

Bridging the Gap:

EMPOWERING COMMUNICATION,
INDEPENDENCE, AND RESILIENCE FOR
PARKINSON'S CAREGIVERS AND LOVED ONES

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The logo for New Mexico State University, featuring the letters "NM" stacked above "STATE" in a serif font, enclosed within a white square that is itself centered within a larger maroon square.

NM
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Who Am I?

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THANK YOU!!



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Goals of Presentation

Enhance communication and emotional connection



Learn strategies to improve communication and strengthen emotional bonds between caregivers and persons with Parkinson's (PWP's).

Goals of Presentation

Foster Independence and Support Autonomy

Discover ways to empower your loved ones to maintain independence and self-worth through supportive caregiving techniques.

AUTONOMY
THE DESIRE TO BE
SELF DIRECTED



Goals of Presentation

Build Resilience and Navigate Ambiguous Loss



Gain tools to cope with the emotional complexities of Parkinson's disease, building resilience together.

Communication and Connection

Good communication is at the heart of every healthy relationship.

- There are some communication changes that happen naturally over time; for example, as we age, we might have a harder time hearing.
- But, persons with Parkinson's Disease (PD), might experience increased challenges:
 - More than one-third of PD Persons are more likely to experience a conversation breakdown due to symptoms specific to PD including:
 - Changes in speech
 - Decreased facial expression
 - Anxiety
 - Social isolation

<https://www.parkinson.org/blog/care/communication>, 2024)



Communication and Connection

- The communication challenges can be hard on everyone; caregivers might feel a wide array of feelings (frustration, sadness, disappointment, distant, etc) and so might PWP (persons with Parkinson's) resulting in a breakdown of communication.
- It is important to remember, the breakdowns are no one's fault; just a result of crossed lines.
- And, crossed communication or communication breakdowns can increase caregiver stress, leading to burnout.

(<https://www.parkinson.org/blog/care/communication>, 2024)



Communication and Connection



Action Steps:

- **Pick a time** a day that might facilitate conversation (think about medication schedule, time in with the PWP is not tired)
- **Be observant** (be aware of social cues/body language)-check for indications the person may have not understood (looking away, disinterest).
- **Eliminate distractions**-turn off the TV, face the person, avoid talking from one room to another.

Communication and Connection






Action Steps:

- **Remain calm**—no need to elevate your voice more and more if a person is not understanding; find another way to communicate.
- **Don't talk over**-allow time for a response, it's ok to go slow.



The SPEECH Method

- Spotlight your face: 
- Pause between sentences: 
- Empathize & be patient: 
- Ease their listening: 
- Control the environment: 
- Have a plan:




(Kerry, 2021: <https://parkinsonsblog.stanford.edu/2021/01/communication-strategies-for-parkinsons-care-partners-webinar-notes/>)




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Foster Independence and Support Autonomy

Independence is an important part of adulthood, but can be challenging in the presence of PD.



Fostering independence and autonomy in PWP conveys respect, preserves dignity, and enhances quality of life.



The following are practical examples of ways in which to foster independence in a safe and supportive manner.

Foster Independence and Support Autonomy

Encourage Participation in Daily Activities

What to Do:

Allow the person with PD to participate in tasks like dressing, eating, and grooming at their own pace.

Why It Matters:

This fosters a sense of accomplishment and maintains motor skills.

Example:

Provide adaptive utensils or slip-on shoes to make tasks easier without taking over completely.

Foster Independence and Support Autonomy

Provide Choices

What to Do:

Offer options whenever possible, such as deciding what to wear, eat, or do for leisure.

Why It Matters:

Giving choices reinforces autonomy and reduces feelings of helplessness.

Example:

“Would you like to wear the blue sweater or the gray one?”



Foster Independence and Support Autonomy

1

Use Assistive Devices

2

What to Do:
Introduce tools like walkers, canes, or voice-activated devices that support independence.

3

Why It Matters:
These devices can enhance mobility, communication, and daily functioning.

4

Example:
Provide a walker with a basket so they can carry items independently.

