



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

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Chapter

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*.

AN
ESSAY
ON THE
SHAKING PALSY.

BY
JAMES PARKINSON,
MEMBER OF THE ROYAL COLLEGE OF SURGEONS.

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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

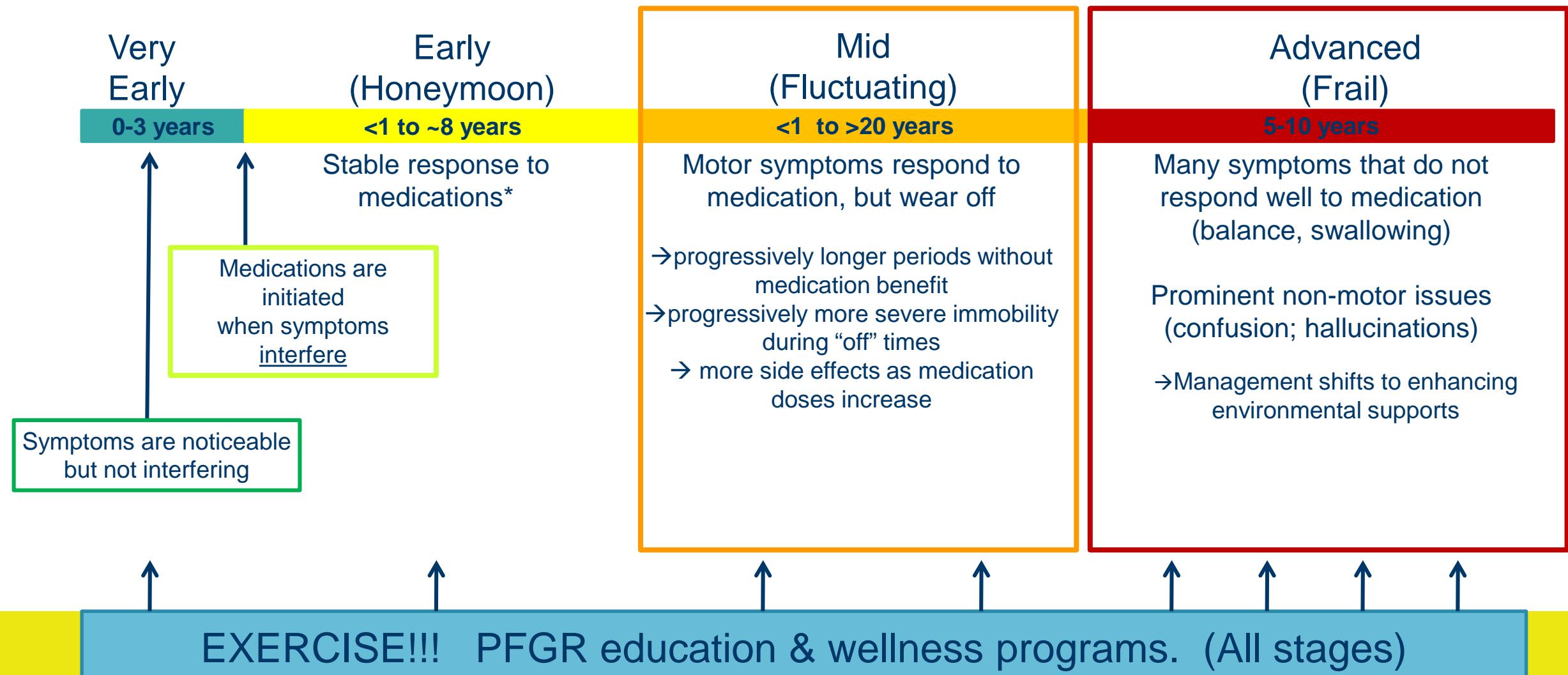
For some, it is a number of months, if not years, getting a diagnosis

