Newly Diagnosed: Living Your Best Life with Parkinson’s

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Disclosures

Parkinson’s Foundation
Allied Team Training for
Parkinson’s Faculty Member
Learning Objectives

1. Understand the importance of patient education, support, and development from point of diagnosis

2. Gain knowledge and raise awareness of preventing and monitoring caregiver burden

3. Understand the palliative care model in Parkinson’s disease

4. Understand the interdisciplinary team approach to care
Parkinson’s Disease Diagnosis

How does a physician determine a diagnosis of Parkinson’s disease?

Four Cardinal Symptoms of Parkinson’s disease
• Slowness (Bradykinesia)
• Stiffness (Rigidity)
• Loss of balance (Postural Instability)
• Tremor (resting “pill rolling” tremor)

To be diagnosed with Parkinson’s disease, the individual must have slowness (bradykinesia) + at least 1 other cardinal symptom

PD is a clinical diagnosis- meaning it is based off history and clinical findings
Possible Symptoms (outside of physical symptoms)

- Constipation
- Loss of smell
- Sleep changes
- Vivid dreams, thrashing in sleep, yelling or talking in sleep
- Mood changes
- Depression, anxiety, apathy
- Speech and memory changes

*These symptoms could have been noticed years before the physical symptoms began*
Coping with Diagnosis

Parkinson’s disease itself can cause changes to mood including:

- Depression
- Anxiety
- Apathy

When a new diagnosis is provided, it can take a toll on the individual and the care partner.

Other times it is a relief to have an answer to the changes you’ve been experiencing and lead to:

- Education
- Connection to resources
- Empowerment
Supportive and comfort care is needed from the start of the diagnosis for both the person with Parkinson’s and the family members

- this type of comfort and support may look different as the needs of each individual changes over time
- support systems continuously evaluate the needs of the person with Parkinson’s as well as their care partner

Physical and psychological needs are connected to quality of life

Health care education, care coordination, and supportive groups are a crucial part of delivering palliative (supportive) care

Supportive Care

Once a person is diagnosed with Parkinson’s disease, their needs must be assessed in order to deliver supportive care and promote an optimal quality of life.

The interdisciplinary team can help!
Movement specialist, nurse, social worker, occupational therapy, physical therapy, speech-language pathology

- Assess the readiness to learn of the patient and family
- Assess patient and family needs
- Provide individualized education based off understanding
- Provide individualized support and resources based off needs
- By supporting each individual, the overall quality of life can improve
5 Steps To Live Better Today

Set your goals and what you would like to prioritize

Find a support system, people you can turn to and talk with

Create healthy habits

Be active mentally, socially, physically

Find an expert in PD!
  • A Movement Disorder Specialist: a neurologist with additional training in Parkinson’s disease and other movement disorders, with knowledge on current research and therapies

In any order that works for you!
How can a health care provider and their team help a person with newly diagnosed Parkinson’s disease and their care partner cope?

- Evaluate their individual needs!
- Educate!
- Connect to resources!
- Empower!
Establish healthy habits early
- Exercise
- Diet
- Dental hygiene
- Find hobbies you enjoy
- Find additional support system outside of significant other

Establish interdisciplinary care team early
- Physical therapy
- Occupational therapy
- Speech and language pathology
- Social work
- Nursing
- Movement Disorder Specialist

*Parkinson’s disease is a diagnosis, but it does not define you and who you are, keep living your best life!
Establishing Healthy Habits: Exercise

According to Ahlskog’s paper:

“Does vigorous exercise have a neuroprotective effect in Parkinson disease?”

- A 2011 study found that exercise may be neuroprotective in Parkinson’s
- PD risk in humans is significantly reduced by mid-life exercise
- Patients who exercise have shown improved cognitive scores
- Ongoing vigorous exercise should be encouraged early on

Establishing Healthy Habits: Exercise

Non-motor benefits of exercise
- Sleep
- Memory
- Mood
- Relief of constipation

Interdisciplinary Team Approach
- Physical therapy
- Occupational therapy
Establishing Healthy Habits: Nutrition

- Controversial information about what the “ideal” diet for people with Parkinson’s disease would be
- Research does show a Mediterranean diet may help improve the decline of mobility
- Increase water intake to help with dehydration, fatigue, and constipation
- Calcium and Vitamin D rich foods for prevention of osteoporosis


Common Question: Organic Food…or Not?
Establishing Healthy Habits: Dental Hygiene

People with Parkinson’s disease can be subject to increased dental caries, tooth loss, and periodontal disease.

Establishing healthy habits early:
Brushing teeth twice a day, flossing, frequent rinsing, and increasing hydration
- Soft toothbrush to protect gums
- Electric toothbrush
- Ensure brushing on the front, sides, and backs
- Regular dental visits and cleanings
- Biotene products for dry mouth
- Hydration

Role of Occupational Therapy

Establishing Healthy Habits: Management of Constipation

**Definition:**
Fewer than 3 bowel movements per week or having to strain to pass stool

- Increase fluids
- Fiber-rich foods
- Pear or prune juice
- Yogurt
- Water rich foods
  - tomato, radish, celery, broccoli, cucumber
- Exercise!
- Physical Therapy
Establishing an Interdisciplinary Team: Speech-Language Pathology

According to the American Speech-Language-Hearing Association, speech-language pathologists treat many types of challenges with communication and swallowing including but not limited to speech sounds, language, social communication, voice, cognitive-communication, feeding and swallowing.

