Young Onset Parkinson’s Disease:
Not What I Planned, For Me or My Family

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Why is it important to distinguish YOPD from PD?
Learning Objectives

• Describe benefits of interdisciplinary care early in diagnosis of YOPD
• Identify three proactive strategies for living well with Parkinson’s at a young age
• Identify at least two steps for planning ahead for your family
What is Young Onset Parkinson’s disease?

• Young Onset Parkinson’s Disease (YOPD) occurs in people with Parkinson's disease (PD) who are diagnosed before age 50

• Up to 10% of total people living with PD in the United States have YOPD

www.parkinson.org/Understanding-Parkinsons/What-is-Parkinsons/Young-Onset-Parkinsons
Understanding the symptoms of YOPD

- Motor and non-motor symptoms are similar in PD and YOPD
  - Tremor
  - Rigidity
  - Bradykinesia
  - Impaired balance
  - Depression
  - Sleep disturbances
  - Mood and memory changes
  - Urinary issues

- Symptom management is generally the same in both YOPD and PD

https://www.parkinson.org/Understanding-Parkinsons/What-is-Parkinsons/Young-Onset-Parkinsons
How is YOPD different from PD clinically?

- Symptoms may progress slower than PD
- More side effects from common PD (dopaminergic) medications
  - Dyskinesia (involuntary movements)
  - More frequent dystonia (a type of dyskinesia)
  - Motor fluctuations with “on” and “off” times
- People with YOPD are more likely to carry genes linked to PD
- Younger brains may have higher neuroplasticity

https://www.parkinson.org/Understanding-Parkinsons/What-is-Parkinsons/Young-Onset-Parkinsons

An unexpected diagnosis

- Busy careers
- New partnerships
- Parenting and growing families
- Caring for elder parents
- Looking forward to retirement

**YOU** are still the same person you were before!
Special considerations in YOPD for providers

Distinguishing social factors should be recognized

• Parenting and caregiving responsibilities
• Time away from work for provider visits
• Future plans
  • continued education
  • career goals
  • pregnancy and growing families

• PD Gene testing
• Make early referrals to interdisciplinary care!
What is interdisciplinary care?

A **collaborative** approach to care with specialists and the patient and family

- Movement Disorders Specialist (MDS)
- Physical therapist (PT)
- Speech therapist (SLT)
- Occupational therapist (OT)
- Social Worker and/or mental health provider
- Pharmacist
- Nutritionist

**Find your closest Parkinson’s Foundation COE by visiting the Parkinson’s Foundation website**
Benefits of interdisciplinary care in YOPD

- Baseline assessments determine opportunities to stay well or for improvement
  - Where do you have the most needs?
  - What are you already doing that is working?
- Learn preventative strategies
- Make a personalized care plan using your priorities
- Younger brains may have higher neuroplasticity
- Higher patient and family satisfaction with quality of *and* actual outcomes improved


Defining YOUR goals and decision making

• One step at a time! Consider choosing your next “care” step based on your priorities and personal and/or professional goals
• Medication – to take or wait?
• Do you want to get involved in a PD focused community?
  • Support Groups
  • Educational Programs
• You decide when/where/with who and how you share your diagnosis
Planning ahead for your family

Planning for the future can alleviate stress in times of crisis...

• Complete Health Care Power of Attorney (HCPOA), Advanced Directives and family care plans

• Familiarize yourself with your disability and long term care insurance/policies

• Talk with your children about PD

“*We have Parkinson’s disease*”
Proactive steps for living well with YOPD

• Exercise!
• Prioritize PD related provider visits
• Create a daily routine to balance personal and professional goals
• Evaluate your support system and grow as necessary
• Remember, you are always evolving, so your plans and goals can change, too!

THIS IS YOUR STORY!

Meet Anna and Paul
Post-Webinar Details & CEUs

CEUs
Health Professionals interested in 1 free CEU from the American Society on Aging refer to link in chat. *Valid until October 15, 2020.*

RECORDING
This webinar is recorded for on-demand viewing and will be available within a week of the live event.

SLIDES
Download webinar slide deck via link in the chat. *Also available at: Parkinson.org/EB*
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
Episode #10: YOPD

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

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

More information on YOPD, visit: Parkinson.org/YOPD
Work it Out: Managing Parkinson's in the Workplace

Tuesday, October 27th | 1:00pm ET

Featuring:

Miriam Rafferty, PT, DPT, PhD & Brad McDaniels, PhD, CRC

with special guest Kelly Weinschreider