Seeing the Whole Person

Advocacy and Everyday Excellence in Parkinson's Care

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Pathways IN AGING

Disclosures:

No disclosures.

Parkinson’s is Personal.

“If you’ve met one person with Parkinson’s…”

You’ve met one person with Parkinson’s.

person

Different symptom profiles

trending_up

Different progression patterns

medication

Different medication responses

groups

Different support systems

favorite

Different goals and definitions of quality of life

The Aging Life Care Manager's 360° View

Health and Disability

Financial

Housing

Family

Local Resources

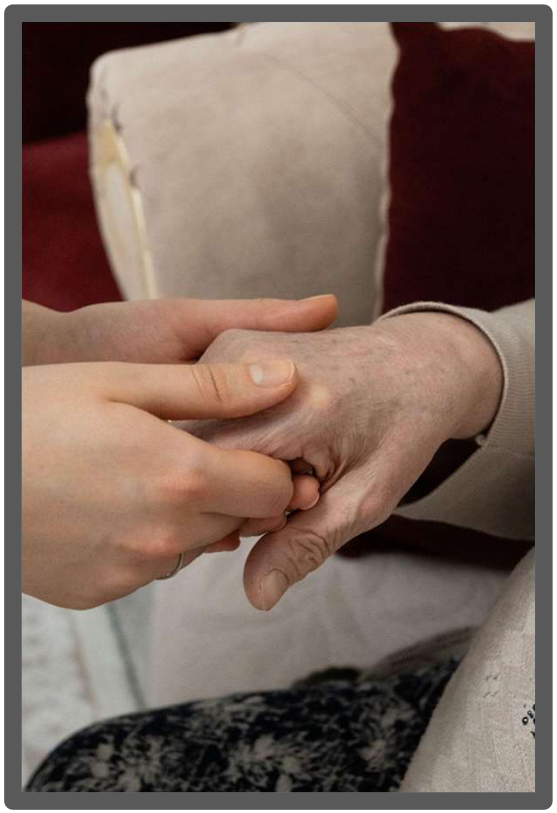
Crisis Intervention

Legal

Advocacy

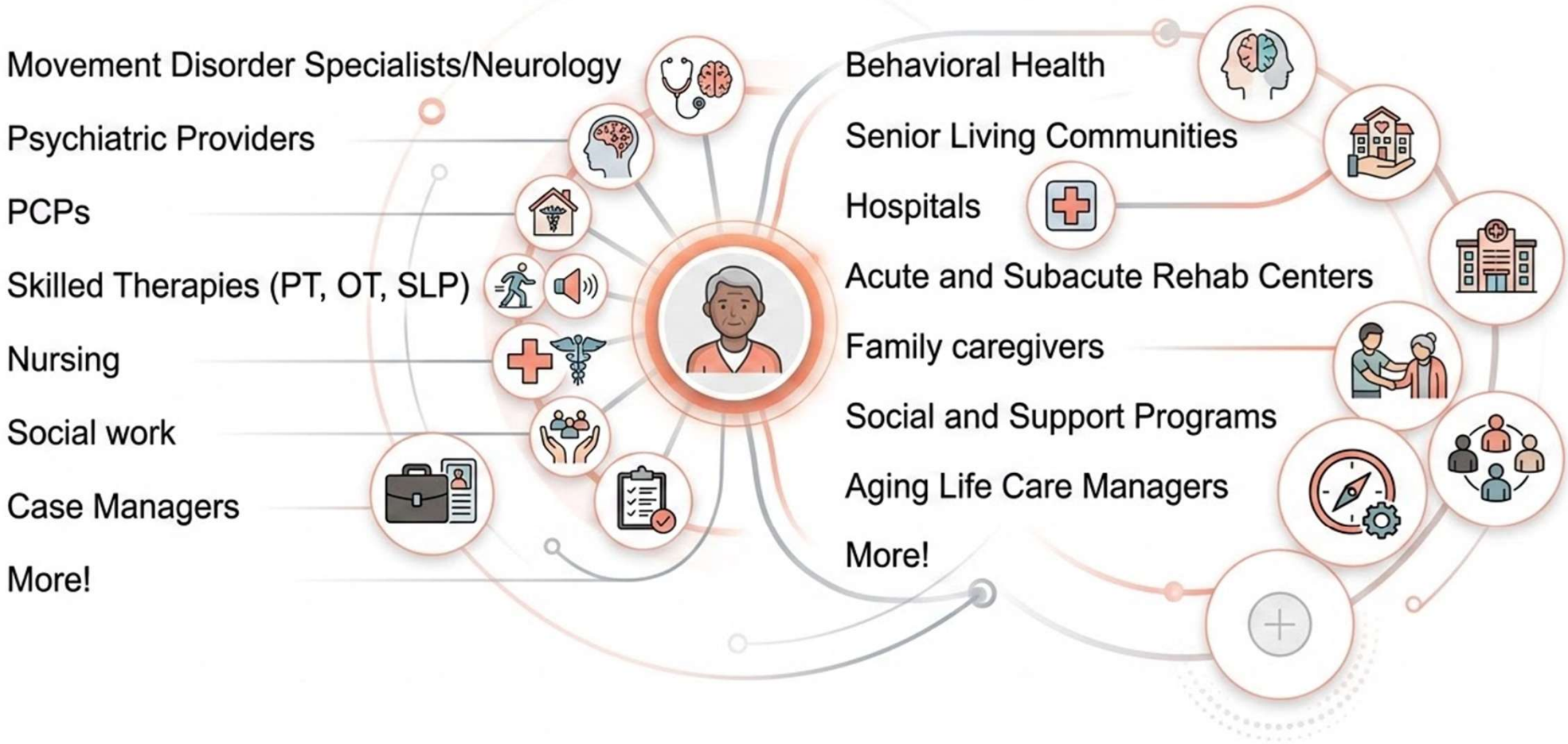
