Parkinson's Fundamentals: Mental Health and Wellness

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My Background

Research Coordinator with Dr. Greg Pontone at the Johns Hopkins School of Medicine

- Quality of life in PD
- Care partners for people with PD

Postdoc at the National
Rehabilitation
Research & Training
Center on Family
Support







- Anxiety related to On/Off Fluctuations
- Mild Cognitive Impairment
- Psychosis

Doctoral Student in Mental Health at Johns Hopkins Bloomberg School of Public Health

 Interventions to improve quality of life for people with PD and their care partners.

Objectives

- 1. Become familiar with how mental health can be impacted for people with Parkinson's disease.
- 2. Recognize signs and symptoms of mental health issues in PD.
- 3. Review the best evidence treatments.
- 4. Discuss general wellness guidelines.

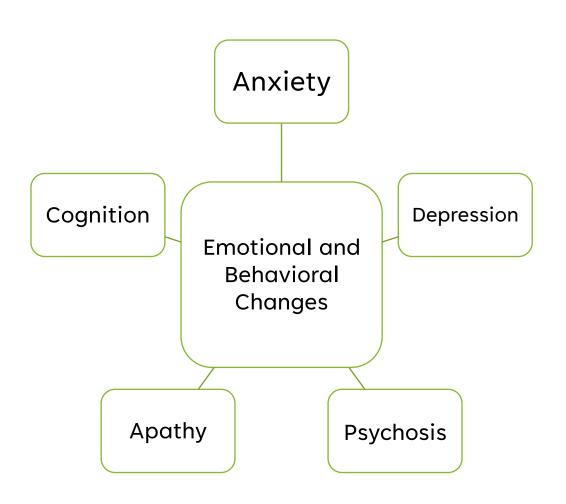
Dealing with a New Diagnosis

- People diagnosed with PD can experience a range of emotions and reactions:
 - Loss and grief
 - Body image and self-concept changes
 - Stigma
 - Uncertainty and unpredictability
 - Decreased quality of life
- Critical time to find resources to help move forward proactively

Mental Health in PD

An Overview

Mental Health in Parkinson's Disease

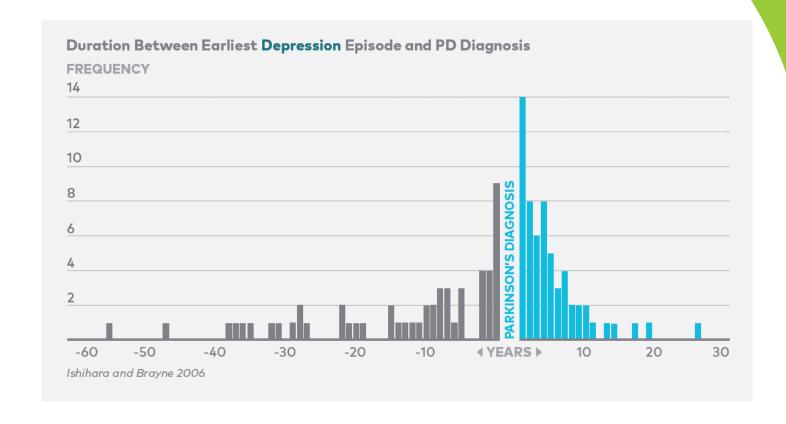


- Non-motor symptoms can impact your quality of life and social interactions
- You are not alone in your experience of these symptoms
- Reminder: Not everyone develops every symptom of Parkinson's disease
- Treatment can improve quality of life and functioning

Depression

Depression

- Up to 50% experience some form of depression
- Tends to be more severe in people with worse motor symptoms.
- More likely to occur in people who experience severe cognitive impairment.





What contributes to depression?

Psychological

- Negative Thoughts
- Social Isolation

Biological

- History
- Brain Changes

Environmental

- Severe Stress
- Medication Side Effects

Depression

How do you detect depression?

- A person must <u>experience</u> one of the following symptoms <u>most of the time over the previous two weeks</u>:
 - Depressed Mood
 - Loss of interest or pleasure in daily activities once enjoyed
- Additional symptoms:
 - Changes in sleep or appetite
 - Decreased concentration or attention problems
 - Increased fatigue
 - Feeling slowed down or restless
 - Feeling worthless and guilty
 - Suicidal thoughts or a wish for death

Most people diagnosed with a serious illness will feel grief or hopelessness at some point, but clinical depression is a distinct medical condition.



