

Parkinson's Foundation

PD Expert Briefing:

Diagnosis PD, Now What?

Managing the First Few Years with Parkinson's

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This session was held on:

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Questions? Contact lhoffman@pdf.org or (212) 923-4700



**Parkinson's
Disease
Foundation**

A division of the Parkinson's Foundation

Disclosures

- No Financial Disclosures

Learning Objectives

- Identify a care team that can help a person to better navigate Parkinson's
- Learn tips for effectively working with your health care team
- Understand how patient empowerment can lead to improved quality of life

Diagnosis

- Clinical testing
- Diagnosis is based on clinical grounds
- No formal blood tests or imaging that can definitively offer a diagnosis
- Can be unsettling to people with Parkinson's and their family

Who Typically Makes the Diagnosis?

- Primary medicine
- Neurology
- Movement disorder neurology
- Other
 - Family
 - Co-workers

Movement Disorders Neurologist

- Neurologist who has specialized training in diagnosing and treating movement disorders
- Responsibility
 - Connect Parkinson's symptoms and evolution with my observation/examination
 - **Pattern a diagnosis**
 - Order appropriate tests if necessary
 - Consider medical treatment when necessary
 - **Educate**
 - **Connect the person with Parkinson's with local resources** to help support their needs

Ideal World

vs. Reality

- Every person with Parkinson's disease is followed by a movement disorders specialist
 - Neurologist steers the care plan with bi-partisan support from person with Parkinson's
 - Care team support
- According to the Foundation, up to 40 percent of people with Parkinson's do not see a neurologist yearly
 - Less than 25 percent of people with Parkinson's see a movement disorders specialist
 - Main provider tends to be the primary care physician

Parkinson's Disease

- Neurodegenerative condition
- Resting tremor
- Bradykinesia – slowness of movement
- Rigidity – stiffness
- Postural instability – imbalance

Preclinical Non-motor Symptoms

- **Anosmia** – loss of sense of smell
- Anxiety/depression
- **Constipation**
 - Colonic transit time
- Sleep disturbances
 - Restless legs syndrome
 - **REM sleep behavior disorder**
 - One large study of 318 RBD pts reported constipation prevalence of 58 percent

Honeymoon Period

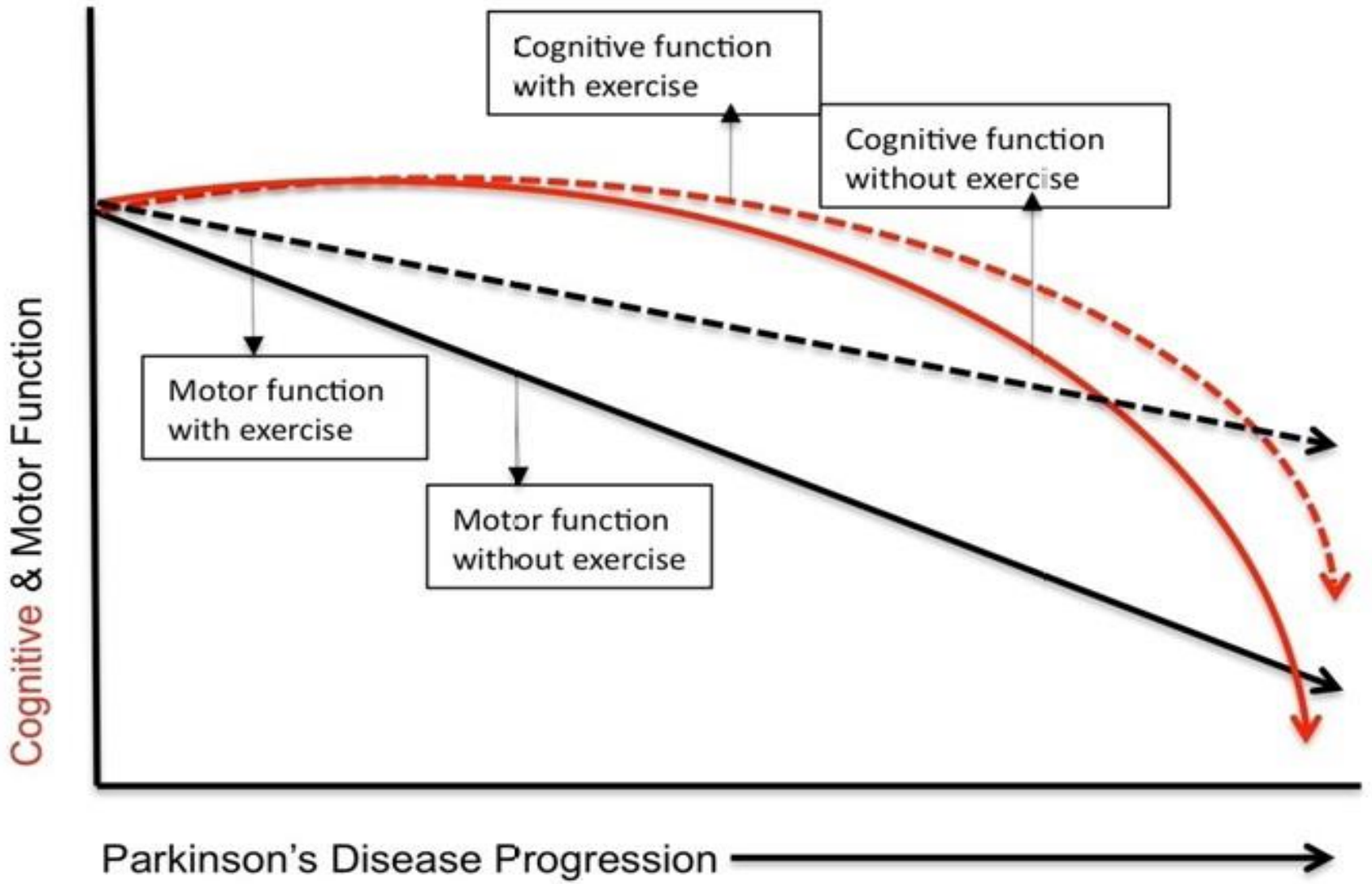
“It seldom happens that the agitation extends beyond the arms within the first two years; which period, therefore, if we were disposed to divide the disease into stages, might be said to comprise the first stage.”

