


INTEGRATED CARE IN PARKINSON'S DISEASE SERIES  
JANUARY 15, 2022

# Exploring Parkinson's Related Grief


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**Presentation Outline**

### OVERVIEW

- Grief in PD
- PD Care Partner Perspective
- Understanding Grief
- Navigating Grief throughout the Disease



## Grief & Loss in Parkinson's Disease




## Grief and Loss: Living with PD

**DISEASE CHANGES OVER TIME**  
Symptoms (motor + non-motor) may fluctuate and/or gradually worsen over time  
Benefit and responsiveness to medications may vary

**SYMPTOMS MAY LIMIT DAILY ACTIVITIES & FUNCTIONING**  
May limit mobility and independence  
May limit engagement in previously enjoyed activities  
May contribute to 'shared' losses with support partner(s)

**IMPACT ON QUALITY-OF-LIFE**  
Presence of grief (independent of depression and motor symptoms) predicts poor quality-of-life ratings



Klueger et al., 2018


## Anticipatory Grief in Parkinson's Disease

**REFERRED TO AS ANTICIPATORY LOSS OR PREPARTORY GRIEF**

Anticipating future or upcoming losses  
Experienced by persons living with PD and care partners  
Not found to lessen post-death bereavement response

**OFTEN APPEARS EARLY IN THE DISEASE COURSE**

*What could life look like if I had never been diagnosed?  
How will this progress?  
How will I manage changes in my walking or thinking abilities?*



Gilliland & Fleming, 1998

## Grief & Loss for PD Care Partners



### PD Care Partner: Here-and-Now Losses

#### REACTION TO DISEASE RELATED LOSSES IN LOVED ONE

Physical, cognitive, emotional, and behavioral changes observed in loved one  
Often experience *multiple, simultaneous losses*

#### CHANGES TO RELATIONSHIP DYNAMICS

May reduce emotional intimacy and sense of closeness (often related to cognitive changes)

#### CHANGES IN ROLES & RESPONSIBILITIES

May assume new and/or additional roles at home and for loved one

### PD Care Partner: Anticipating Future Losses

#### ANTICIPATORY GRIEF

Recent research indicates anticipatory grief is common in PD care partners  
Associated with high levels of burden  
Present in long-distance care partners

#### CARE PARTNER ANTICIPATORY GRIEF HIGHER IN RELATION TO:

- Presence of PD hallucinations
- Cognitive impairment (repetitive questions) and agitation
- More advanced disease stage
- Younger age of loved one
- Mobility restrictions
- Sleep disturbances
- Assisting with feeding, bathing, dressing, & eating



## Understanding Grief & Loss



### Overview of Grief

- Emotional response to loss (typically, sadness & pain)
- Expression of grief varies widely
- No predictable trajectory through grief phases
- Timeline for grief varies widely
- May be acute or longer period of time depending on other factors

Hoopes Foundation of America

### HOW MIGHT GRIEF APPEAR?

#### Emotions

- Sadness related to loss
  - May or may not manifest as tearfulness
- Apathy
- Emotional numbness
- Anger regarding loss
- Helplessness
  - Learned to anything to stop the progression
- Trouble experiencing positive emotions

#### Thoughts

- Preoccupation (heightened attention) with loss and reminders of loss
  - I am constantly reminded of what I cannot do anymore
- Difficulty adjusting or acknowledging loss
  - I just want my old life back before PD

#### Physical

- Fatigue
- Sleep disturbances

#### Behaviors

- Social isolation
- Absentminded behavior



Worden, 2018

### WHEN MIGHT GRIEF (OR ANTICIPATORY GRIEF) APPEAR IN PD?



#### Initial Diagnosis

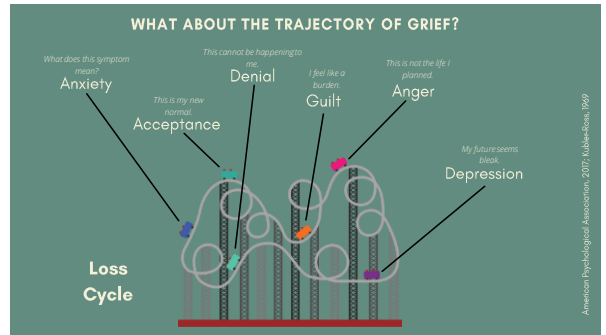
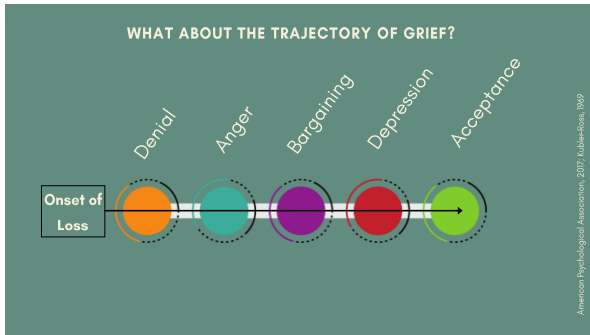
Planning for the future

