How can we best support caregivers/care partners of people with Parkinson’s disease?

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Your presenter:

- MSW
- Multiple decades of work experience, mostly serving individuals living with chronic illness and resulting disability
- Powerful Tools for Caregiver’s trainer
- Caregiver/Care partners support group leader
Objectives for this session:

- Have a comprehensive understanding of Parkinson’s disease symptoms and course.
- Understand the common misconceptions about the disease and impact on family.
- Become acutely aware of the impact the disease can have on caregivers/care partners.
- Be knowledgeable about regional and national resources that support caregivers for people with Parkinson’s disease.
What Is Parkinson’s Disease?

Parkinson’s disease is defined (diagnosed) by its effects on *movement*. 
Diagnosing Parkinson’s Disease

There is no test that “proves” someone has PD
Diagnosis is based on history and exam
Diagnostic testing is used to identify other possible causes of symptoms
For some, it is a number of months, if not years, getting a diagnosis
The main finding in brains of people with PD is loss of dopaminergic neurons in the area of the brain known as the *substantia nigra*.
The timeline of Parkinson’s disease

<table>
<thead>
<tr>
<th>Stage</th>
<th>Time Period</th>
<th>Features</th>
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<tbody>
<tr>
<td>Very Early</td>
<td>0-3 years</td>
<td>Medications are initiated when symptoms interfere</td>
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<td>Early (Honeymoon)</td>
<td>&lt;1 to ~8 years</td>
<td>Stable response to medications*</td>
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<tr>
<td>Mid (Fluctuating)</td>
<td>&lt;1 to &gt;20 years</td>
<td>Motor symptoms respond to medication, but wear off</td>
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<td>→ progressively longer periods without medication benefit</td>
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<td>→ progressively more severe immobility during &quot;off&quot; times</td>
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<td>→ more side effects as medication doses increase</td>
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<td>Advanced (Frail)</td>
<td>5-10 years</td>
<td>Many symptoms that do not respond well to medication (balance, swallowing)</td>
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<td>→ Prominent non-motor issues (confusion; hallucinations)</td>
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<td>→ Management shifts to enhancing environmental supports</td>
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EXERCISE!!! PFGR education & wellness programs. (All stages)
How many people are living with PD?

Rochester, NY: 4,000
New York State: 42,000
US: 1 million
World: 10 million

Men are 1.5 times more likely to have PD

How many caregivers/care partners, family/friends might there be?
What are the most common Parkinson’s symptoms?

Common Motor Symptoms

- Muscle stiffness (“rigidity”)
- Bradykinesia
- Rhythmic shaking (“tremor”)
- Freezing/shuffling
What are the most common Parkinson’s symptoms?
What makes Parkinson’s disease challenging? Confusing? Misunderstood?

Parkinson’s symptoms vary enormously from person to person.
PD is defined (diagnosed) by its effects on movement ("motor symptoms").
Parkinson’s can also affect other parts of the nervous system, leading to “non-motor symptoms.”
Unpredictability of course
Dealing with the unknown – will that be me?
Common, often misunderstood symptoms: early, maybe before dx

- Loss of smell or taste
- Constipation
- Acting out dreams
- Trouble falling or staying asleep
- Mood symptoms
  - Anxiety, depression, apathy, irritability
  - Fatigue
  - Pain from muscle stiffness
  - Cognitive changes
  - Slower thinking; difficulty multi-tasking
- Sexual problems
  - Erectile dysfunction; delayed orgasm;
Common, often misunderstood symptoms: disease progression

- Apathy
- Low blood pressure when standing*
- Dizziness; fainting
- Heat intolerance; excessive sweating
- Hallucinations*
- False beliefs (delusions)*
- Behavior changes
- Impulse control problems*
- Unprovoked crying
- Vision changes
- Global cognitive decline ("Dementia")
Common misconceptions:

- It’s only an older person’s disease
- It’s only motor symptoms (some people have no motor symptoms)
- The course of PD is predictable
- Symptoms are the same day to day
- There is nothing you can do about a PD diagnosis
- It’s not genetic
Treatments/approaches to manage disease

Sinemet - combination of levodopa and carbidopa
- by mouth, time release, stomach pump

Deep Brain Stimulation – specific criteria to qualify

Physical Therapy/Exercise of high intensity – boxing, yoga, cycling, just move

Diet – no one specifically recommended
Most challenging for care partners?

REM sleep disorder
Lewy body dementia
Bradykensensia
Hallucinations
Delusions
Caregivers and Parkinson’s
Impact on caregivers/care partners:

- Physical, mental & emotional exhaustion
- Shutting out the caregiver/partner – not allowing partner to attend medical appointments, stubbornness
- Paranoia/delusions – you’re cheating on me
- Dealing with hallucinations – hugely frustrating for some
- Dealing with the fallout of impulsive behaviors – shopping, gambling
Impact on caregivers/care partners:

- Anxiety – what we will do for $, insurance, refusal to stop driving
- Injury – (REM sleep disorder)
- Ignoring their own health & well being
- Isolation
- Financial implications
Tried and tested helpful suggestions:

Build a team
Prepare as much as possible early in the disease
Connect with the support that works for you – a formal support group, an informal support group, online groups, a therapist, attend a PTFC class
Respite, respite, respite, respite, respite, respite – which we do not have nearly enough of.
A diagnosis of Parkinson’s Disease is *not* the end of the road!

**TEAMWORK**
will be key in your journey with PD.
Include family, neighbors, friends, health care providers, and the PF chapter community.
The Parkinson's Foundation makes life better for people with Parkinson’s disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.
Parkinson’s Foundation

- **Helpline:** 1.800.4PD.INFO (473-4636)
- Research (new genetics initiative happening)
- **Centers of Excellence** (PD specialists)
- Education, education, education
  - print literature, webinars, podcasts
- **Community Grants**
- Aware in Care kits
- **Professional education programs for RNs, PT’s OT’s**
- PPAC (people w/PD and caregivers)
- Research Advocates
National & maybe local resources:

- Parkinson’s Foundation Helpline: 1.800.4PD.INFO
- Parkinson.org
- Michael J Fox Foundation
- Davis Phinney Foundation
- American Parkinson Disease Association
Non-motor symptoms of PD: Thinking & Memory

- Repeating questions despite paying attention to the answer
- Needing to rely on a “backup brain” (medications, appointments, finances, etc.)
- Significant word-finding difficulty (may sound incoherent)
- Confusion
- Getting lost

More serious changes (concerning for possible dementia)
Non-motor symptoms of PD: Thinking & Memory

Changes are common, and do not necessarily signify dementia

- Slower thinking
- Difficulty with
  - Multi-tasking
  - Solving problems
  - Finishing tasks without getting distracted
- Mild word-finding difficulties
  - "tip-of-the-tongue" problems
- Losing train of thought