



◦ **Ambiguous Loss and Grief**
[All along the Dementia Journey]

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&

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Webinar Objectives


1. Underline the importance to family caregivers of having **supportive** opportunities to name, explore, understand and express their grief all along the dementia journey
2. Enhance 'literacy' of Caregiver Grief
3. Discuss some strategies to **welcome & support** caregiver's grief

Welcoming Grief: Why?

“Grief is the constant yet hidden companion of Alzheimer’s Disease and other related dementias”

“Grief is a companion to Alzheimer’s Disease at all phases of the disease and following death”

From: Doka, K. J. Grief and Dementia. In Doka, K. J. (Ed.) *Living with Grief - Alzheimer’s Disease*. Washington, D.C.: Hospice Foundation of America, 2004, Pages 139, 144.

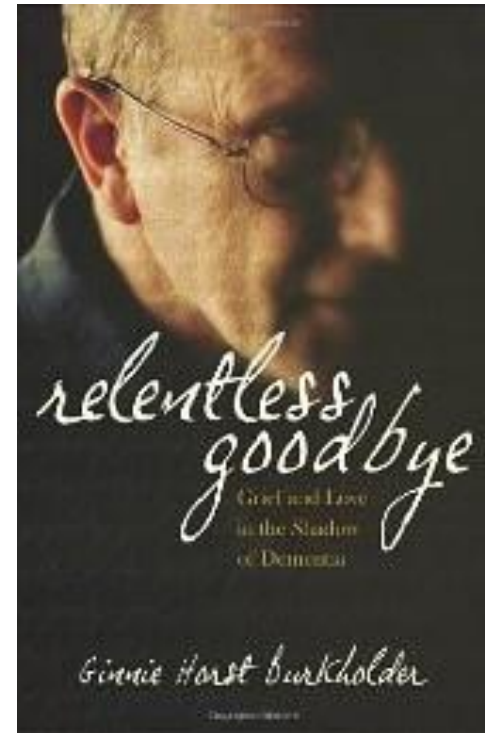


Alzheimer Disease is *'death not by a thousand cuts but by a thousand subtractions'*

Shenk, David. The Forgetting. New York, Random House,
2001

Caregiver's Need

“I needed to give voice to the whole story – to the reiterated loss, ongoing grief, underlying pain and the constant struggle in and out of acceptance”



Ginnie Horst Burkholder: Relentless Goodbye: Grief and Love in the Shadow of Dementia.

Harrisonburg, VA: Herald Press, 2012, Page 21

What's the importance of providing opportunities for Dementia Caregivers to give voice to their grief?

The Power of Listening to the Pain Is The Foundation of Healing

Without a listener, the healing process is aborted. Human beings, like plants that bend toward the sunlight, bend towards others in an innate healing tropism. There are times when being truly listened to is more critical than being fed emotional alchemy




Grief 101



Grief is
the universal process
and
necessary response
to any personally significant loss,

during the early, middle and late
stages of the progression of dementia,
not just at the time of death



Grief is
a normal human experience
and
needs to be supported



Grief is experienced in all facets of one's being:

- Physical
- Behavioural
- Thinking
- Socially
- Spiritually
- Emotionally



Grieving takes energy!

Key Pinchpoints When Grief is Acute

Noticing symptoms

Diagnosis of dementia ← **DIAGNOSIS**

Increasing loss of memory
and cognitive functioning

Loss of driver's license

No longer can go out alone

No longer can be left alone

Help with personal care
required

Need for outside assistance

Need for respite

Incontinence

← **PLACEMENT**

Aggressive or embarrassing
behaviours

Caregiver no longer
recognized

Develops connection to
another resident

Loss of communication

Loss of mobility

Inability to swallow

Declining health and
palliative care

Death and bereavement ← **DEATH**

Key Milestones along the Dementia Journey:

Pinchpoints when grief may upsurge

Components of Caregiver Grief

- Ambiguous Grief
- Chronic Sorrow
- Anticipatory Grief
- Disenfranchised Grief

- Heartfelt sadness for the person with dementia*
- Grief for personal losses*
- Worry & Felt Isolation*