Challenges with Depression in PD

- Can be overlooked
 - Sleep problems
 - Feeling slowed down
 - Hypophonia
 - Facial masking
- Often undertreated
- Can interfere with a person's ability to function at home or work.
- Intensified by movement and cognitive symptoms of PD

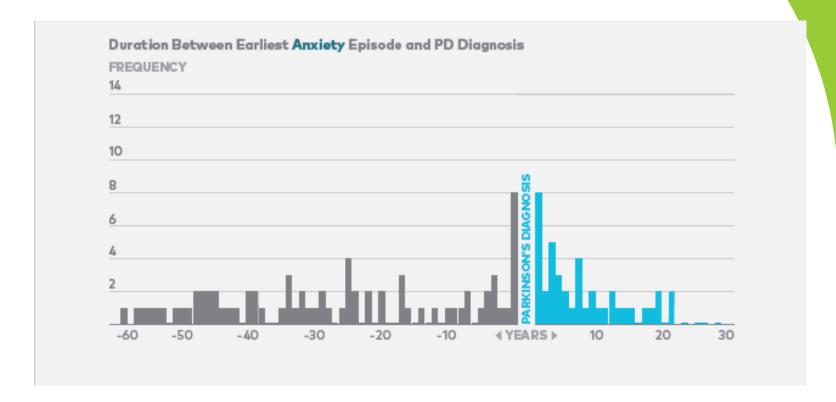
Ask a care partner or loved one if they notice mood changes.

Discuss concerns with your healthcare team.

Anxiety

Anxiety

- Worry, unease or nervousness that persists and interferes with daily activities.
- Up to 55% have clinically significant anxiety symptoms
- 31% of people have an anxiety disorder.





Anxiety Disorders

Туре	Symptoms	Prevalence
Generalized Anxiety	Recurring thoughts of worry and fearWorry more than is normally expectedFeeling out of control	14%
Panic Disorder	sudden, severe sense of physical and emotional distressTrouble breathing, heart attack-like symptoms	6.8%
Social Phobia	 Avoid everyday social situations because of fear of embarrassment Social situations induce severe anxiety 	13.8%
Specific Phobia	- Intense, irrational fear of something that does not pose danger.	13.0%
Anxiety Not Otherwise Specified (NOS)	- Anxiety that interferes with daily functioning.	13.3%

What contributes to anxiety?

Psychological

- Fears and worries
- Social Isolation

Biological

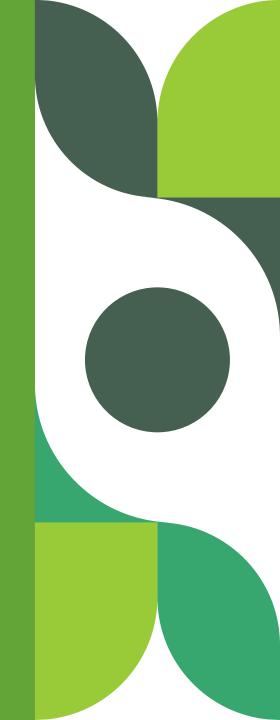
- Brain Chemicals
- "Off" periods

Anxiety

How do you detect anxiety?

- Difficulty concentrating
- Muscle tension
- Sleep problems
- Increased heart rate
- Changes in blood pressure
- Increased sweating
- Hot and cold flashes

Tip:
Keep notes
about the
timing of your
symptoms.



