



Living with Grief Long Before Death

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We will answer these questions:

- When does grief begin?
- What is the difference between grief, mourning and bereavement?
- What does normal grief look like?
- How many kinds of grief are there?
- Am I living with Ambiguous Loss and Grief?
- Am I living with Anticipatory Loss and Grief?
- What do I do when I get stuck in my grief?
- How can I help myself and my loved ones?
- What is resilience in the face of uncertainty?

Language uncertainty

Principle-based concept analysis is a method used when a concept lacks consistent usage in the scientific literature. By examining a concept in relation to four principles (epistemological, pragmatic, linguistic, logical), theoretical components found in the scientific literature can be fused into a clear definition. Future research with the concept is therefore grounded in a meaningful, scientifically based definition (Penrod & Hupcey 2005).

Quoted from: Lindauer, A. & Harvath, T.A. (2014) Pre-death grief in the context of dementia caregiving: a concept analysis. *Journal of Advanced Nursing* 70(10), 2196–2207. doi: 10.1111/jan.12411

Some types of grief found in literature/research

- Anticipatory grief or mourning
- Ambiguous
- Normal
- Delayed
- Masked
- Complicated
- Prolonged
- Traumatic
- Absent
- Frozen
- Ongoing
- Pre-loss G
- Latent
- Bereavement
- Caregiver G.
- Mourning
- Chronic grief or sorrow, reaction
- Cumulative
- Distorted
- Abnormal
- Exaggerated
- Inhibited
- Collective
- Abbreviated
- Non-death grief
- Pre-death/pre-bereavement G.
- Disenfranchised
- Grief (G)
- sorrow

ALOHA

- Hello and goodbye
- Life is a series of hellos and goodbyes.
- When the hellos matter, the goodbyes are hard.
- Goodbye to expectations, hope, function, relationships, life and so many other things
- Hello to all of the adjustments that need to be made and perhaps unexpected gifts



Mourning

- The public display of your grief
- Is only allowed and expected after death
- **Your mourning prior to death will not likely be acknowledged which leads to disenfranchised G. (no one else feels it)**
- What does your community expect from you?
- What if you have already finished your grieving, had a conflicted or abusive relationship or only feel relief?

Bereavement:

- your long term adjusting to the absence of your loved one or valued object/role/etc.
- New roads, uncertainty, constant adjustment
- Milestones, anniversaries, etc. may be particularly difficult
- Affected by both grief and mourning and while is usually described as occurring after a death the ongoing losses and adjustments required in living with life-altering and life-limiting conditions results in both grief and bereavement
- A solitary experience

Grief is healthy

- A healthy response to any loss or perceived loss, challenge or threat to something or someone we prize or value or the death or ending thereof.
- Examples:
 - Relationships
 - Jobs/identity
 - Missing people
 - Injury
 - Health conditions

Grief

- Your sensations and realities when you experience the loss or potential loss or losses of something or someone you value/prize
- No right or wrong
- It just is
- What do we do when our grief is not acknowledged by others (anticipatory and ambiguous grief)?

The Heart has its reasons, which Reason does not know

(Blaise Pascal, found in Pensees, published posthumously in 1670)

When dealing with life-altering conditions, emotions always dominate.

Making decisions based solely on emotion will likely lead to regret (demanding futile treatment, refusing consent for organ donation)

Grief: “My Heart...”



“is broke.”



It is our tears and our grief

- That cleanse the edges of the wound to allow the heart to heal
- Tears are not weakness, they do not impair your ability to reason or problem-solve
- They express emotion and often what words cannot express
- If we do not do the work of grief (ignore it, push it aside, etc.) the wound will fester and may not heal at all

“When the world as we know it is shattered, we need to come up with ways to restore meaning.”

- All of our views of our world and our role and place in it, the role and place of loved ones is challenged
- Humans are hard-wired for certainty
- How do we react when our world shifts and the future is uncertain?
- How does our community view and treat us?