Speech evaluation and exercises
- improve volume and strength as well as confidence with speech
- cognition and mental health exercises, speed and processing
- ability to communicate at work, at home, socially

Red flags: soft voice, drooling, slowness to swallowing, weight loss, coughing while eating or drinking

Establishing an Interdisciplinary Team: Physical Therapy

According to the American Physical Therapy Association, physical therapists are movement experts who utilize exercise, hands-on care, and education. They teach how to achieve long-term benefits, reduce pain, restore function, and prevent disability.

Assist with balance, walking, falls prevention, exercise advice, bowel and bladder training.

Personalized treatment plans and exercises to prevent injury and promote safety.

http://www.apta.org/AboutPTs/
Establishing an Interdisciplinary Team: Occupational Therapy

According to the American Occupational Therapy Association, Occupational therapy practitioners have a holistic perspective, in which the focus is on adapting the environment and/or task to fit the person, and the person is an integral part of the therapy team. It is an evidence-based practice deeply rooted in science.

Assist with everyday activities:
Handwriting, drawing, manipulating eating utensils, brushing teeth, fastening buttons, typing, using a computer mouse, adapting the home and work environment, cognitive exercises

Occupational therapy and adaptations, exercises, and tools help you continue to do everyday tasks and those you also enjoy!

https://www.aota.org/Conference-Events/OTMonth/what-is-OT.aspx
Establishing an Interdisciplinary Team: Social Work and Mental Health

According to the International Federation of Social Workers, social workers help people find positive ways forward in the challenges they face in their lives.

Social work
- Supportive groups
- Coping and adapting with diagnosis and change of roles
- For the person with Parkinson’s disease and their care partners
- Mental health promotion
- Assist with connecting to home and community resources

Supportive systems
- Friends, family, co-workers
- Exercise groups
- Book clubs
- Musical groups
- Educational classes

https://www.ifsw.org/what-is-social-work/
Establishing an Interdisciplinary Team: Nursing

According to the International Council of Nurses, Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles. (ICN, 2002)

Collaborate with the interdisciplinary team, coordinate care, provide support and education, and promote overall good quality of life and safety, mental health promotion.

https://www.icn.ch/nursing-policy/nursing-definitions
Interdisciplinary Support for the Care Partner

Utilize the resources at your local Movement Disorders Center
- **Social worker** - coping, support, community resources, mental health
- **Nurse** - coordination of care, education, support system, medical questions
- **Physical therapist** - teaching safe maneuvering
- **Occupational therapist** - adaptations of home and safe ADL techniques
- **Speech-language pathologist** - improved communication techniques with partner

Create Support system outside of the support from your partner
- Friends, family, community groups, hobbies
- Care for yourself with regular doctor’s visits, exercise, nutrition

Come prepared to office visits with partner
- Prepare questions for the provider
- Eases anxiety of the care partner during visit
- Ensures questions are answered during visit
- Remember the “5 steps” not only for your partner- but for yourself!
5 Steps To Live Better Today
For the Care Partner and the PWP

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https://www.parkinson.org/5steps
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References


Thank You
SLIDES

You can download slides via the link in the CHAT or by visiting our website at Parkinson.org/ExpertBriefings

CEU

For Health Professionals interested in 1 free CEU from the American Society on Aging, visit Parkinson.org/ExpertBriefings

Valid until July 9th, 2020.
Ongoing Virtual Events

PD Health @ Home

Mindfulness Mondays
Expert Briefings Tuesdays
Wellness Wednesdays
Take Time Thursdays
Fitness Fridays

2020 Care Partner Summit

A place to ask your Parkinson’s questions, connect with others living with the disease and be part of a network of support (PDConversations.org)

PD Conversations

View the archived 2020 Care Partner Summit | Cumbre Para Cuidadores at Parkinson.org/Summary.
Parkinson’s Foundation Resources

National Helpline
Specialists answer calls about all aspects of Parkinson’s in addition to helping you locate your local PD trained allied health professional therapist. 1-800-4PD-INFO Helpline@Parkinson.org Mon- Friday 9 am to 8 pm ET

Podcast: Substantial Matters
New episodes every other Tuesday featuring Parkinson’s experts highlighting treatments, techniques and research. Parkinson.org/Podcast

Fact Sheets and Publications
Get the resources and information you need to start living a better life with Parkinson’s.

Newly Diagnosed Kit
Designed to help you get started on your journey to living well with PD
Parkinson.org/NewlyDiagnosed

Aware in Care Kit
Includes tools and info for people with PD to share with hospital staff during a planned or emergency hospital stay. Parkinson.org/Awareincare

Order on Parkinson.org/PDLibrary or call the Helpline (1-800-4PD-INFO)
Announcing our New Expert Briefing Series!

Fall 2020

Young Onset Parkinson's Disease (YOPD)

Sept: Not What I Planned For Me or My Family
Oct: Work it Out: Managing Parkinson's in the Workplace
Nov: Partnering: The Dance of Relationships and Romance

Winter 2021

Symptom Management: Is it PD, Medication or Aging?

Feb: Exploring Motor Symptoms: Coping with Physical Symptoms of PD
March: Exploring Non-Motor Symptoms: Neuropathy, Fatigue, GI issues
April: Mental Well-being and Memory

Registration open soon! In the meantime, visit our on-demand Webinars at Parkinson.org/Webinar