Apathy

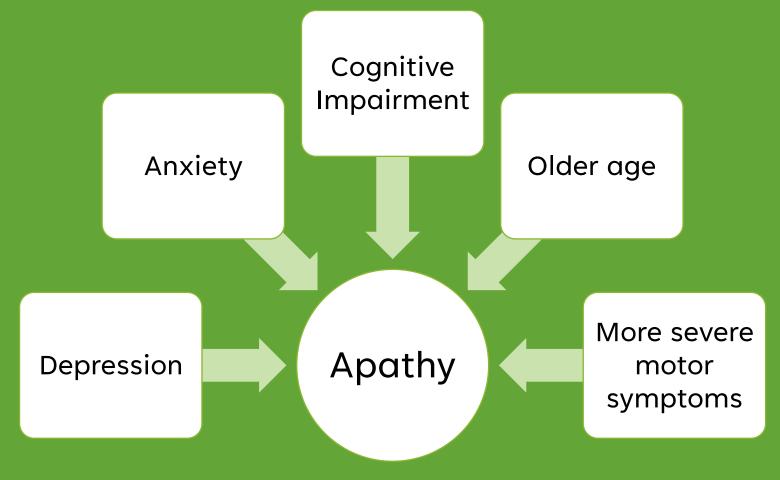
Apathy

- Lack of interest, enthusiasm or motivation
- 1/3 of people with PD
- It can be brief or longterm





What contributes to apathy?



How do you detect apathy?

Do you have energy for daily activities?

Does someone have to tell you what to do each day?

Do you have plans and goals for the future?

Are you interested in learning new things?

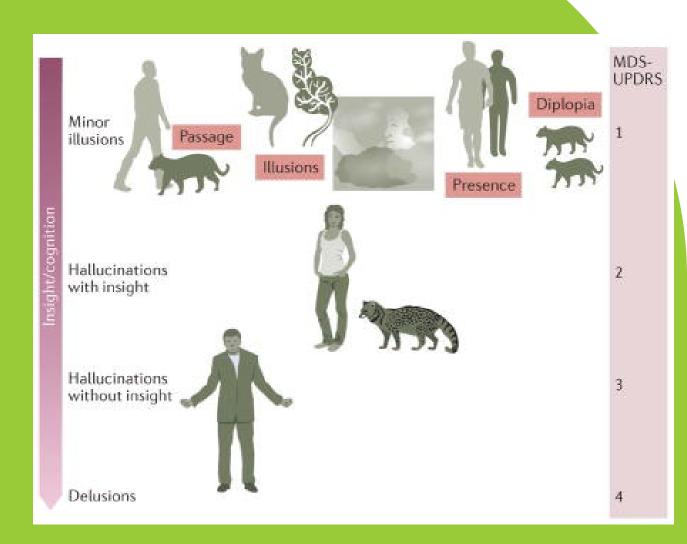
Are you neither happy nor sad, just in between?

Remember that apathy is a symptom of the disease, and the person with PD isn't necessarily being lazy or making excuses.

Psychosis

Psychosis

- Between 20-40% experience of hallucinations or delusions
- Illusions
- Hallucinations
 - Visual, auditory, olfactory, tactile, gustatory
- Delusions
 - Jealousy, persecutory, somatic

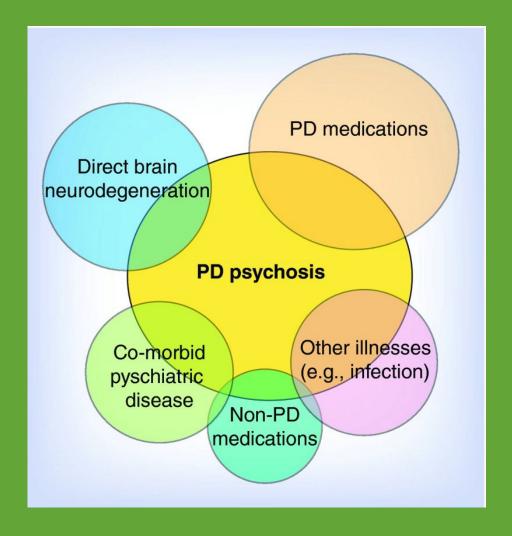


What contributes to psychosis?

- Medications (dopaminergic drugs, anticholinergics, amantadine)
- Dementia
- Delirium
 - Infection
 - Imbalance of electrolytes
 - Other disease
 - Vitamin B12 deficiency
- Risk Factors
 - Depression
 - Sleep disorders
 - Impaired vision
 - Older age
 - Advanced or late-stage PD

Tip:

Keep an up-todate list of your medications to share with your clinicians.



