Young Onset Parkinson’s Disease

Work it Out
Managing Parkinson’s in the Workplace

Miriam Rafferty, PT, DPT, PhD
Bradley McDaniels, PhD
Kelly Weinschreider

October 27, 2020
Speakers

Miriam Rafferty, PT, DPT, PhD
- Research Scientist Shirley Ryan AbilityLab
- Assistant Professor Department of Physical Medicine & Rehabilitation and Department of Psychiatry & Behavioral Science at Northwestern University’s Feinberg School of Medicine

Bradley McDaniels, PhD, CRC
- Certified Vocational Rehabilitation Counselor
- Assistant Professor Department of Rehabilitation and Health Services University of North Texas

Kelly Weinschreider
- Age 47
- Diagnosed in 2002, at age 29
- Worked until 2012 (age 39)
- Various volunteer roles with the Parkinson’s Foundation
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Disclosures and Acknowledgements

Miriam Rafferty
• Employed by Shirley Ryan AbilityLab, a provider of Vocational Rehabilitation Services.
• National Institute on Disability, independent Living, and Rehabilitation Research Grant 90RTEM000101 Center on Employment for People with Disabilities (Parkinson’s: Intervening Early Concerning Employment 2018-2023).
• Parkinson’s Foundation: Virtual Vocational Rehabilitation Community Grant Recipient 2020. Parkinson’s Outcomes Project Steering Committee Member. PT Faculty Training Program Evaluator. Exercise Competency Leadership Committee Member.

Bradley McDaniels
• None

Kelly Weinschreider
• Parkinson’s Foundation People with Parkinson’s Advisory Council member and Women and PD Initiative leader. Parkinson’s Advocate in Research.
M1 Polling Question

If you are a person with Parkinson’s disease, are you employed?

• Yes, Full-time
• Yes, Part-time
• No, but I would like to be
• No, retired
• No, on disability
• Not applicable (not a person with Parkinson’s)
Background: Employment Challenges in Parkinson’s
Employment Challenges in PD

Movement
• Difficulty moving around the workplace
• Difficulty writing and typing
• Trying to hide symptoms/self-conscious

Communication
• Voice projection
• Facial Expression

Mood
• Apathy
• Fatigue
• Anxiety and Depression

Cognition/Thinking
• Multi-tasking
• Organization
Employment Challenges in PD

Disclosure
• To whom and how much?
• When?

Accommodations
• Formal accommodation requests through HR
• Informal adaptations

Disability or Retirement
• On average, leave the workforce ~5 years early.
• Complicated paperwork and financial planning

Peer-reviewed literature indicates presence of employment challenges (17 articles found)

- Describe workplace challenges
- Describe leaving the workforce early
- Physical therapy was more effective in people who were employed
- Vocational rehabilitation (rehabilitation counseling) could be beneficial

Information sheets from major PD advocacy groups

What Information is Available to Guide Addressing Employment Challenges in PD?
## Needs Assessment Focus Group Results: People with PD (PwP) and Clinicians

<table>
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<tr>
<th>Need</th>
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<tr>
<td>PwP and clinicians need information</td>
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<td>PwP need someone to start the discussion about employment challenges</td>
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<td>Employment-related intervention needs to be individualized and proactive</td>
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Rafferty et al. *JOOR*. 2020. in press?
Vocational Rehabilitation Program

Open now thru March 2021
Contact Sydney Achler at sachler@sralab.org
Kelly Weinschreider, age 47
The Spoon Theory, by Christine Miserandino

https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/
K1 Poll Question

What are YOUR employment challenges? Pick TWO biggest concerns.