Foster Independence and Support Autonomy

Promote Social Interaction

What to Do:

Encourage them to engage in social activities, hobbies, or community groups.

Why It Matters:

Social connections improve mental health and reduce dependency on caregivers.

Example:

Help them join a local Parkinson's support group or art class.



Foster Independence and Support Autonomy

Patience	Be Patient and Avoid Over-Helping
What to Do:	Resist the urge to step in unless necessary, even if it takes longer for them to complete tasks.
Why it Matters:	Over-helping can undermine confidence and create dependency.
Example:	Allow them to button their shirt, offering assistance only if asked.



Build Resilience and Navigate Ambiguous Loss

- **Ambiguous Loss**-first defined by Pauline Boss, a family therapist, in the 1970s.
- Refers to a loss that is unclear or unconfirmed and does not have a resolution.
- It can be a response to a psychological absence (i.e. a person is physically there, but not emotionally or mentally available).
- As PD progresses, it is not uncommon for caregivers to experience this type of loss and grief.



Build Resilience and Navigate Ambiguous Loss



- With PD, many aspects of personhood may be lost:
 - *Loss of aspects of former personality,*
 - *Loss of identity and sense of control over one's life,*
 - *Loss of meaning in life, and loss of the expected or planned future.*
- Family members may feel frozen, missing the person their loved one used to be, and yet the loved one is still there – just different. Families cope with grief in different ways.



Build Resilience and Navigate Ambiguous Loss

All the feelings associated with ambiguous loss are important to feel and be aware of.

Can range from helplessness, hopelessness

- Sadness to anger
- Uncertainty



Build Resilience and Navigate Ambiguous Loss

- The goal is to work toward building resiliency to live with ambiguous loss because there may be no solution to make these feelings go away.
- Sometimes it is necessary to adjust our natural need for control and certainty in life, to accommodate change and factors over which we have little or no say.



Build Resilience and Navigate Ambiguous Loss: How to Do It



**Finding or making meaning:
making sense of your losses.**

Name your problem.

Making meaning is a responsibility – no one else can do it for us.

Reaching out for and accepting support from others.



**Understanding the role of control:
adjusting the need for control and
accepting uncertainty.**

Accept lack of control.

Decrease self-blame.

Don't focus on uncertainty.

Focus on what you know and can control.



Build Resilience and Navigate Ambiguous Loss: How to Do It

Who am I now? Weathering the change of identities:

Be honest about the changes in yourself and others.

Discuss roles and expectations. Include other family members too. Often, they want to be included.

Be open to change.