#### Adjusting to Changes in Symptoms or Functioning

Continuing to recalibrate to a 'new' normal

#### End-of-Life Care

Discussing final wishes  
Anticipating bereavement



### WHAT ABOUT THE STYLES OF GRIEF?

#### Intuitive Grievers

- Experience grief as strong waves of emotions
- Transparent expression of emotions
- Healing occurs through feeling and processing emotions
- Might benefit from support groups

#### Instrumental Grievers

- Experience grief as cognitive and physical manifestations
- Less outward expression of emotions
- Healing occurs through introspection and problem-solving
- Traditional support groups might not be best fit
- Think distractions (activities/projects), and informational/educational groups

Doka & Marmen, 2011

### Navigating Grief Across the Disease Course

### CULTIVATING SELF-AWARENESS

Grief responses will vary but look inward for your unique experience

*Move gently toward your grief - It is ok to feel it.*

Ask Yourself:  
 - What am I feeling in my body?  
 - What am I feeling emotionally? [LABEL IT]

You can make room for both abilities and losses simultaneously in your mind

Considering sharing with your care or support partner

### Recognize Your Grief Symptoms

### ADAPTATION TO LOSS

PD related losses can seem overwhelming and unending

Internal Adjustment:  
 Adjusting to a new sense of self with a changing body  
 Recognize preserved (or adapted) abilities  
 What makes you feel like you?  
 Where do you have control in your life?

External Adjustment:  
 Could additional supports lessen the burden of change?  
 Openness to accepting help

### Adjusting to Losses

Perkinson's Foundation

**ADAPTATION TO LOSS –  
ALONGSIDE YOUR CARE PARTNER**

Family units and individual members experience vast differences in coping to loss

Family or dyad tasks:

- **Acknowledge** the loss and meaning
- Allow for **emotional expression** from all members
  - *Is emotional sharing hindered or encouraged?*
- Determine need for **role readjustment within family** (reduces chaos)
- Continual **readjustment** may be needed in context to PD changes
  - *What are the unspoken rules for sharing in your family?*

**Adjusting to Losses as a Family Unit**



Worden, 2018

**EXPECT THE UNEXPECTED**

Day-to-day activities may need to have a "back-up" plan to account for symptom changes

- Fatigue
- Motor symptoms

May increase sense of control

Emphasis on flexibility and adaptability

With practice, 'Plan B' planning becomes more routine

**Create a Back-Up Plan**



Kalb et al., 2012

**GRIEF HAS A TENDENCY TO TAKE OVER – IMPORTANCE OF MAINTAINING YOUR OVERALL HEALTH**

Task: Allowing yourself to grieve and caring for other dimensions of health

- Maintaining your physical activities (or exercise)
- Rest breaks/naps
- Medication schedule
- Engaging in social activities
- Fueling your body with healthy foods

**The Power of Self-Care**



**STRENGTH THROUGH YOUR SUPPORT SYSTEM**

Examine your current support network

- *Any room for changes to fit your needs?*

Composition may change over the course of the disease continuum, as your needs change

- Start building your team early
- Adjust along the continuum

Examples:

- Primary support partner
- Family/friends
- Others living with PD (or other PD care partners)
- Religious/spiritual leader
- Mental health provider

**Build your Grief Care Team**



**COUNSELING**

Encourages healthier ways to adapt to grief and loss

Individualized to your unique situation and goals for treatment

May be beneficial to consider:

- If grief response interferes with daily and self-care activities
- In cases of complicated or prolonged grief responses

**Mental Health Therapy**



**AMBIGUOUS GRIEF SERIES**

Parkinson's Foundation Program

- Online **Care Partner Series on Ambiguous Loss**

Link: <https://parkinson-foundation-online-courses.thinkific.com/courses/care-partner-program-ambiguous-loss>

**Grief Support for PD Care Partners**



## Summary

GRIEF CAN BE COMMON AND  
UNDERRECOGNIZED IN PD

GRIEF AND LOSS ARE NORMAL BUT  
HIGHLY INDIVIDUALIZED  
EXPERIENCE

MULTI-STEP APPROACH CAN HELP  
NAVIGATE GRIEF AND LOSS RELATED  
TO PD