ALCA 8 knowledge areas

Advocacy is Everyone's Job.



	Anticipating problems
	Connecting systems
	Removing barriers
	Amplifying the patient's voice
	Supporting care partners

The Parkinson's Care Ecosystem



The Problem—Fragmentation

Common consequences:

- Delayed communication
- Medication errors
- Repeated assessments
- Conflicting recommendations
- Caregiver overwhelm
- Preventable crisis

When everyone owns a piece, who owns the whole?

My Solution - Pathways in Aging’s “Secret Sauce”

7 ingredients for better outcomes.

✓ Person-centered care

✓ Proactive communication

✓ Clinical vigilance

✓ Education

✓ Collaboration

✓ Protection of joy

✓ The Dual Care Plan

Ingredient #1: Person-centered Care

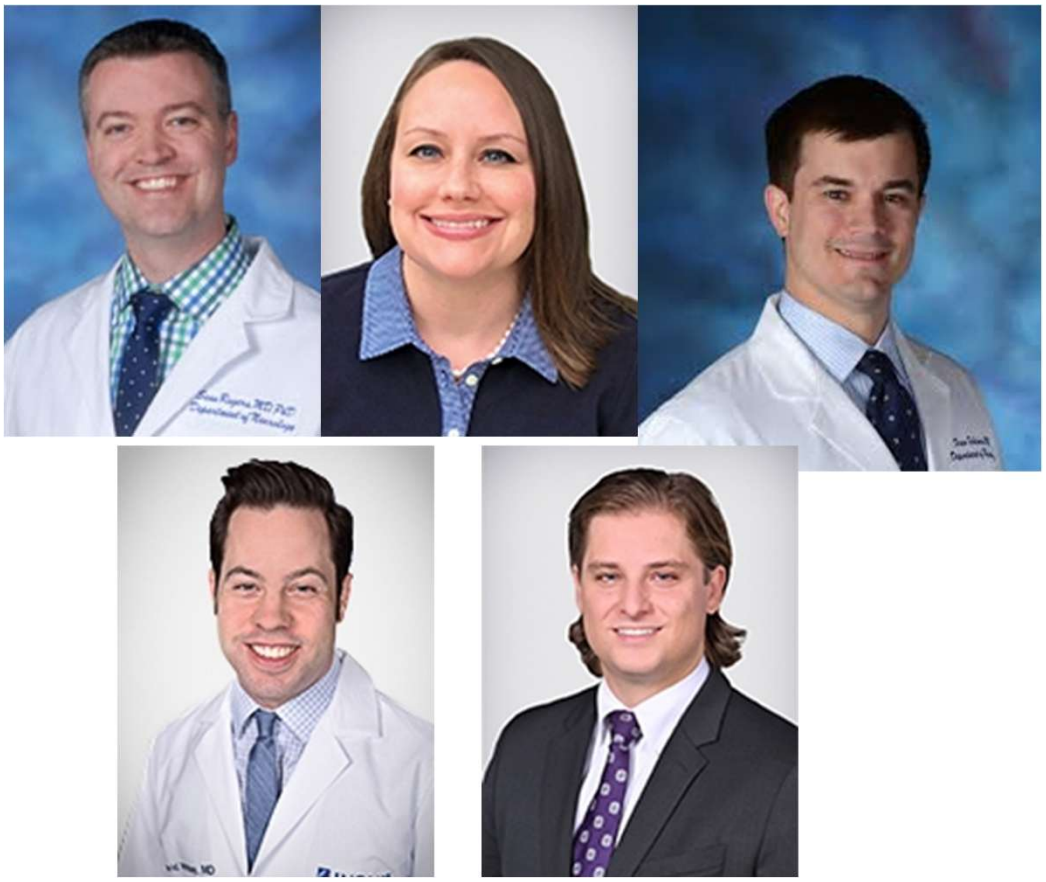
Ask:

- What matters most?
- What worries you most?
- What are you hoping to keep doing?
- What does a good day look like?

Ingredient #2: Proactive Communication

What works:

- Pre-appointment preparation
- Concise updates (SBAR!)
- Organized observations
- Triage the need (sudden changes usually aren't PD)
- Don't call! MyChart instead.



Support the providers.

Ingredient #2: Proactive Communication

Instead Try:

- Mobility and gait
- ADL performance
- Falls
- Freezing, tremor, rigidity
- Sleep changes
- Hallucinations or delusions
- Drooling
- Engagement in joyful activities

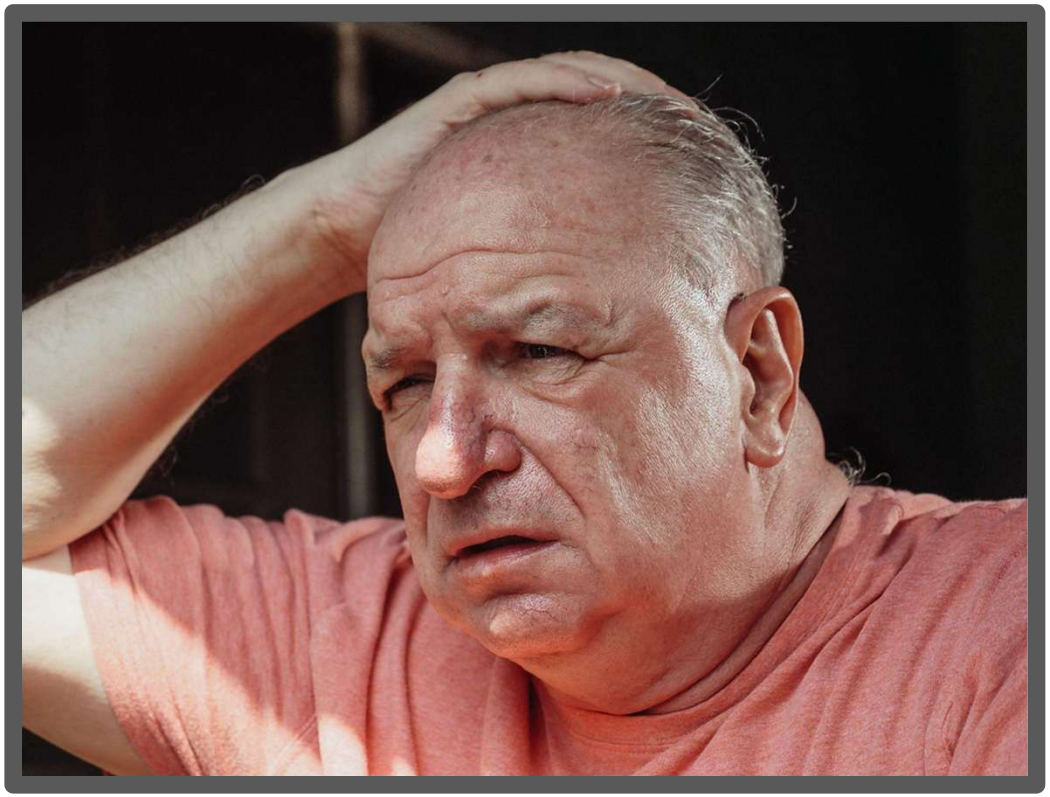
Functional language matters.

