The PD ExpertBriefing:

Parkinson’s Disease and its Treatment: Secrets, Myths, and Misconceptions

Presented by: Melissa J. Nirenberg, M.D., Ph.D.
Weill Cornell Medical College
New York, NY

Will begin:
Tuesday, September 29, 2009
at 1:00 PM ET
Welcoming Remarks

Robin Elliott
Executive Director
Parkinson’s Disease Foundation
Parkinson’s Disease and its Treatment: Secrets, Myths, and Misconceptions

Presented By:
Melissa J. Nirenberg, M.D., Ph.D.
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Parkinson’s Disease Foundation
Hope through Research • Education • Advocacy
Topics to be discussed

- Secrets: Things you might not know
- Myths: Pervasive but incorrect ideas
- Misconceptions: Partial truths
Goals:

- Provide new information
- Dispel myths and misconceptions
- Reassure and empower you
- Improve your quality of life
**Misconception:**
PD only affects movement
Reality:
Many PD symptoms are invisible

- “Non-motor” symptoms of PD
- These are commonly overlooked
Non-motor symptoms: which systems are affected?

<table>
<thead>
<tr>
<th>Sensory</th>
<th>Autonomic</th>
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<tr>
<td>Sleep</td>
<td>Mood</td>
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<td>Cognitive</td>
<td>Fatigue</td>
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Reality: people are biased towards what they can see
Secret: Since non-motor symptoms are invisible

- Write them down
- Tell your doctor
- Seek treatment
**Good news:** most non-motor symptoms are highly treatable

- Physical therapy & exercise
- Medications – PD and others
- Non-medical treatments
Misconception: If someone with PD looks good, then they are doing well
Reality: PD fluctuates ("ons" and "offs")

People are usually seen at their best
Secret: You need to tell your doctor

- My medicine wears off
- It lasts for _ hours
- I am now at my best (or worst)
**Myth:** wait as long as possible to take the next dose of Sinemet

- “Less is more”
- Wait until you need it
Secret: If you wait too long, then it may never “kick in”
Secret: Take your medications on time!
Myth:
You can blame PD for everything

- Common assumption
- Potentially dangerous
- Use common sense
Case #1:
80-year-old man with PD, develops sudden, severe back pain

- Highly functional at baseline
- Chronic mild low back pain
Over the next 5 days, his symptoms worsen dramatically

- More severe back pain
- Leg weakness
- Unable to walk
He went to a local ER

- X-rays normal
- Blood tests normal
- Discharged home

*Told that his symptoms were caused by PD*
What are the red flags here?

- **Time course** - too rapid for PD
- **Symptoms** - inconsistent with PD
What was actually going on?

- Slipped disc
- Unrelated to PD
- Required emergency surgery
**Secret:** some symptoms should not be attributed to PD

- fever
- weight loss
- headache
Secret: some symptoms should not be attributed to PD

- true weakness
- vision loss
- back pain

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Myth: There are PD “exacerbations”

- Common assumption
- Potentially very dangerous
Case #2:
75-year-old woman with worsening PD over the past week

- Moderate baseline symptoms
- Had been doing well on Sinemet®
- No recent medication changes
Worsening PD symptoms

- Stiffer, slower, more tremor
- Easily fatigued
- Difficulty walking
The patient saw her internist

- Diagnosed with “PD exacerbation”
- Advised to increase her Sinemet® dose
Sinemet® dose was increased

- Lightheadedness
- Confusion, hallucinations
- PD symptoms just as bad
Reality: PD changes slowly, not over days or weeks

- Something else must be going on!
- This cannot be attributed to the PD
- Need to find the underlying cause
What can cause rapid worsening of PD symptoms?

- Infection
- Other Illness
- Medications
Secret:
What is one of the most common silent causes for a “PD exacerbation?”

Urinary tract infection
Secret: Which medication changes can worsen PD symptoms?

- Nausea medications
- Antipsychotic medications
- Reduction of PD medications
Myth: levodopa (Sinemet®) stops working after 5 years

- Simply not true
- Medical folklore
Reality: levodopa (Sinemet®) continues to work for decades

- Increases lifespan
- Improves quality of life
Myth: Different generic brands of Sinemet® are different colors
Reality:
Sinemet® 25/100 mg is always yellow
Secret: a change in color often means a different form of Sinemet

- 25/100 mg regular
- 25/250 mg regular
- 25/100 mg extended-release
- 50/200 mg extended-release
Myth: Your doctor can predict your future
Secret: Your doctor can’t predict the future, but you can change it.
Research: Helping to change the future

- Neuroprotection
- Mood/anxiety
- Gender
- Imaging studies
- Genetic studies
- Early diagnosis of PD
- Stem cell research
- Treatment trials
Misconception: I don’t have PD, so I can’t participate in research studies
Reality: There are research opportunities for caregivers as well.

Another way that you can help.
Weill Cornell Parkinson’s Disease & Movement Disorders Institute

428 East 72nd Street, Suite 400
New York, NY 10021
www.weillcornell.org/movement
(212) 746-2584
Questions and Answers
Closing Remarks

Robin Elliott
Executive Director
Parkinson’s Disease Foundation
The archive for this *PD ExpertBriefing* will be available on

**Monday, October 5**

Please visit [www.pdf.org](http://www.pdf.org) for more information
PD ExpertBriefings Schedule

How to Take Care of the Caregiver  
Barbara Habermann, Ph.D.  
Tuesday, November 17, 2009 at 1PM ET

Nutrition and Parkinson’s Disease  
January 2010 *

Understanding Legal for People with Parkinson’s  
February 2010*

What’s in the Parkinson’s Pipeline?  
April 2010 *

Fatigue, Sleep Disorders and Parkinson's Disease  
Joseph Friedman, M.D.  
Tuesday, June 1, 2010 at 1PM ET

* Final date to be confirmed.
PDF HELPLINE

DO YOU HAVE QUESTIONS ABOUT PARKINSON’S DISEASE?
We can help.
Call Monday through Friday, 9 AM to 6 PM ET
Submit your questions online and hear back in 8 to ten days.

(800) 457-6676

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Browse Clinical Trials

All Trials: View all posted clinical trials.

By Location: Locate clinical trials in your area.

By Trial Type: Browse by clinical trial objectives.

By Symptom: Browse trials by Parkinson's symptoms.

By Keyword: Search by keyword to help find trials.