Life after diagnosis:

- Families living with life-altering and life-limiting conditions experience momentous losses: e.g.: finances, function, role, identity, purpose, control, and life itself
- Some health conditions result in relentless and all-encompassing losses or changes
- Other conditions come with such uncertainty that it becomes impossible to plan ahead

Primary, secondary, tertiary, etc. losses



Cheung, J. and Hocking, P.
(2004). **The Experience of
Spousal Carers
of People With Multiple
Sclerosis.** QUALITATIVE
HEALTH RESEARCH, Vol. 14 No.
2, February 2004 153-166
DOI:
10.1177/1049732303258382

In the face of a life-altering diagnosis, when does grief begin?

- It may begin at the beginning
- When symptoms appear or a diagnosis is given
- This grief helps us to prepare for what is or may be coming (anticipatory grief)
- We ask questions, gather information, prepare, make decisions, communicate, grieve, and hold on to today

What does normal grief look like?:

- Dry mouth and throat
 - Uncontrolled trembling,
 - Sleep disturbances
 - Loss of appetite
 - Sadness,
 - Fleeting hallucinatory experiences
 - Anxiety
 - Helplessness
 - Shock
 - Stomach pain
 - Guilt
 - Hypersensitivity to noise
 - Shortness of breath
 - Weeping
 - Startling easily
 - Relief
 - Loneliness
 - Anger
 - Yearning
 - Tight chest
 - Lack energy, listless
 - Numbness
- (Corless, 2001)

Factors that Influence Grief

- Perceived Cause of the illness
- Seriousness/length of illness
- Initial and ongoing impairments/losses
- Social value of relationship to deceased (age, role)
- Gender
- Nature of the relationship with the deceased
- Financial situation
- Cultural differences
- Ability to find meaning/assign blame
- Mental and physical health of grieving person(s)
- Mental and physical health of the person living with the condition
- Coping skills
- Other life stresses
- Past death/grief experiences
- Religious beliefs
- Coping mechanisms
- Presence of family/outside support
- Ability or inability to use social support

Getting Stuck in Grief

- Complicated grief (7 – 10% of all grief experiences)
- Unable to complete tasks of daily living 4 months or so after they need to be completed
- Feeling stuck: “can’t get off the merry-go-round”
- Complex family situation
- History of mental health/substance use/other health concerns
- Can’t get past the blaming or need to find a reason/excuse
- Seek help: support groups, professional grief therapists (check philosophy)

Healthy Grief requires

- A feeling of mastery and acceptance of changes (due to natural/unavoidable circumstances, not failure)
- Can you make sense of the loss and incorporate it into a new reality?
- Can you work with your family to come to terms with this new reality?

The Work of Grief (based on Worden, 2009)

1. Accept the reality of the loss
2. Work through the pain of grief
3. Adjust to an environment in which the deceased person (affected person) is missing (psycho/socio/spiritual/emotional)
4. Emotionally relocate the deceased (this energy) and move on with living your life in your new reality (jettison grief: do something positive with it)

Anticipatory Grief

- Healthy response to anticipated death, even years in advance
- Separation anxiety may be experienced by everyone living with the condition
- May begin at time of diagnosis
- Allows time for completion of 'unfinished business'



Ambiguous Loss or Grief

- First described by Pauline Boss in 1999 in her book, *Ambiguous Loss, learning to Live with Unresolved Grief*
- “Goodbye without leaving”
- Refugees, MIAs, abductions/runaways/missing, changes due to illness/injury
- “I’m a widow waiting to happen”

Ambiguous Grief

- They are here, but they are not (need for reason)
- They are here, but we are losing pieces of them bit by bit
- What's going to happen today
- Our losses are not acknowledged
- We have no control over the situation

- “it's a miracle, you should be grateful”

- “at least...”
- ‘there's no point in visiting, he's not there”

Ambiguous Grief

- The lights are on but nobody's home

**As I was walking up the stair
I met a man who was not there.
He was not there again today.
Oh how I wish he'd go away**

Ambiguous Grief

- Physical and psychological presence and/or absence
- Constant uncertainty
- A shifting of relationships and dynamics
- No relief
- No ideal of what will come tomorrow
- Loss of intimacy, support, communication
- Our experiences are not shared by our larger community and we become separate from them

Living with Non-death related loss:

“...As time progressed, I was no longer looking after the person I had courted, married, and loved. I was looking after a person. I found, if I kept trying to look after the person I loved, it just made things worse, it presented barriers. I had to become disconnected to that part of it. . . . You have to break away from the person [who] was a lover to a person that you’re caring for.”