Ingredient #3: Clinical Vigilance

Sudden change? Think:

- Infection
- Dehydration
- Constipation
- Medication issues
- Metabolic abnormalities

Parkinson's is slow.



Ingredient #3: Clinical Vigilance

Watch For Psych Symptoms:

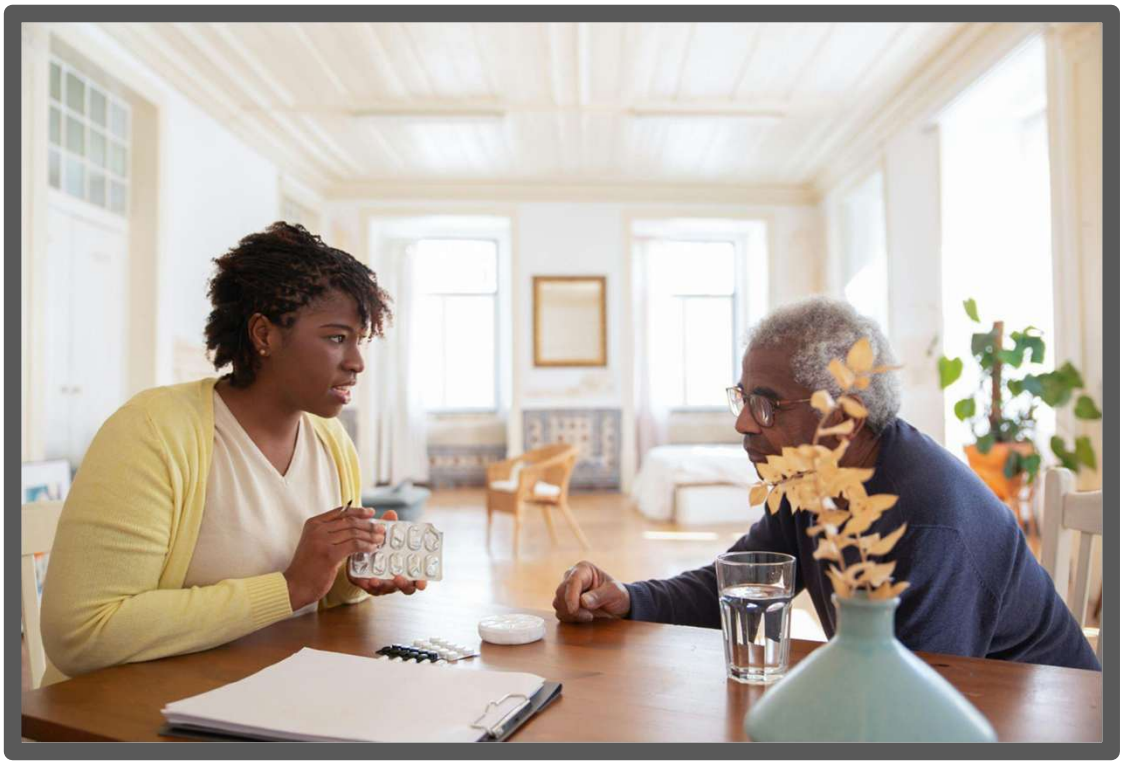
- Sense of presence
- Passing shadows
- Peripheral visual phenomena
- Mild insight-preserved hallucinations
- Mild Paranoia

Early recognition results in better outcomes.