* MM Caregiver Grief Inventory



Disclaimer I:

Each caregiver will experience grief
in
a unique and individual way

Disclaimer 2:

Grieving Styles – A Continuum



**Intuitive: Feeling-based & Expressive
based & Active**

Instrumental: Cognition-

Most people fall somewhere along the continuum

(Based on Martin, T & Doka, K. *Men Don't Cry... Women Do: Transcending Gender Stereotypes of Grief*. Philadelphia: Brunner/Mazel, 2000)

Caregiver Grief is composed of:

Ambiguous Grief

Grieving the psychological changes
of the person with dementia:

the 'goodbye without leaving'



AMBIGUOUS LOSS AND GRIEF

A resource for health-care providers

"All family caregivers will be grieving. It's important to address and name grief so people can talk about it and understand it. When people understand what's happening, they may be less likely to blame themselves and see themselves as a failure, and that's empowering." – Betty Anderson, caregiver grief educator and developer of "Coping with Transitions in Dementia Caregiving" education series and support group.

http://www.alzheimer.ca/~ /media/Files/national/For-HCP/for_hcp_ambiguous_loss_e.ashx



Caregiver Grief is composed of:

Chronic Sorrow

(non-finite Grief)

Pervasive, Profound, Continuing & Recurring
Grief

Relentless

[It is easier to adapt to a change that is final]



Unending Loss: An Introduction to Chronic Sorrow in Family Caregivers

By Jan Spilman
Insights Into Clinical Counselling
December 2012, Pages 5-8, 32

(published by the BC Association of Clinical Counsellors)

A comment about the 'myth' of *Closure*:

'Closure is a fabricated concept that doesn't even exist, a concept that is doing us more harm than good'

Berns, Nancy. Closure: The rush to end grief and what it costs us. Temple University Press, 2011

Her TED talk:

<http://tedxwomen.org/2012/08/16/nancy-berns-on-the-space-between-joy-and-grief/>



Caregiver Grief is composed of:

Anticipatory Grief

The present reaction to the losses that will occur in the future



Caregiver Grief is composed of:

Disenfranchised Grief

Loss that is not openly acknowledged,
socially supported or publically shared



Caregiver Grief is composed of:

**Heartfelt Sadness* for the
losses
experienced by
the person with dementia**

* MM Caregiver Grief Inventory



Caregiver Grief is composed of:

Grief for Personal Losses

- what the caregiver gives up to function in the caregiver role
- *“Personal Sacrifice Burden”**

*MM Caregiver Grief Inventory



Caregiver Grief is composed of:

**Worry
And
Felt Isolation**

*MM Caregiver Grief Inventory

Marwit-Meuser Caregiver Grief Inventory

Marwit, S.J. & Meuser, T.M.

Development and Initial Validation of an Inventory to Assess Grief in Caregivers of Persons With Alzheimer's Disease

The Gerontologist, 2002, Volume 42, Issue 6,
Pages 751-765

There is both a long (50 items) version & a short version (18 items)

Tim Jordens

Tim's mother, Shirley, aged 84 years

- Symptoms first noticed 2006
- Diagnosed in 2008
- Lives in her own home
 - Home support workers 3 times daily
 - Attends day program weekly 'to help friend Gert'

Welcoming & Supporting Caregiver Grief

- Invite
- Listen
- Be aware of a wide range of grief reactions: sadness, anger, worry etc
- Name, normalize & validate grief, which is often not acknowledged nor supported

Welcoming & Supporting Caregiver Grief con't

- Encourage 'grief work': *What are you doing to address your grief?*
- Offer resource materials & workshops about caregiver grief
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*Coping with Transitions in Dementia
Caregiving: Dimensions of Loss and Grief*

- 6-part education series for family caregivers (piloted Fall 2008)
- explore the loss and grief issues of the caregiving experience

Workbook
(electronic version is included
with DVD)

Available from:

Multimedia Services
Vancouver Island Health
Authority
Royal Jubilee Hospital
1952 Bay Street
Victoria, BC V8R 1J8

