

Talking about Grief & Coping

Grief is normal.

What is grief?

Unlike burden, grief is often carried alone, without meaningful social recognition or support.

- ☞ Dementia grief is different than for other terminal illnesses due to communication disruption; no opportunity to resolve and reflect with the individual.
- ☞ More than just “sadness”. Grief is the *emotional work* of dealing with loss.

When does grieving *start*?

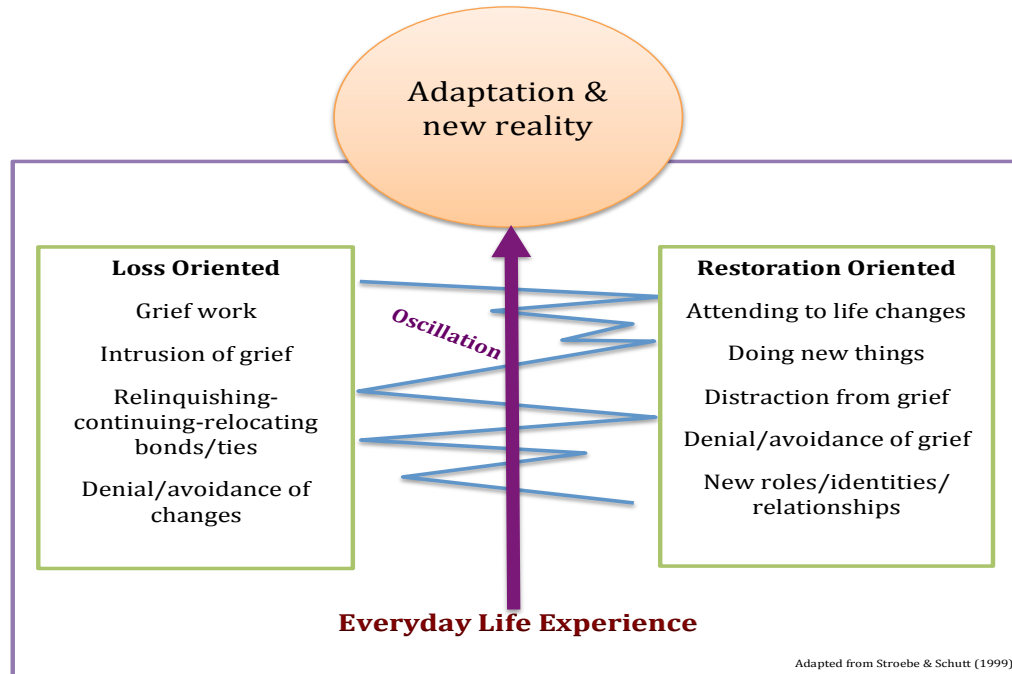
- ☞ “a series of mini-deaths”, “ambiguous loss” of the person disappearing before your eyes while being physically present still,
- ☞ “the long goodbye”

Dementia care partners experience multiple losses over time:

- ☞ Companionship/intimacy
- ☞ Communication
- ☞ Plans for life/relationship
- ☞ Freedom and loss of control
- ☞ Opportunities to resolve the past
- ☞ Losses yet to come (making hard decisions)
- ☞ LTC decisions
- ☞ End of life decisions and dying

Successful grieving requires *both* loss-oriented & restoration-oriented work, and people may be in different places at different times.





Grief characteristics of “prototypical” caregivers (adapted from Meuser & Marwit, 2001); Note that individuals may move between these stages in a non-linear, fluid way.		
	Adult child CGs	Spousal CGs
Mild/early stages	<ul style="list-style-type: none"> Minimization/avoidance of feelings Very <u>task oriented</u> Intellectualized Avoidance of loss-related discussion 	<ul style="list-style-type: none"> Openly experiencing grief <u>Reality oriented</u> w regard to future Acceptance of changes <u>Recognition and acknowledgment</u> of losses
Moderate/mid-stages	<ul style="list-style-type: none"> <u>Rapid transition</u> to reality of care Emotions are <u>raw</u>- frustration, anger may be intense, guilt, wishing parent would die, fatalism, sadness for what was Grief focused on <u>self</u> Loss focused on <u>other</u> (parent) 	<ul style="list-style-type: none"> <u>Smooth transition</u> to reality of care Emotions deeply felt but <u>not raw</u>- mainly sadness, compassion, empathy, mild frustration Grief focused on <u>other</u> Loss focused on <u>self</u>- aloneness
Severe/later stages	<ul style="list-style-type: none"> Burden lifted primarily by NH placement Interpersonal <u>regret</u>, lost relationship and opportunities Emotional shift <u>from raw</u> to reflective Focus on <u>loss</u> 	<ul style="list-style-type: none"> Burden of care eased by NH placement New burden of caring for self <u>Losses are intense</u>- identity as member of a couple, distance from family and friends Emotional shift <u>to rawness</u>- uncertainty about future, anger, bitter, sad Focus on building a new identity
Trajectory overall	<u>Most intense at mid-stage</u> , lessens somewhat at later stage; At death, also lose the identity of CG	<u>Linear increase</u> through stages; At death, also lose the identity of CG <u>and spouse</u>