker, the new challenge. *Transition* is the psychological process people go through to come to terms with the new situation. Change is external, transition is internal.

adapted from William Bridges

Which is it



- **It is asserted that resistance to change has less to do with resistance, denial, or a bad attitude;
Rather, the issue is loss, perceived, anticipated or already experienced**

Loss and Fear

- **Refers to being deprived of or ceasing to have something that one formerly possessed or to which one was attached**
- **Fears about the future or about one's competence or about one's fit can and will have an impact on responses to change**

Things That Affect The Experience Of Loss

Nature Of Attachment

**Personality Variables, Including Tolerance
For Change**

Choices, Power, Control

History Of Losses

Social Variables

Life-change Events

Shattered Dreams

Based On work Of Wm. Worden

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.

KEN HARDY



**Loss
of
Dreams:**

*A
Special
Kind
of
Grief*

Ted Bowman

Shattered Dreams

**Losing An Emotionally
Important Image
Of Oneself, One's Family,
One's Life, One's Work,
Even One's Death**

**Losing The Possibilities Of
"What Might Have Been"**

**Abandonment Of Plans For
A Particular Future**

The Dying Of A Dream

Cue Words - Shattered Dreams

“I didn’t expect this...”

“I feel hopeless!”

“Why did I even bother...?”

“I thought it would...”

“It doesn’t matter...”

“If only”

“I don’t care any more”

“I never imagined this”

“I can’t live the way I am”

“Will I ever...?”

“You decide...”

“You don’t understand”

Inquiries about Shattered Dreams

- *When you pictured this time in your life, what did you picture?*
- *When you thought about being _____, what did you picture?*
- *If and when you thought of losses in your family, how did you think it would be, how would it happen?*
- *Tell me about the plans you and (the name of the person had)?*

Storying And Restorying After Loss

Involves Grieving The Old Story

**Before Creating The Next
(Not Necessarily New) Story**

Listen For

**Major Components/Themes/Values
Of The Old Story**

**How Can They Be Reframed In
The Next Story**



Ambiguous Loss

Losses that are:

unclear,

confusing, and for which

**future stories / outcomes
are unknown**

Etymology: “driven in both ways”

Boss

Ambiguous Loss: Conundrum

Psychological Presence

And

Physical Absence

Physical Presence

And

Psychological Absence

Responses to Ambiguity

- **Label what people are experiencing (responses will vary)**
- **Provide a structure and setting for contact**
- **Provide information**
- **Increase tolerance for ambiguity**
- **Be flexible, adapt routines, minimize helplessness, normalize situation**
- **Emphasize what can be changed or addressed and what can not...**
- **Move from “either/or” choices to “both/and choices’**

Differences:

Chronic Sorrow and Complicated Grief

- **Both contain sorrow that can be ongoing**
- **Both contain elements of depressive emotions and experience**
- **The Key Difference Is The Ability To Grow Life, Experience Joy And Fullness Regularly, Even While Also Grieving**

JOY



**SHRINKING
GRIEF**

**GROWING YOUR
WORLD**



Responses To Loss

Name Losses

Grieve Losses

Put The Loss In Perspective

Reinforce Or Build Support Connections

Set Limits

(Saying No To Some Things

So You Can Yes To Others)

Develop A Healing Plan

Use Rituals For Grieving And Healing

Resiliency

- **The capacity to spring back, rebound, and successfully adapt to adversity** – Bowman from many sources
- **Also the capacity to spring forward...**
- **Resilience is the process of, capacity for, and outcome of successful adaptation despite challenging or threatening circumstances** – Masten

Relational Resilience

- **The ability to connect, reconnect, and resist disconnection in response to hardships, adversities**

Relationships are a primary source of one's ability to be resilient in the face of personal and social hardships or trauma. Furthermore, relationships are a primary source of experiences that strengthen the individual characteristics commonly associated with resilience.

Linda Hartling

Examples of Resiliency

- **Accepted What They Could Not Change, Changed What They Could**
- **Manageable Pieces/Steps**
- **Realized: Bad Things Happen To Good People**
- **Used Creativity**
- **Healed Themselves By Helping Others**
- **Did Not Allow Bitterness To Consume / Define Them**
- **Hopeful Visions Of Future**
- **Drew On Spiritual Resources**

Dual-processing model

(Stroebe and Schut 2001)

Loss Orientation

Grief work

Intrusion of grief

Denial and
avoidance of
restoration changes

Restoration Orientation

Attending to life changes

Doing new things

Distraction, denial,
avoidance of grief

New roles, identities,
relationships

Reasonable Hope

Reasonable hope is relational

Reasonable hope is a practice

Reasonable hope maintains that the future is open, uncertain, and influenceable

Reasonable hope seeks goals and pathways to them

Reasonable hope accommodates doubt, contradictions, and despair

Weingarten