Cheung, J., Hocking, P (2004). The Experiences of Spousal Carers of People with Multiple Sclerosis. *QUALITATIVE HEALTH RESEARCH*, Vol. 14 No. 2, February 2004 153-166
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Ambiguous/Non-death grief

“These spousal carers thought that there was no understanding by people in general about what it is like to be a carer. In addition, they felt that although paid employment appeared to be valued, their commitment to caring for their partner at home was not valued.”

Cheung, J., Hocking, P (2004). The Experiences of Spousal Carers of People with Multiple Sclerosis. *QUALITATIVE HEALTH RESEARCH*, Vol. 14 No. 2, February 2004 153-166
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Ambiguous Grief

- Uncertainty is immobilizing
- Living with it is exhausting
- There are no social rituals that mark the changes thus no external validation (think of a funeral as validation of a death)
- Social networks withdraw

It's OK to ask why, even when there are no answers. N. Roberts (2011). The Next Always.



Pre-death grief: Marwit and Meuser caregiver Grief Inventory (MM-CGI) (designed for dementia)

- 1. Personal Sacrifice and Burden (loss of time, freedom, sleep, health)
- 2. Worry and Felt Isolation (loss of personal connection to others, worries about future)
- 3. Heartfelt Sadness and Longing (emotional response to loss of relationship)





Palliative Approach to Care and Grief

- To palliate: to cloak, cover, lessen or reduce
- Cloak and cover the symptoms, lessen and reduce the suffering for individuals and their families living with life-limiting and life-threatening illness with the goal of enhancing quality of life as you define it
- Plan for death and expect to live the best quality of life each and every day until you draw your last breath
- Advance care planning, decision-making, completion, legacy, preparation, excellence in pain and symptom, etc.

Palliative care and its emerging role in Multiple System Atrophy and Progressive Supranuclear Palsy

- Wiblin, L., Lee, M. Burn, D. (2017). In Parkinsonism and Related Disorders, 34, 7 – 14.
- DOI: <https://doi.org/10.1016/j.parkreldis.2016.10.013> |

Some things you need to know if you are grieving:

1. You are lovable even when you are a confused mess.
2. Crying is a gift.
3. Almost every thought, feeling, and behaviour is normal.
4. You are not alone.
5. People are uncomfortable with grieving people.
6. No matter how bad you feel, you will survive.
7. It takes as long as it takes.

What do I do with my grief?

1. Don't 'do' anything.
2. Remember that grief is normal and healthy.
3. Don't try to keep it all together.
4. If you need help, get it.
5. Be yourself no matter what.
6. Cry, if you can.
7. Take care of your body.
8. Keep it simple.
9. Let time pass.
10. Be with caring people.