Understanding and Managing Loss and Grief



A Workbook for Dementia Caregivers

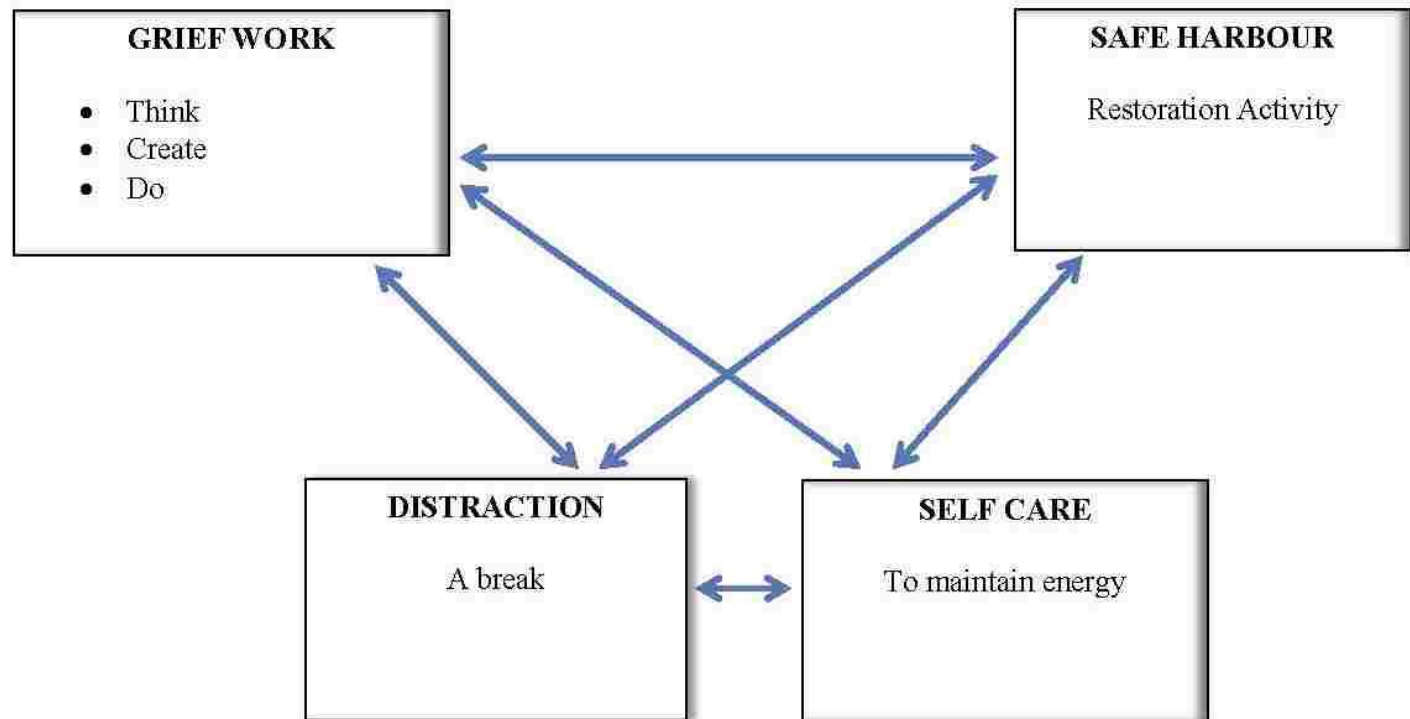
Grief Work

- A term that embraces the intellectual, emotional, physical and spiritual effort of adaptation that is required following any personally significant loss or change
- **Do** whatever puts you in touch with your feelings – in order to ‘let a little bit of air at a time out of your grief balloon’

DO

- **Think** about the losses
- Do something **creative** to acknowledge and honour the losses
- So something **practical** in honour of the losses

Grief Work is best done by 'zigzagging'





As yet, a little explored area

**How best to welcome & support
the grief of the person with
dementia?**

Professional Grief

Witness to the Relentless Goodbyes

Definition:

my own grief responses when working with a person impacted by dementia (person with dementia or caregiver)

- Will impact me as a person
- Will impact my ability to work in this 'high loss work environment'



Questions?