



# Ambiguous Loss and Grief in Dementia

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# Overview

1. Down's Syndrome and Alzheimer's disease
2. Defining ambiguous loss
3. Defining types of grief
4. "Paradoxical Thinking"
5. Support



# Alzheimer's disease in people with Down syndrome

- People with Down syndrome have an additional copy of the 21st chromosome, which can cause an over-production of the protein that develops Beta-amyloid plaques in the brain - a hallmark characteristic of Alzheimer's disease
- The incidence of AD is 3 to 5 times greater than in the general population
- 25 percent of individuals with Down syndrome, over the age of 35, display the symptoms commonly associated with Alzheimer's disease (NDSS, 2009)
- Risk increases with age
- Not everyone with Down syndrome develops Alzheimer's disease.



# Down syndrome and Alzheimer's disease

Alzheimer Society

## Down syndrome and Alzheimer's disease

### What is Alzheimer's disease?

Dementia is a syndrome consisting of a number of symptoms that include a reduced ability to perform familiar tasks, impairment of memory, judgment and reasoning, and changes in mood and behaviour. Some dementias are caused by treatable conditions such as depression, thyroid disease, infections or drug interactions. However, treatments are not yet available for the progressive, irreversible dementias in which nerve cells in the brain become damaged and eventually die. Alzheimer's disease is the most common type of dementia, and currently there is no cure available.

In 2022, the Alzheimer Society of Canada released the Landmark Study Report, stating that there are 600,000 people in Canada living with dementia<sup>1</sup>. Other types of dementia resemble Alzheimer's disease in that they also involve a progressive degeneration of brain cells that is currently irreversible. Some other types of dementia are vascular dementia, Lewy body dementia, frontotemporal dementia, Creutzfeldt-Jakob disease and mixed dementia. The brain abnormalities that occur with Alzheimer's disease can start as early as one's 30's or 40's. However, for most people symptoms usually begin in one's 60's or 70's. Improved testing techniques, plus the willingness of people to consult a doctor at the first signs of symptoms, are now leading to earlier diagnoses of Alzheimer's disease.

### What is Down syndrome?

Down syndrome is a genetic disorder in which an individual has three copies of the 21st chromosome instead of two. In Canada, the incidence of Down syndrome is approximately 1 in every 750 live births<sup>2</sup>. The condition is not related to gender, race, nationality or socio-economic status and the exact cause of Down syndrome is still not known.

Down syndrome is the most common genetic cause of severe learning disabilities in children<sup>3</sup> associated with developmental delays, learning difficulties, health issues and some physical abnormalities. Individuals with Down syndrome vary in their abilities, and it is important to recognize that each person has unique attributes and strengths.

Life expectancy of individuals with Down syndrome has increased due to improvements in health care and decreased infant mortality. The life expectancy of an individual with Down syndrome tends to be in the 60's. Persons with Down syndrome may be predisposed to certain illnesses and medical conditions, but that genetic arrangement does not guarantee their development. The same illnesses and conditions are also present in the general population<sup>4</sup>.

<https://alzheimer.ca/sites/default/files/documents/Down-syndrome-and-Alzheimers-disease-Alzheimer-Society-2024.pdf>

1 Alzheimer Society of Canada (2022). 2 Congenital Anomalies in Canada: A Perinatal Surveillance Health Report, Public Health Agency of Health Canada (2013). 3 MayoClinic.org (2014). 4 The Canadian Down Syndrome Society (2009).