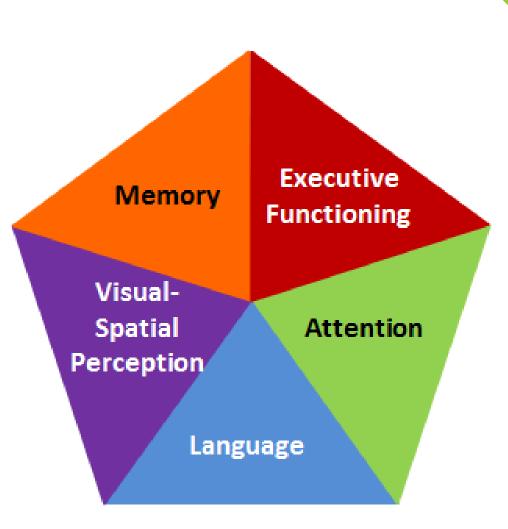
How do you detect psychosis?

- Presence of at least one of the following:
 - Illusions
 - False sense of presence
 - Hallucinations
 - Delusions
- Symptoms occur after the diagnosis of PD
- Recurrent continuous symptoms for 1 month
- Exclusion of other causes

Cognitive Changes

Cognitive Changes

- Mild cognitive impairment
 - Distractable
 - Disorganization
 - Finding it difficult to plan and accomplish tasks
 - Challenging to divide attention
- Approximately 50% of people with PD





What contributes to cognitive changes?

Brain cell damage **Psychosis** and death Changes in Brain Delirium Chemicals Cognitive Changes

How do you detect cognitive changes?

	Changes
Attention	 Difficulty with complex tasks that require maintaining or shifting attention Problems with concentrating during a task.
Mental Processing	 A delay in responding Taking longer to complete tasks
Executive Function	 Trouble planning and completing activities Difficulties in generating, maintaining, shifting and blending different concepts
Memory	Difficulty with common tasks (e.g., making coffee, balancing a checkbook)
Language	 Issues with word-finding, known as "tip of the tongue" phenomenon. Difficulty with language when under pressure or stress. Problems in naming objects
Visuospatial	Difficulty with measuring distanceDifficulty with depth perception

Treatment Options

Mental Health Support Team



Neurologist

Diagnosis and treatment of PD.



Neuropsychologist

Diagnosis and treatment of cognitive and behavioral disorders.



Primary Care Provider

Manage overall health



Psychiatrist

Diagnosis and treat psychiatric disorders, including prescribing medication.



Social Worker

Connect with important resources.



Occupational Therapist

Help develop healthy routines to maintain physical and mental health.



Psychologist/Counselor

Coping with diagnosis and managing stress.



Family & Friends

Provide social support and can help recognize symptoms.

Depression Treatment

- Treatment Options:
 - Psychotherapy (e.g., CBT)
 - Medication (e.g. SSRIs)
 - Electroconvulsive therapy (ECT)
 - Experimental Therapies
 - Lifestyle interventions:
 - Exercise
 - Social support
 - Nutrition
 - Complementary therapies

Successful treatment of depression is one of the most significant ways to decrease disability and improve quality of life.

Guidelines to help prevent or get treatment for depression:

- Get screened for depression at least once a year.
- Discuss mood changes with your doctor.
- Bring a family member to your doctor appointments who can help you talk about depression symptoms.

Anxiety Treatment

- Medications
 - SSRIs
 - Benzodiazepines
- Psychotherapy
- Exercise
- Relaxation Techniques