Ingredient #4: Empower Everyone with Education

Educate:

- Patients
- Care partners
- Professional caregivers
- Nursing staff
- Community providers



Ingredient #4: Empower Everyone with Education

Key Parkinson's Medication Reminders:

- Give medications on time
- Avoid contraindicated medications
- Encourage provider-to-provider discussion before medication changes in hospital/SNF
- Bring trade name medications from home during hospitalization/SNF stays
- IPMDC Hospital Letter! https://ipmdc.org/hospital/

Ingredient #4: Empower Everyone with Education

Avoid Contraindicated Medications!

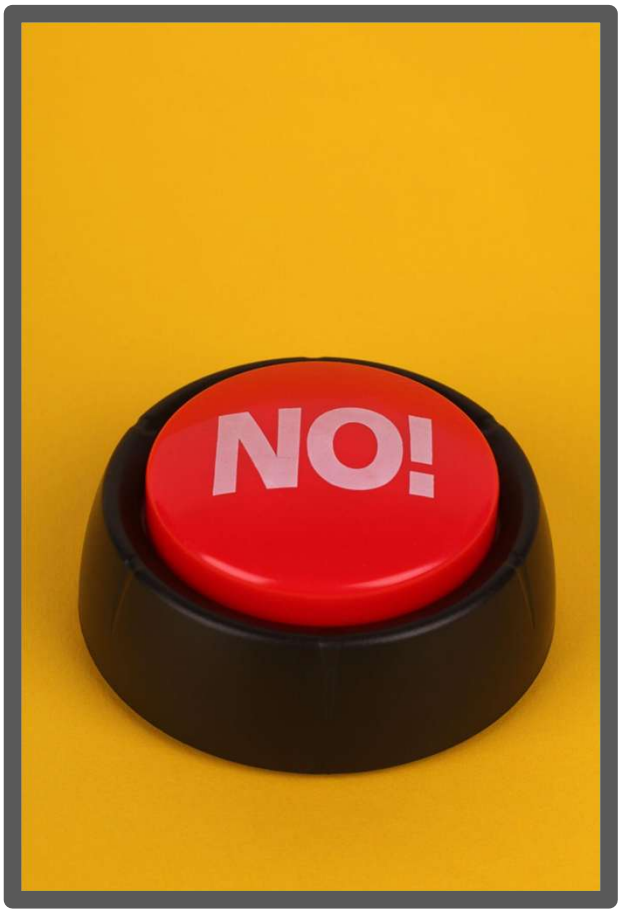
Haldol

Compazine

Phenergan

Inapsine

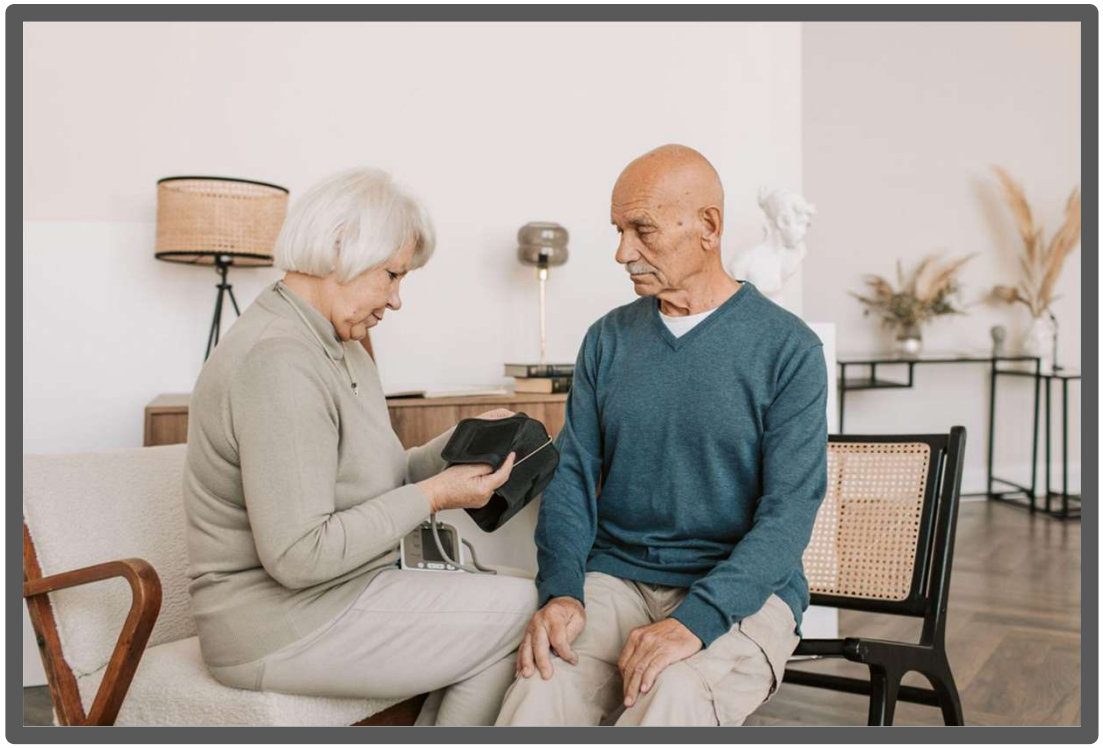
Reglan



