Answering Your PD Questions: From Newly Diagnosed to Caregiver Resources

Nina Browner, MD
University of North Carolina, Parkinson’s Foundation Center of Excellence

Amy Goyer
AARP, Family Caregiving

Moderator: Julia Wood, MOT, OTR/L
University of Pennsylvania, Parkinson’s Foundation Center of Excellence

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Answering Your PD Questions

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University of North Carolina, Parkinson’s Foundation Center of Excellence
Decrease production of dopamine in the brain creates

- Slowness of movements
- Muscle tightness
- Balance problems
- Tremor
Parkinson’s disease: non-motor symptoms

WHAT ELSE RUNS ON DOPAMINE

SEXUAL FUNCTION

SMELL

COGNITIVE FUNCTION

SLEEP

MOOD
I am diagnosed with PD, now what?

Breathe...

PD ≠ end of your life as you know it

There are many treatment options

Meeting another person with PD ≠ your reflection in the mirror
I don't have any choice whether or not I have Parkinson's, but surrounding that non-choice is a million other choices that I can make.

--Michael J. Fox

Between stimulus and response, there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.

-Victor Frankl
I am diagnosed with PD, and then what?

Take care of your whole self

• Be kind to yourself and give yourself time to process your diagnosis

Be flexible and “go with the flow”

Take back control

• Establish new routines / new roles

Keep Moving!

• Find something you enjoy and that motivates you
It Takes a Village

- Your partner/ your buddy/ your rockstar
- The right doctor
  - Neurologist
  - Movement Disorders Specialist
- Beyond neurologist – the Parkinson’s healthcare team
  - Physical therapist
  - Occupational therapist
  - Primary care provider
  - Speech therapist
  - Mental health worker
  - Pharmacist
A very important step…

… build the best care team
Take Home points

Please take your time to process the new diagnosis

Turn around and find your village

Keep moving!

Get involved with our amazing, inspiring and welcoming Parkinson Community
My life is full. I act, I give talks, [and] I do my podcast, which I love. If you get a diagnosis, keep moving!

- Alan Alda

EVERYONE WITH PD HANDLES IT DIFFERENTLY. DON'T LET IT GET IN THE WAY OF LIVING. LIFE IS TOO GOOD. REMEMBER, KEEP GOING — THE SKY’S THE LIMIT.”

MICHAEL RICHARD CLIFFORD (NASA ASTRONAUT)
Key Issues for those Newly Diagnosed with Parkinson’s Disease and their Care Partners

Amy Goyer
AARP Family & Caregiving Expert
Family Caregiving

• 41 Million unpaid relatives, friends, neighbors providing most of care in U.S.
• 60% also work a paid job
• 1 in 4 are Millennials
• 60% female, 40% male
• AARP wants to ensure caregivers have what they need when they need it
Poll #3

Which of these 5 issues is most important to you right now?

1. Starting conversations around current and future care
2. Lining up my care team
3. Making an overall care plan
4. Finding professional support
5. Caring for myself
5 Issues to Address in Your Caregiving Journey

1. Start the Conversation
2. Form Your Team
3. Make a Plan
4. Find Support
5. Care for Yourself
1. Go to aarp.org/preparetocare
   Download by choosing a version / Click and request a print copy
2. Call AARP at 877-333-5885
   Select option 1 and request the "Prepare to Care: A Planning Guide for Families," item #D20152
Points to Ponder

- Stress
- Family relationships
- Health
- Finances
- Legal
- Care coordination
- Providing hands-on care
- Medical/nursing tasks
- Self-care
- Work
Family Caregiving

CAREGIVER RESOURCE CENTER
Helping you navigate your role as a family caregiver

CONNECT WITH US
AARP Caregiving Community
AARP Caregivers Facebook Group
AARP Caregiving Support Line

CORONAVIRUS
Combating Loneliness
Coping With Anxiety
Crisis Planning
Dealing With Confined Quarters
Experts’ Tips to Reduce Risk
Facts

DEMENTIA
Care Plan
Memory Cafés
Memory Care
Mild Cognitive Impairment
Online Safety
Signs and Symptoms
Sundown Syndrome

FINANCIAL
Costs of Caregiving
Getting Paid for Caregiving

LEGAL
Advance Directive
Federal Family & Medical Leave Act
Guardianship
Health Care Surrogate
Living Will
Power of Attorney
State Family Leave Laws
Support for Adult Disabled Children

LIFE BALANCE
Adult Day Care

MEDICARE: DOES IT COVER?
Acupuncture
Assisted Living
Cataract Surgery
Chiropractic Services
Colonoscopy
Dental Care
Dentures
Glasses
Hearing Aids
Home Health Care
Nursing Homes

aarp.org/caregiving
Poll #4

If you are currently working, or were before the COVID-19 outbreak, does your employer know that you or your care partner are living with Parkinson’s disease?

a) Yes
b) No
Working Family Caregivers

- 60% have worked at some point in past year
- Among **millennials**, 73% working
- More likely **male (66%)** than female (55%)
- **Half are older workers** age 50+
- 56% **work full time**
- 1 in 6 are **self-employed** or own business
- 37% of employed family caregivers say **highly stressful**
- Family caregivers tend to **modify work to fit caregiving**, rather than modifying caregiving to fit with work
Possible Work Adjustments for Caregivers

- **Work hours/schedule:** flexible hours, start earlier or later, request predictable schedule, compressed work week, part time, job sharing, phased retirement

- **Work Location:** telecommuting (working remotely), working at a different office location closer to loved ones

- **Leave:** Paid or unpaid, vacation, sick, personal, caregiving, bereavement, FMLA (up to 12 wks) or military caregiver (up to 26 wks), donated, leave of absence
• Find alternative care and continue current work (care partners)

• If you are considering leaving a job, getting a new job, phased retirement, full retirement:
  o Try to look ahead: Consult financial advisor; consider loss of income, future employment options vs. cost of care
  o Also consider stress emotional strain, relationships, loved ones’ current and future needs
My true success as a caregiver lies in being resilient and being fully, lovingly present with my loved ones in this unpredictable journey.

From *Juggling Life, Work and Caregiving* by Amy Goyer
HOME & FAMILY / COMMUNITY VOICES
Veterans, Military and Their Families

AARP Veterans and Military Discount
Save up to 30% when you join AARP

Supporting Military, Veteran and Family Caregivers
Tips to update your journey during COVID-19

AARP’s Military Caregiving Guide
For veterans, service members and their families
Upcoming Virtual Events!

Moving Day USA – Virtual Walk (now virtual!)
May 9th, 2020, 1 pm EST
Visit MovingDayUSA.org for registration and more information.

2020 Care Partner Summit | Cumbre Para Cuidadores (now virtual!)
Planning for the Unpredictable Path of Parkinson's Caregiving
May 16th, 2020, 12 -3:30 pm EST
Visit Parkinson.org/Summit for registration and more information.
Ongoing Virtual Events

PD Health @ Home (new!)
Responding to the needs of the PD community (Parkinson.org/PDHealth)

in-person events          virtual events 5 days a week

PD Conversations
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)

Join today to be part of the community
Expert Briefing Series: Up Next

**Newly Diagnosed: Living Your Best Life with Parkinson’s**

Tuesday, June 9th | 1:00pm ET

Jenna Iseringhausen BSN, RN, NYU Langone Marlene and Paolo Fresco Institute for Parkinson’s and Movement Disorders.

Register for upcoming webinars (and view our library of archived webinars):
Parkinson.org/Webinar
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)