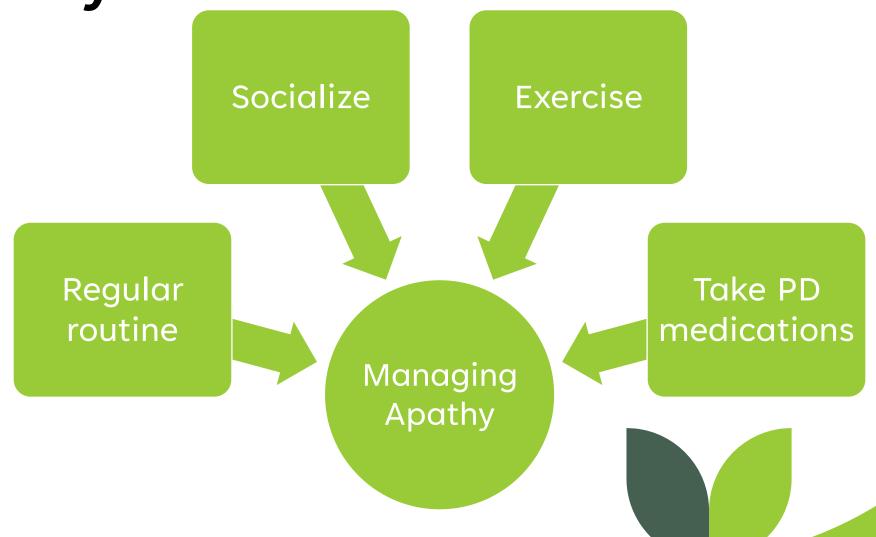








Apathy Treatment



Psychosis Treatment

Controlling triggering factors

Treat infection

Balance electrolytes | Treat sleep disorder

Reduce medications

Reduce psychiatric medications

Reduce antiparkinsonian drugs

Add medications

Add atypical antipsychotics

Add cholinesterase-inhibitors

Psychosis Treatment

Caution:

Treat in

Reduce ps

Many antipsychotic medications can worsen motor symptoms and should not be prescribed for people with PD. Some of these medications, such as haloperidol (Haldol), are commonly prescribed in the hospital setting for patients who are agitated or anxious.

Add atypic

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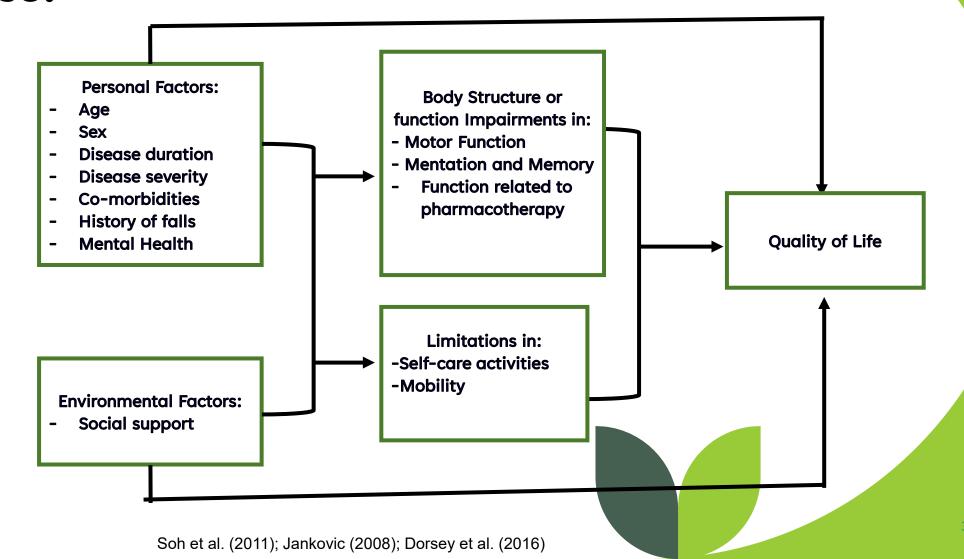
Treatment for Cognitive Changes

Awareness: concept of cognitive reserve; brain protecing lifestyle Mulditdomain lifestyle (including combined/digital interventions) interventions Cognitive Interventions with cognitive training Cognitive training Cognitive rehabilitation Cognitive stimulation Reminiscence therapy PD without Healthy individuals cognitive PD-SCI PD-MCI Prodromal PD PDD impairment Target group

Quality of Life in PD

Perspectives of people with PD and their care partners

What affects Quality of Life in Parkinson's Disease?



Data Collection and Analysis

Aim: Explore care partner and PD care recipient perspectives on quality of life.

Dyads referred from
Johns Hopkins
Parkinson
Foundation Center of
Excellence Clinicians

Care Partners and
People with PD
recruited for
interviews

Interviews conducted via Zoom



Themes derived from collaboration with team

Transcripts analyzed using constant comparative method

Interview Focus:

How does PD affect QOL?