Ingredient #4: Empower Everyone with Education

Caregivers/Care Partners need to know about:

- OH
- Reinforcing skilled therapy work
- Nutrition and Hydration
- Constipation
- Exercise
- Social Support
- Mood and Behavior



Ingredient #5: Collaboration as a Clinical Intervention:

Ask:

Who else needs this information?

Who is missing from the conversation?

Who can reinforce this recommendation?

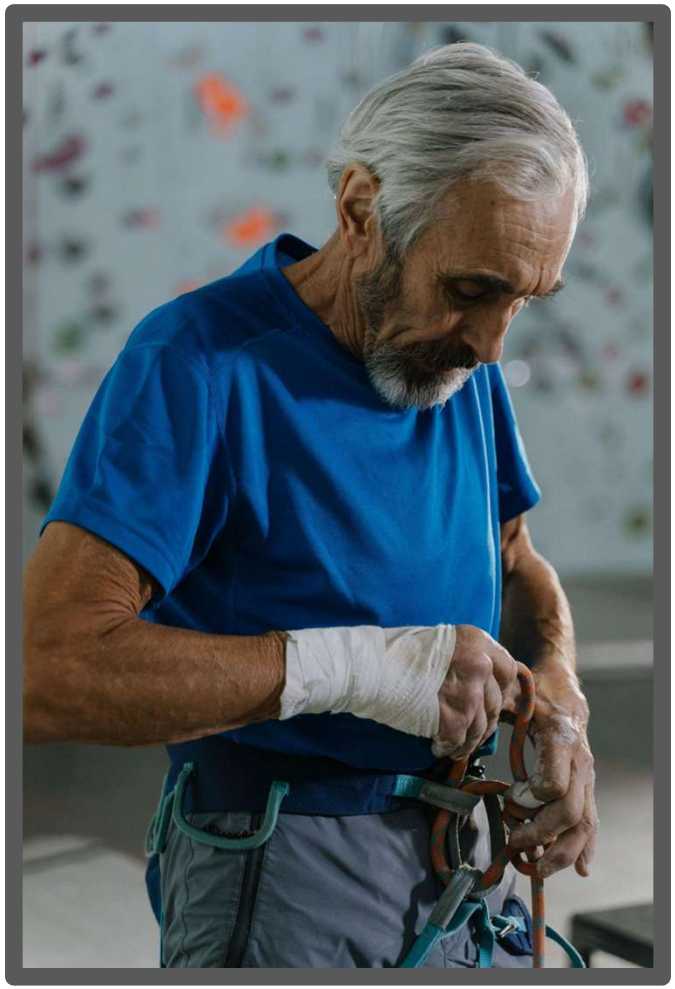
Build the safety net.

Ingredient #6: Protecting Joy

Support:

- Meaning
- Purpose
- Relationships
- Hobbies
- Community
- Spirituality

People are more than their symptoms.



Ingredient #6: Protecting Joy

Focus

Abilities

Adaptations

Successes

Opportunities

What can people still do?