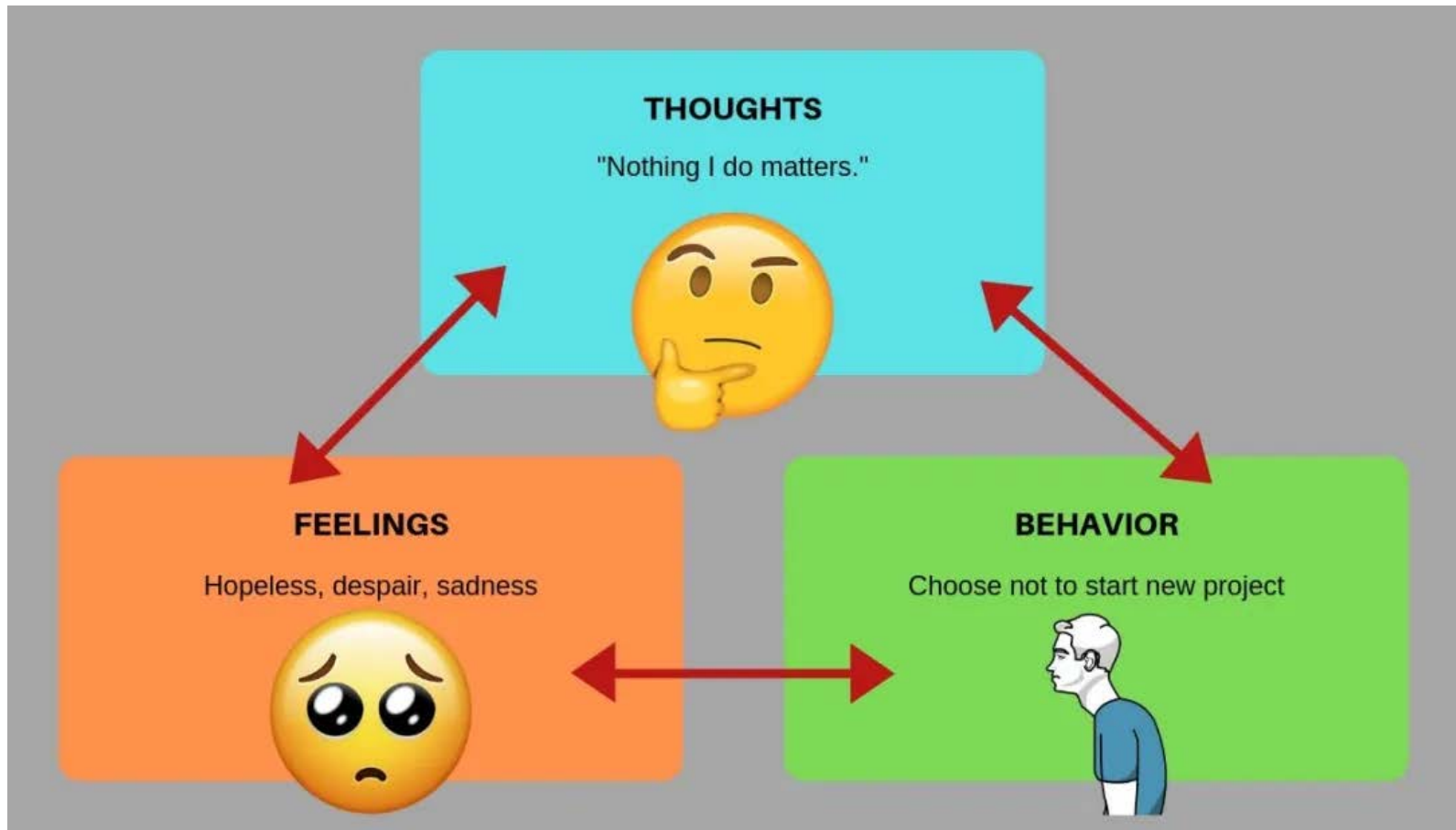
Build Resilience and Navigate Ambiguous Loss: How to Do It



Thoughts Matter:

1. Try to minimize negative thinking, or that you should just “get over” your feelings.
2. It is okay to normalize all feelings (anger, frustration, sadness, etc.), but try to express your feelings in a healthy, non-harmful way.
3. Accept ambiguity; practice both/and thinking: rather than feeling one specific way to the exclusion of other feelings, you can feel both love for the person you are caring for AND grieve that they are no longer who they used to be.

Thoughts and Feelings



Getting Rid of ANTs (automatic negative thoughts)



ANT

Adaptive Thought

“I’m failing as a caregiver.”

“Being a caregiver doesn’t mean I have to be perfect; I’m doing my best to love and support my PWP and help manage challenges to the best of my ability.”

“I have no time for myself, but this is really selfish of me.”

“Taking care of myself isn’t selfish, it’s necessary! And, when I take care of me, I’m able to re-charge and better equipped to care for others.”

“If they are upset, it’s my fault.”

“It’s natural for PWP to feel frustrated by the challenges they face. I can’t control the emotions of others, but I can offer understanding and compassion.”

“I should have done more to prevent this from happening.”

“Parkinson’s is a complex disease with many factors, and I am doing the best I can with the knowledge and resources I have.”

I hope by now...



- You can implement strategies to improve communication and strengthen emotional bonds between caregivers and PWP.
- You can empower your loved ones to maintain independence and self-worth through supportive caregiving techniques.
- You can apply tools cope with the emotional complexities of Parkinson's disease, building resilience together.





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