What strategies are used to maintain QOL?

Study Sample Characteristics

Dyad Number	PWP Gender	Care Partner Gender	Relationship	Interview Type	Duration of PD (years)	PWP Reported Symptom Impacting QOL the Most
1	Male	Female	Spouse	Individual	7	Gait
2	Female	Male	Spouse	Individual*	7	Depression
3	Male	Female	Spouse	Individual	6	Tremor & Balance Issues
4	Male	Female	Spouse	Dyad	12	Communication/Speech
5	Male	Female	Spouse	Dyad	6	Depression/Hopelessness
6	Female	Female	Mother/Daughter	Dyad	15	Vision/Processing
7	Male	Female	Spouse	Individual	19	Anxiety
8	Male	Female	Spouse	Dyad	8	Anxiety
9	Female	Male	Spouse	Dyad	8	Sleep problems
10	Male	Female	Spouse	Individual	15	Tremor/motor symptoms

Key Findings

Changes with PD

Problematic Symptoms for PWP

Relationship Changes

Care partner Sacrifices and Adjustments **Managing PD**

Coping Methods

Treatments

Support Systems Adapting to a Caregiving Role

Care partner Coping Methods

Care partner Tasks

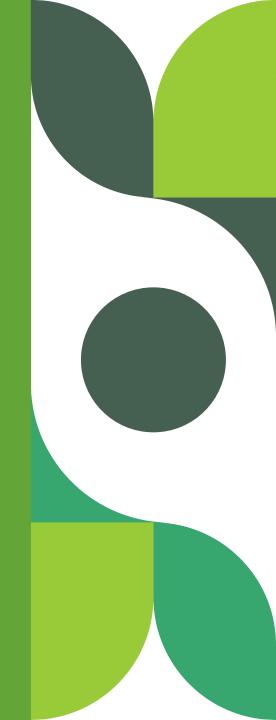
Care partner Feelings about Role

Facilitators of Role

Challenges of Caregiving

Barriers to Role as a Care partner

> Impact of Caregiving Role



Theme 1: Changes with PD

CP reported

PWP reported

Relationship Changes

Problematic Symptoms Care Partner
Sacrifices
and
Adjustments

Changes
with
Parkinson's
Disease

Care Partner Reported PWP Reported Anxiety 11% 50% 11% 10% Apathy **Cognitive Impairment** 66% 50% Depression 22% 50% **Embarrassment** 40% **Fatigue** 33% 20% **Mood Changes** 66% 30% **Motor Problems** 66% 100% 44% **Personality Changes** 0 **Swallowing** 0 20% Sleep Changes 11% 20% **Social Changes** 77% 90% **Vision Problems** 22% 20% **Voice Changes** 20% 0 Weakness 22% 10%

Theme 1: Changes with PD

Problematic
Symptoms

Changes

Changes

and
Adjustments

Changes

with

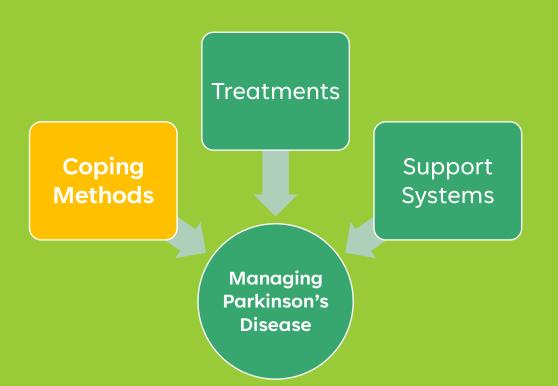
Parkinson's

Disease

"I've lost my partner, my friend, my lover, my confidant, everything and this other person is living here now. I still love him. But he's not the same person. And he's not aware that he's not the same person. He doesn't understand why I'm upset. He honestly has no idea what this has done to my life or our lives." care partner 10

"I think our relationship is actually at least as strong if not stronger, than it was before Parkinson's." PWP 1

Theme 2: Managing PD



"I was active in the support group in [Place], there was a woman ... she had been in the role of sort of conducting the sessions. And she was wonderful."