Ingredient #7: The Dual Care Plan

Caregiver burnout can predict crises before disease severity does.

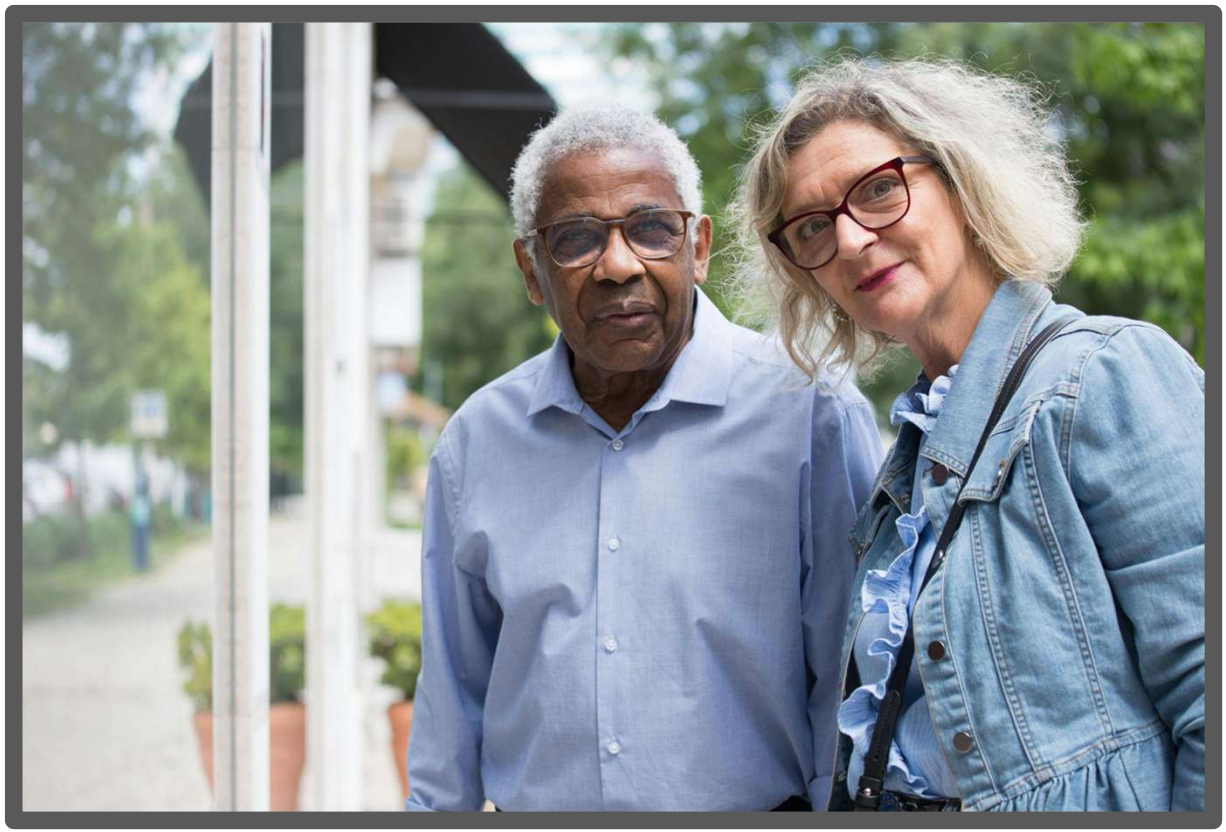
Ingredient #7: The Dual Care Plan

Patient needs:

- Medical
- Functional
- Emotional

Care partner needs:

- Education
- Respite
- Support
- Mental health care
- Future planning



Our “Secret Sauce” for Exceptional PD Care

- ❑ Person-centered care
- ❑ Proactive communication
- ❑ Clinical vigilance
- ❑ Education
- ❑ Collaboration
- ❑ Protection of joy
- ❑ The Dual Care Plan

Seeing the Whole Person

The future of Parkinson's care won't be built by any one profession. It will be built by all of us becoming better advocates, better collaborators, and better at seeing the whole person behind the diagnosis.

Pathways
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