*Grief* and *loss* are often associated with death



Photo credit: theguardian.com

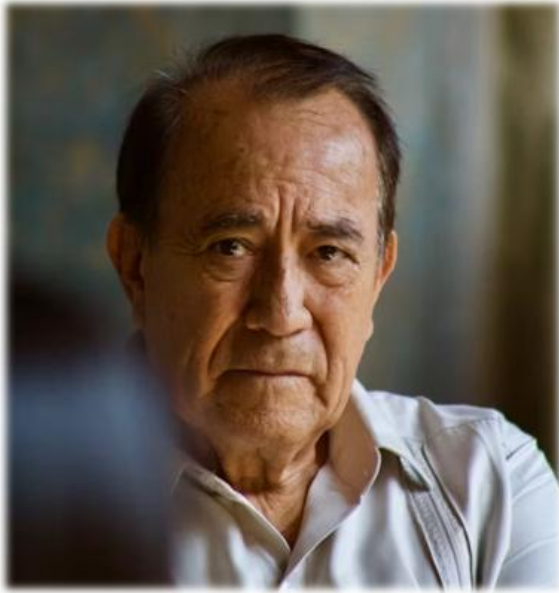




*Ambiguous loss* is associated with dementia



# 3 Types of Grief



**Anticipatory  
Grief**



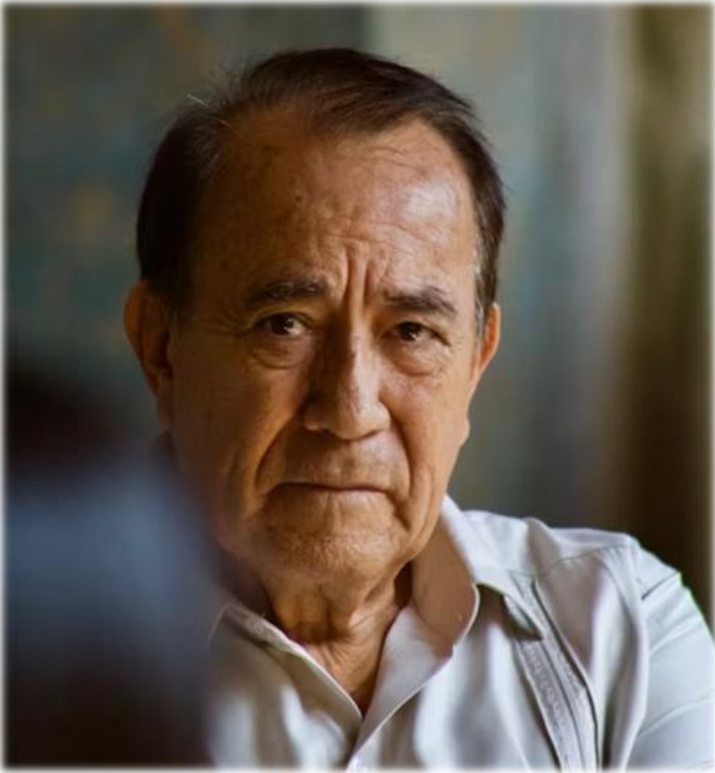
**Ambiguous  
Loss**



**Disenfranchised  
Grief**



# Anticipatory Grief



Is the present reaction to the losses expected in the future.

Feelings are related to future loss; what you thought life was going to be like





# Ambiguous Loss



## Physical Loss

Physical absence and psychological presence



## Psychological Loss

Physical presence and psychological loss

# Ambiguous Loss

Defined as a loss that occurs without completeness or closure

- psychological loss
- physical loss

Incomplete or unclear loss, causing confusion and distress



# Disenfranchised Grief

Refers to grief which is hidden or not validated



# Grieving styles

## Instrumental Grieving Style



## Blended Grieving Style



## Intuitive Grieving Style



Do

Feel & Do

Feel



# Grieving is a normal and healing response to loss



# Paradoxical Thinking

- “**Both-and thinking**” is knowing that there is truth in two contradictory ideas (Boss, 2011, p. 19)
  - Being able to see the person as both *here* and *gone*
  - Balancing two different ideas at once is less stressful than constantly looking for an absolute solution
- Try to avoid absolute thinking



# Paradoxical thinking

**“Both-And”** thinking is knowing that there is truth in two contradictory ideas

(Boss, 2011, p. 19)

Instead of “either/or” ....	Try “both/and” ....
I can <u>either</u> take care of the person living with dementia <u>or</u> myself.	I can take care of <u>both</u> myself <u>and</u> the person living with dementia
I <u>either</u> care about the person with dementia exactly as they are now, <u>or</u> I miss how they used to be.	I <u>both</u> care about the person living with dementia exactly as they are now <u>and</u> miss how they used to be.
I <u>either</u> ....., <u>or</u> I .....	I <u>both</u> ....., <u>and</u> I .....





Many caregivers agree that although their work is difficult, it also has its rewards.



# The Affects of Ambiguity

- Impacts relationships
- Affects the staff and family well-being
- Confuses the decision-making process
- Freezes grief
- Blocks coping





## DEMENTIA AND STAFF GRIEF

A resource for healthcare providers

*"The residents are very active in programs, we have a lot of fun together and a special bond develops. When a resident passes away, it gets stuck in my mind for a while. If I want to cry, I'm going to cry."*

[https://alzheimer.ca/sites/default/files/documents/as\\_dementia-and-staff-grief\\_1.pdf](https://alzheimer.ca/sites/default/files/documents/as_dementia-and-staff-grief_1.pdf)



- What is grief?
- Why is the issue of staff loss and grief important?
- The impact of unattended grief on staff and quality of care
- Grief support for staff is essential to person-centred care
- The impact of unattended grief on person-centred care
- Educating staff in a palliative approach enhances care and supports their emotional health
- Case study: A palliative approach to caring for people with late-stage dementia
- Valuing what you do in end-of-life care
- Honouring and remembering the person after death
- What employers can do to support staff in managing loss and grief
- Peer support strategies to help manage grief and improve care
- Case study: Peer-led debriefings offer meaningful grief support for direct care staff
- Strategies to support grief and loss in the workplace
  - Self-care strategies for staff: Taking the time to look after yourself
  - Employer strategies: Supporting staff effectively
- Additional Resources

# **Acknowledging Staff Grief When Working with Dementia: It Is Vital**

<https://vimeo.com/119876282>







## SUPPORTING CLIENTS THROUGH AMBIGUOUS LOSS AND GRIEF

Strategies 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."*

<https://alzheimer.ca/sites/default/files/documents/Ambiguous-Loss-Health-Care-Providers-Alzheimer-Society-2024.pdf>



