



MIND MATTERS

An interactive series hosted by the
O'Donnell Brain Institute's
Total Care Program in partnership
with DFW Parkinson's Resource

SESSION 2: BUILDING CONNECTION AND BELONGING IN PARKINSON'S

Addressing Loneliness, Stigma and Social Barriers

This toolkit is designed to help you better understand, reflect on, and navigate the emotional aspects of Parkinson's with clarity and compassion.

INTRODUCTION

Belonging is not a luxury — it is part of health, coping, and quality of life.

Parkinson's can impact how we connect with others — not because connection matters less, but because it often becomes harder.

This toolkit is designed to help you:

- Understand the barriers to connection
- Reflect on your own experiences
- Practice real-life responses
- Take small, meaningful steps toward connection

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UNDERSTANDING CONNECTION

Three Key Experiences

EXPERIENCE	MEANING
CONNECTION	• Feeling like you belong and matter
ISOLATION	• Not enough interaction or opportunity
LONELINESS	• A gap between the connection you want and what you have

Loneliness isn't about being alone — it's about feeling unseen.

WHY THIS MATTERS

- Connection impacts quality of life
- Loneliness is linked to worse symptoms and well-being
- Social roles protect identity (friend, partner, community member)

Connection is not “extra” — it is part of living well with Parkinson's.

WHY CONNECTION GETS HARDER

- Physical changes (movement, voice, fatigue)
- Communication challenges
- Anxiety, apathy, or low confidence
- Stigma or fear of being misunderstood
- Logistics (transportation, timing, energy)

Many people withdraw not because they don't value connection — but because the effort becomes greater.

STIGMA

People with Parkinson's are often misread:

- "You don't look sick"
- "Why do you move like that?"
- Assumptions about ability or interest

"My face or voice may not reflect what I'm feeling."

STIGMA-RESPONSE BUILDER

When You're Caught Off Guard...

Common comment:

"You don't look sick."

Example responses:

- "Parkinson's looks different for everyone."
- "Some symptoms aren't visible."
- "I'm managing, but it can be challenging."

My version:



There is no "perfect" response; just one that feels right for you.

REFLECTION EXERCISE

- Have you experienced moments of being misunderstood?
- How did that impact you?
- What kind of response would feel most natural or comfortable for you?

LONELINESS AND DISCONNECTION

Understanding Loneliness

Loneliness can show up as:

- Feeling unseen or misunderstood
- Losing roles or routines
- Pulling back from social situations
- Feeling alone — even when not physically alone

CONNECTION MAPPING WORKSHEET

Your Circle of Connection

Inner Circle (closest support):

Outer Circle (friends, community, providers, etc.):

- Who feels easiest to reach right now?
- Who have I drifted from — but still miss?
- Where could new connection come from?

Who Do I Miss?

- Who do I think about but haven't contacted?
- What has stopped me from reaching out?
- What would a small reconnection look like?

Care & Appreciation: Connection Through Appreciation

Write down 3 things you appreciate about someone in your life:



Connection isn't about perfection — it's about being seen and valued.

Improving Communication

- Reduce distractions
- Allow time to respond
- Use clear, direct language
- Choose the right time (energy, medication timing)

In Medical Visits

- Write down top concerns
- Name sensitive topics directly
- Ask for clarity and pacing



Prepare, pace, pause, and check understanding.

30-DAY CONNECTION PLAN

One Small Step Forward

- One person I can reach out to (who feels safest and easiest to reach out to right now?):
- One place I feel comfortable connecting (where is connection most manageable - phone, coffee shop, class, group):
- One routine I can build (weekly call, exercise call, lunch, prayer group):
- One small ask that would help (what would make connection easier - reminder text, slower pace, ride?):



The goal is not to be more social — it's to feel more connected.

CARE PARTNER SECTION

- One role I want to maintain outside of caregiving:
- One support I need right now:
- One way I can ask for help:

CARE PARTNERS GUIDE

Dr. Bradley McDaniels, Board Member of DFW Parkinson's Resource, recently co-authored the *Facing Parkinson's Together Care Partners Guide*, developed by the Michael J. Fox Foundation. Download your copy [here](#).



"I care deeply, and I also need support to keep doing this well."

You are not alone.

The emotional side of Parkinson's is real — and support is available.
You don't have to navigate this alone.

Take what feels helpful, and return to these tools
when you need them.



TotalCare

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For continued support and additional resources,
please reach out to us at info@dfwparkinsons.org

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