Grandpa Al and Jake, April 2016

Grandpa Al: Comfort and Resilience





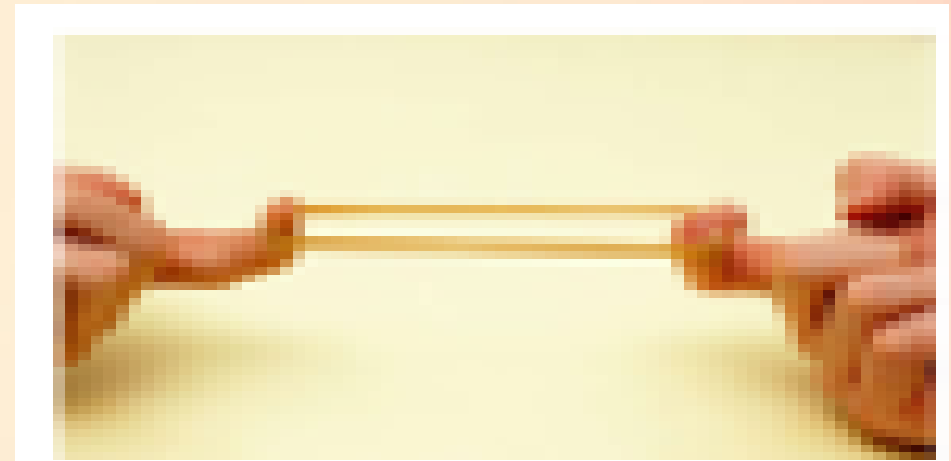
Isabelle - Peaceful



Isabelle - Rapture

Developing and Enhancing Resilience

- Resilience is the ability to regain your own shape after being stretched
- It develops when you can think about your own death and the death of your loved ones, ongoing losses and changes, do not project your fears, need or wants onto others
- Recognize what belongs to whom



We Develop our own resilience through:



Exercise!!! Diet
and Nutrition



Laughter



Doing something positive with
our emotions

Resilience



Learn something
new and fun



Read and talk
about dying



seek counsel and support

Find comfort and support by:

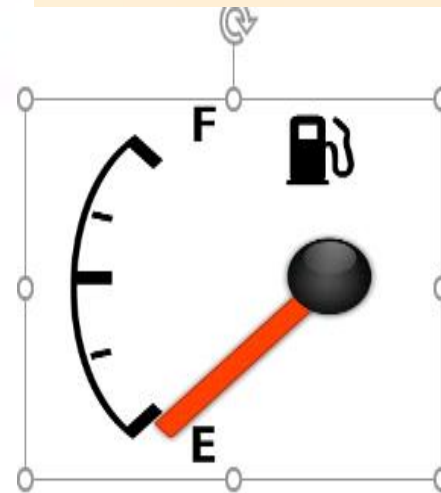
- Knowing very few individuals and professionals recognize ambiguous/pre-death/life altering grief
- Ignore well meaning clichés and false reassurances: “count your blessings” “at least...” “everything will get better” “have faith” “you need to stay strong” etc.
- Distraction therapies (music, books, movies)
- Jettisoning therapies (volunteer, garden, create, exercise)
- Expressive therapies (journaling, art, dance, poetry)
- Acceptance therapies (being present, WAIT, gentle massage, touch, energy, aroma, music therapies)



Say "NO"

Put yourself first (can't give what you don't have)

Journal/ confidant/pray/find meaning and joy in moments



Useful Resources

- Fox, S. Azman, A. Foley, MJ, O'Toole, O. ,Timmons, S. (2017). Anticipatory grief in carers of persons with Parkinson's Disease, *Age and Ageing*, 46: iii13–iii59
doi: 10.1093/ageing/afx144.99
- Lindauer, A. & Harvath, T.A. (2014) Pre-death grief in the context of dementia caregiving: a concept analysis. *Journal of Advanced Nursing* 70(10), 2196–2207. doi: 10.1111/jan.12411

Useful Resources

- Shear, M.K., Ghesquiere, A., Glickman, K. (2013) Bereavement and complicated Grief. *Current Psychiatry Reports*, 15:406. <https://doi.org/10.1007/s11920-013-0406-z>
- Niemeyer, R.A. (2012). *Techniques of Grief therapy, Creative Practices for Counselling the Bereaved*.
- Search: grief, your province
- Search: support groups, your condition
- Search: provincial/local mental health clinics

Useful Resources

- J.H. Carter a,* , K.S. Lyons b, A. Lindauer b, J. Malcom. (2012). Pre-death grief in Parkinson's caregivers: A pilot survey-based study. *Parkinsonism and Related Disorders*, v18, S15 – S18
- Sandra L. Neate*, Keryn L. Taylor, George A. Jelinek, Alysha M. De Livera, Chelsea R. Brown and Tracey J. Weiland. (2018). Psychological Shift in Partners of People with Multiple Sclerosis Who Undertake Lifestyle Modification: An Interpretive Phenomenological Study.. *Frontiers in Psychology*, January 2018, 9:15. doi: 10.3389/fpsyg.2018.00015