AlzheimerSociety



## AMBIGUOUS LOSS AND GRIEF IN DEMENTIA

A resource for individuals and families

*"The word 'ambiguous' helped me understand what was going on. I'm still married to my wife. I love her, but I don't live with her. I've always been crazy about her and still am. She's looked after, but it is a huge loss for me. The ambiguity is exactly how I feel."*

[https://alzheimer.ca/sites/default/files/documents/ambiguous-loss-and-grief-for-individuals-and-families\\_1.pdf](https://alzheimer.ca/sites/default/files/documents/ambiguous-loss-and-grief-for-individuals-and-families_1.pdf)





# Pauline Boss' Seven Guidelines for the Caregiving Journey



# 1. Find Meaning

- How do you make sense of this?
- **Name it** - it helps to recognize that this is ambiguous loss
- Use **paradoxical thinking** (both/and)
- Find forgiveness and spirituality
- Continue, but adapt rituals





## 2. Balance Control with Acceptance

- The main cause of distress is not being able to resolve the problem...not the burden of caregiving or the severity of the disease.

### What Helps?

- Recognizing that you can't control everything
- Decreasing self-blame and externalizing it to the ambiguity
- Mastering one's internal self (e.g. meditation, prayer) helps to decrease stress



# 3. Broaden Your Identity

- **Examine roles in your life:**
  - Who's in?
  - Who's out?
  - Who plays what roles now?
- **Focus on reconstructing the roles that you play**
- “The goal is to revise your identity to fit the ambiguity” (*Boss, 2011, p. 119*)



# 4. Manage Your Mixed Emotions

- **Learning to live with ambivalence:**
  - “You can benefit from having small rituals along the way to mark each new loss as it occurs” (*Boss, 2011, p. 95*)
  - Acknowledge the mixed emotions associated with supporting a person with dementia
  - Normalize anger and guilt
  - Accept that conflicting feelings are normal
  - Talk about feelings with someone



## 5. Hold on and Let Go

- Recognizing the person is both here and gone
- Grieve what is lost
- Celebrate what remains:
  - Creating new memories, oral history, scrapbooks
  - Finding new connections



# 6. Rediscovering Hope

- What gives you hope?





# 7. Take the Time to Mind Yourself

- Seek professional support if you feel hopeless and depressed
- Find a regular support or social group to become involved in



What is one thing you have been doing to  
take care of yourself?

What is one thing that brings you energy  
and/or joy?



# References

- Alzheimer Society Canada Loss and grief materials.
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*.
- Boss, P. (2011). *Loving someone who has dementia: How to find hope while coping with stress and grief*.
- Vancouver Island Health Authority (2012). *Understanding and managing loss and grief*.



# Programs and Services

Supportive  
Counselling

Education  
Sessions

The Music  
Project

Social and  
Recreational

Finding Your  
Way

Minds in  
Motion

AlzEducate

Resource  
Library

Group  
Sessions

We welcome people of any age, gender identity and expression, race, colour and sexual orientation.



Create your Alzeducate account at [www.alzeducate.ca](http://www.alzeducate.ca)

Questions? Email: [alzed@alzon.ca](mailto:alzed@alzon.ca) or visit [www.alzeducate.ca](http://www.alzeducate.ca)

### **For Health Care Providers:**

- Introduction to Dementia (certificate program)
- U-First! (certificate program)
- Aging and the Senses
- Communication
- Person Centered Care
- Dementia Friendly Communities
- Finding Your Way
- Medication Overuse in Older Adults ....and more





# High-quality, best-practice dementia education for all.

Empowering people to live well with dementia or care for someone living with dementia.

New to ALZeducate? Create an account!

# Living Safely with Dementia: Finding Your Way®



**FINDING Your Way®**

*For people with dementia,  
every step counts.*

Finding Your Way® offers practical advice on how people with dementia can stay safe and active.

It shows how to best deal with the risk of going missing.

**[www.findingyourwayontario.ca](http://www.findingyourwayontario.ca)**

**<https://www.youtube.com/watch?v=pJYTGzErPRs&list=PLeFtAiSQ7yBE02oNu6NVM5zhT1GDHVSQx&index=9>**





# For people with dementia, every step counts.

**Finding Your Way®** helps people living with dementia, their families, caregivers and communities to recognize the risk of going missing, be prepared for incidents of going missing, and ensure that people with dementia can live safely in the community.

60 percent of people with dementia-related memory problems become lost at some point. **Watch the video below** to explore the ways Finding Your Way® can help.

**Important:** If you know someone with dementia who has gone missing, please call **911 Immediately**.

[Watch Video >](#)

[Download the Identification Kit! >](#)



# Contact us!

Phone: 519-742-1422 or 519-836-7672

Web: [www.alzheimerww.ca](http://www.alzheimerww.ca)

- Kitchener-Waterloo: 831 Frederick Street
- Cambridge: 1145 Concession Road
- Guelph: 202- 25 Wellington Street West



# Questions & Comments

## Thank You!