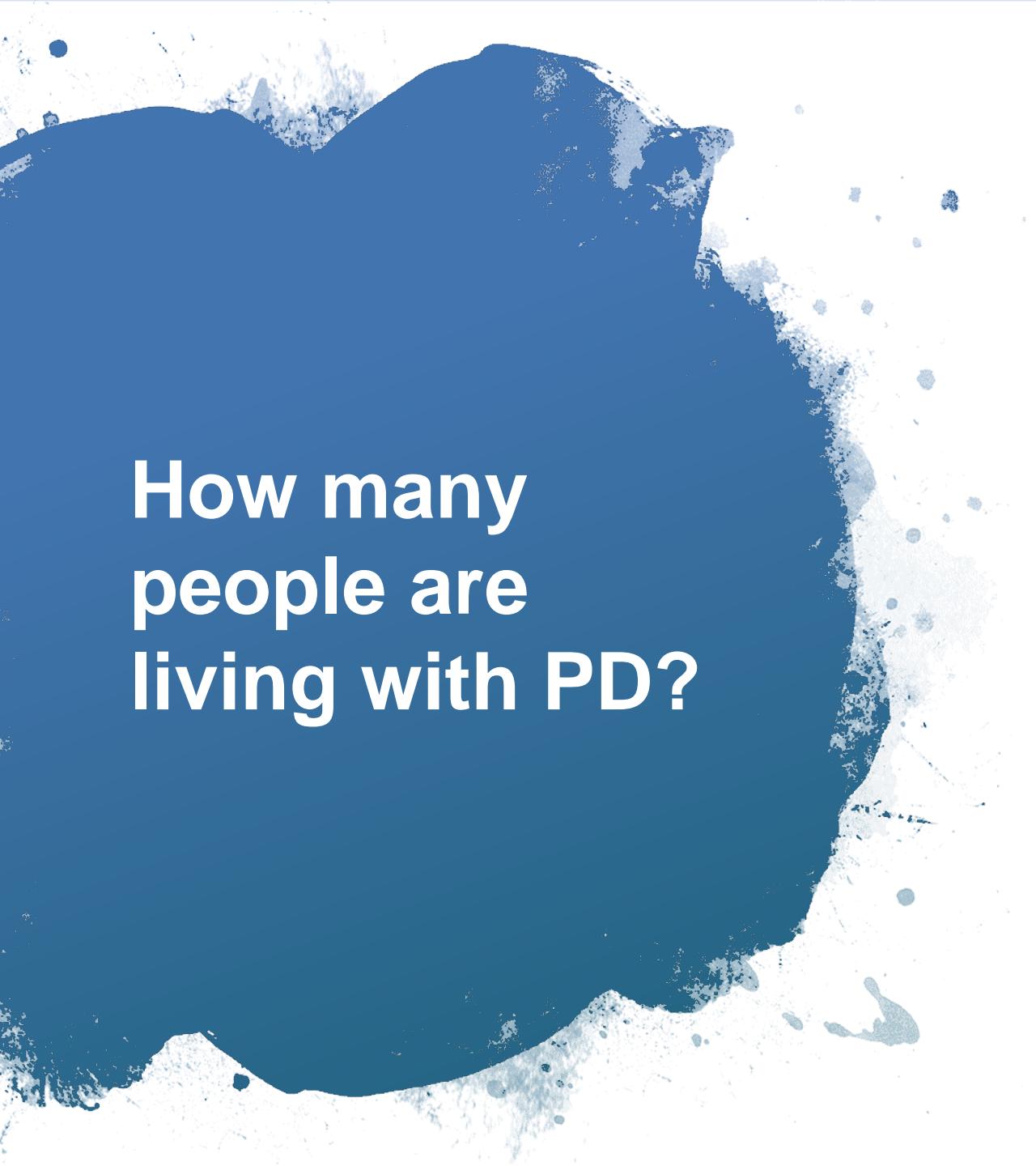
Parkinson's disease



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





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?

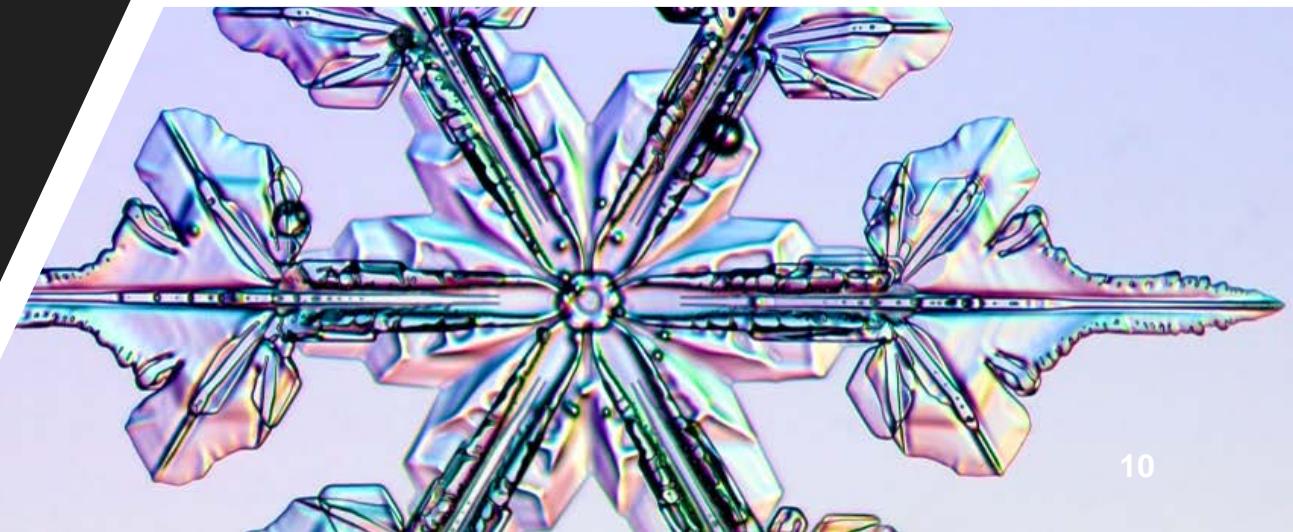
Parkinson's symptoms vary enormously from person to person.