- Handwriting
- Computer use
- Speaking softly
- Safety in the workplace and risk of injuring others
- Safety in the workplace and risk of injuring self
- Multi-tasking and staying organized
- Working fast enough
- Transportation (driving or commuting)
Employment Policies and Parkinson’s
An Introduction to Disability Legislation and Vocational Rehabilitation
Bradley McDaniels, PhD, CRC
What is Vocational Rehabilitation?
• Federal funded, state-operated program designed to access, plan, develop, and provide services to people with disabilities

Who is eligible?
• A person with a disability who requires and can benefit from services

What services are available?
• Vocational, physical and mental services, specific training, payment for some job-related costs, assistive technology, among others

How to find a Vocational Rehabilitation Counselor?
• https://askearn.org/state-vocational-rehabilitation-agencies/
Americans with Disabilities Act (ADA) 1990; amended 2008

**Title I: Employment**

- Goal is to prohibit discrimination of *qualified* individuals with a disability
- Discrimination includes not making *reasonable accommodations*, denying jobs or benefits based on one’s disability, and using qualification standards to screen out people with disabilities

**Title V: Miscellaneous**

- Prohibits coercion or threatening acts against people with disabilities who are asserting their ADA-protected rights
Disclosing PD in the Workplace

Do I have to disclose?
• NO! The only time you need to disclose your PD to your employer is if you will require reasonable accommodations to perform your job duties.

How do I disclose?
• Focus on the limitations involved with PD that are affecting your work, and frame it in functional terms

Accommodations
• Know what accommodations you will need to continue to perform the required job tasks; don’t make the employer figure it out.
To whom should I disclose my PD?
• Your immediate supervisor is usually best
• HR may be notified to assist with reasonable accommodations

General comments about disclosing
• Symptoms
• Avoid discussing the ADA
• Be prepared with the necessary facts
• Keep the focus on your desire to continue as a productive employee
• Talk in non-medical terms about specific, disability-related challenges that might benefit from reasonable accommodation
I haven’t told anyone at work, but I’m afraid that they will start to notice.

Physical/visible symptoms, tremor dominant, trying to keep hand in pocket, struggling at work with handwriting notes and typing.
If I disclose, I think I will lose my job. Do I have to disclose? If so, what and to whom?

Job responsibilities include driving.
When are people going to notice? Do I need a Lawyer?

Traditional Interdisciplinary Team Response

Vocational Rehabilitation Response
I love my job, but have been really struggling to stay on top of things.

Difficulty with multi-tasking, organization, note taking, completing tasks in a timely manner, and staying focused. Feeling very stressed about work because supervisor has expressed concern.
Take Home Points

1. People with Parkinson’s disease may have individual challenges with their work based on their symptoms and their job.

2. Challenges may include changes in movement, mood, communication, and cognition/thinking.

3. Individually-tailored advice may be needed.

4. Vocational rehabilitation counselors have expertise in navigating disclosure and accommodations.
Your Questions
Virtual Vocational Rehabilitation Program for People with Parkinson’s Disease

Open now thru March 2021
Contact Sydney Achler at
sachler@sralab.org
Resources

Job Accommodation Network (JAN)
- AskJan.org/disabilities/Parkinson-s-Disease.cfm
- Consumers can call JAN Helpline to reach Vocational Rehabilitation Counselor: 1-800-526-7234

Getting Hired
- GettingHired.com

My Employment Options
- MyEmploymentOptions.com
Thank you!

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Post-Webinar Details & CEUs

CEUs
For Health Professionals interested in 1 free CEU from the American Society on Aging click on the link in the chat. Valid until November 27, 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.
Expert Briefing Series: Up Next

Young Onset Parkinson’s Disease:
Partnering: The Dance of Relationships and Romance
Tuesday, November 10th | 1:00pm ET

Featuring:
Dr. Sheila Silver, MA, DHS, ACS, Alma Aragon & Carlos Gonzales

Register at Parkinson.org/ExpertBriefings
Upcoming AARP Partnership Webinar

Parkinson’s Foundation & AARP Partnership Webinar Series:

Fall Prevention and Living Safely at Home with Parkinson’s

Tuesday, November 19th | 1:00pm ET

Featuring:
Rose Wichmann, PT, Danielle Airgoni and Adolfo Diaz, BSBA, PTA

Register at Parkinson.org/ExpertBriefings
Resources

Newly Diagnosed
There is no right way to process a Parkinson’s diagnosis, but the right information can help. Order your Newly Diagnosed kit at Parkinson.org/NewlyDiagnosed

PDGENEratation
National Initiative offers genetic testing for Parkinson's-related genes and counseling at no cost. Parkinson.org/PDGeneration

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

Fact Sheets and Publications
Get the resources and information to start living a better life with Parkinson’s. Parkinson.org/Employment