PWP6

"She had been doing exercise classes online with a with a Parkinson's group... But that was something she would do a couple of days a week and I'd set the zoom up for her and she do her exercises. We know exercise is important." Care partner 6

Theme 2: Managing PD

Coping Methods

Managing Parkinson's Disease

"I mean, Xanax, I get an anxiety attack almost every morning. Like around nine o'clock to 10 o'clock, I'll take a Xanax. And that'll kind of level off. I can't stand being in crowds anymore." PWP8

"I went to therapy, and, you know, all kinds of I went through Neurofeedback and eventually got back on my feet, you know, in a better place, let's put it that way." PWP2

"I've taken speech therapy several times and advanced speech therapy several times. It helps me when the vision become not the voice becomes halting." PWP5

Theme 2: Managing PD

Treatments Coping Methods Managing Parkinson's Disease

Systems

Support

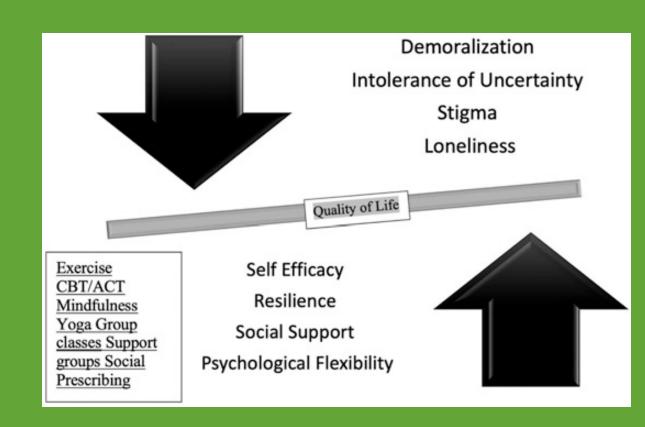
"I mean Rocksteady. I get there like about 20 minutes to 30 minutes early and some of the other boxers we shoot the shit, you know? And that's always nice. I actually go there early just to make sure I can converse with others, because they're in the same boat." PWP1

"A spouse or significant other is a big part of it. I think and having living with someone who understands and appreciates what you're, what you're going through, is really reassuring to me." PWP6

"Definitely have somebody to speak with someone who is aware of Parkinson's, and its effects on the brain." PWP2

Wellness Strategies

- Seek Support
- Self-Compassion and Selfcare
 - Do something everyday you enjoy
 - Socialize with friends, family
- Exercise
 - Strength training, aerobic activity, balance, agility & multitasking, flexibility



Activity for People with a New PD Diagnosis

From the Parkinson Foundation

What are some things that are most important to you?

Think about what is most important to you

Based on what's important to you, determine your personal goals and priorities. This will help you create an action plan to continue doing the things you love and care about most.

The mind is not separate from the body. It directly affects the quality of life for people with PD and their care partners.

- **Gretchen,** person with Parkinson's diagnosed 2017

Who is someone you can talk to?

- 2 Find someone you can talk to
 - We now have a whole network of people who understand. It may be hard at first, but connect with other people who are living with PD. You'll be glad you did.
 - Karen, care partner, husband diagnosed 2002

When you're ready, we encourage you to talk to someone, whether that is calling our Helpline, **1.800.4PD. INFO (473.4636)** to ask questions, or reaching out to a family member or friend, or another person with Parkinson's. Don't isolate yourself, you are not alone.

What is a goal you can set to adopt or maintain a healthy habit?

3 Create healthy habits

Choosing healthy foods may help your medications work better and improve your energy. Getting enough sleep can help your body and brain recharge. Small changes can make a big difference and creating a healthy routine may help you feel better. Learn from others through our online community, **Parkinson.org/NewlyDiagnosed**.

What is an activity you enjoy doing?

Be active in whatever way works best for you

- Take a walk. Climb those stairs. Keep moving. Find activity everywhere you go.
 - **Dave,** person with Parkinson's diagnosed 2004

It's a fact: exercise can improve your quality of life. Visit our website,

Parkinson.org/NewlyDiagnosed,
to learn about the importance of exercise and find a Moving Day event near you. Get up, get out there, get active.

Thank You!

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