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")



- 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

Common misconceptions:



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

Bradykinesia

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.



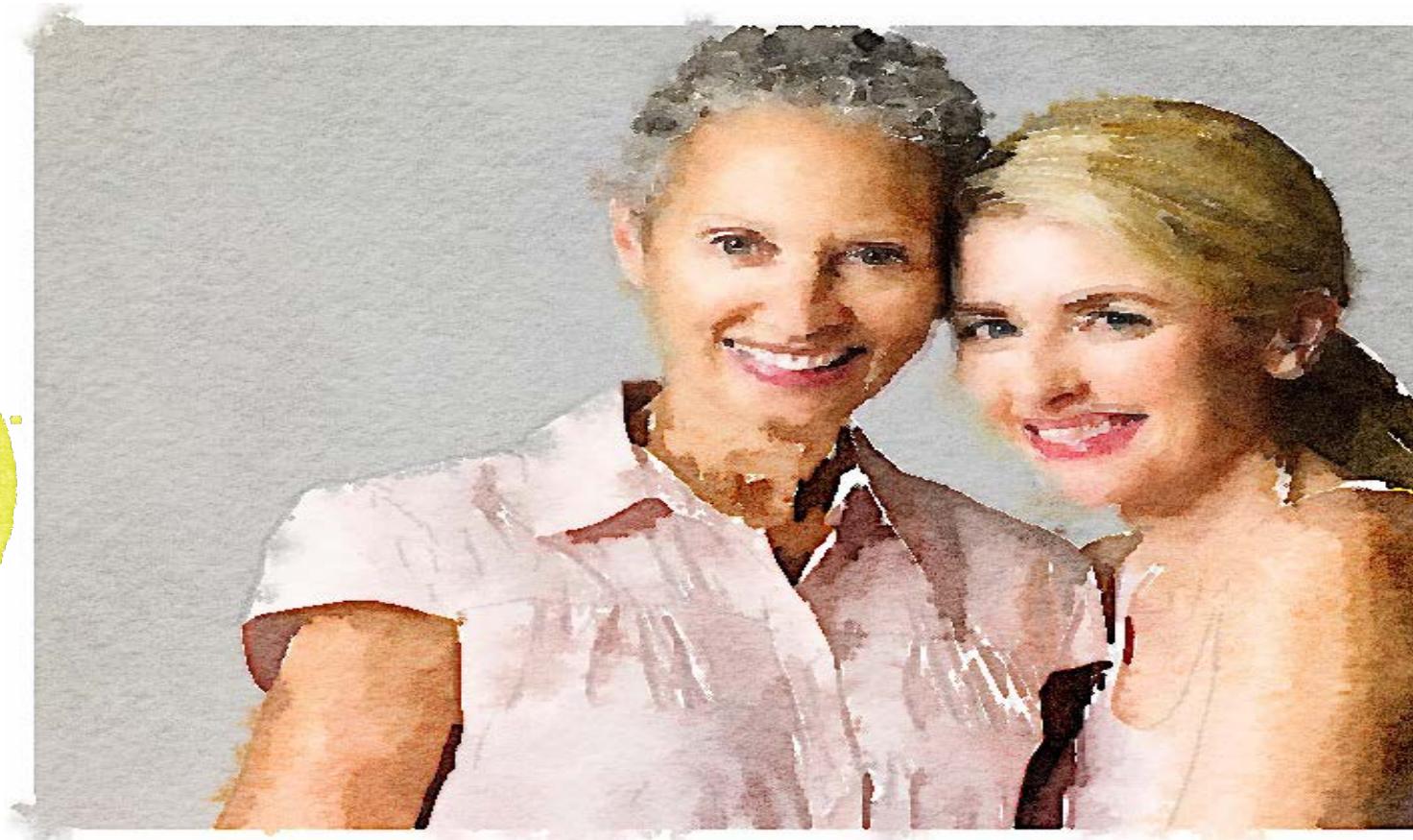
A diagnosis of Parkinson's Disease is *not* the end of the road!



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.

- **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

More serious changes (concerning for possible dementia)

- 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

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