Honeymoon Period

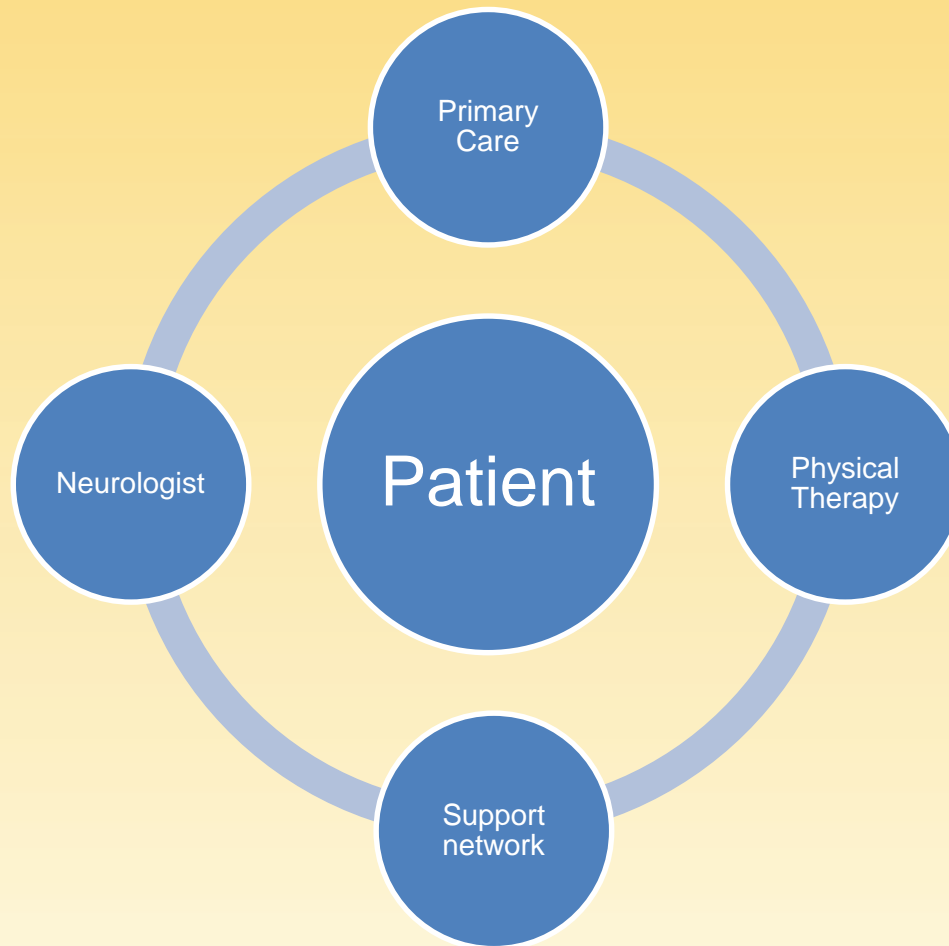
- Typical scenario
 - Diagnosis
 - Three to five years
 - Delay in medication or other treatment options
 - Infrequent medical assessment/engagement
 - Episodic crisis-driven care

*“In this period, it is very probable that **remedial means** might be employed with success: and even, if unfortunately deferred to a later period, **they might then arrest the farther progress of the disease.**”*

Was Dr. Parkinson speaking to traditional medical treatments or exercise?

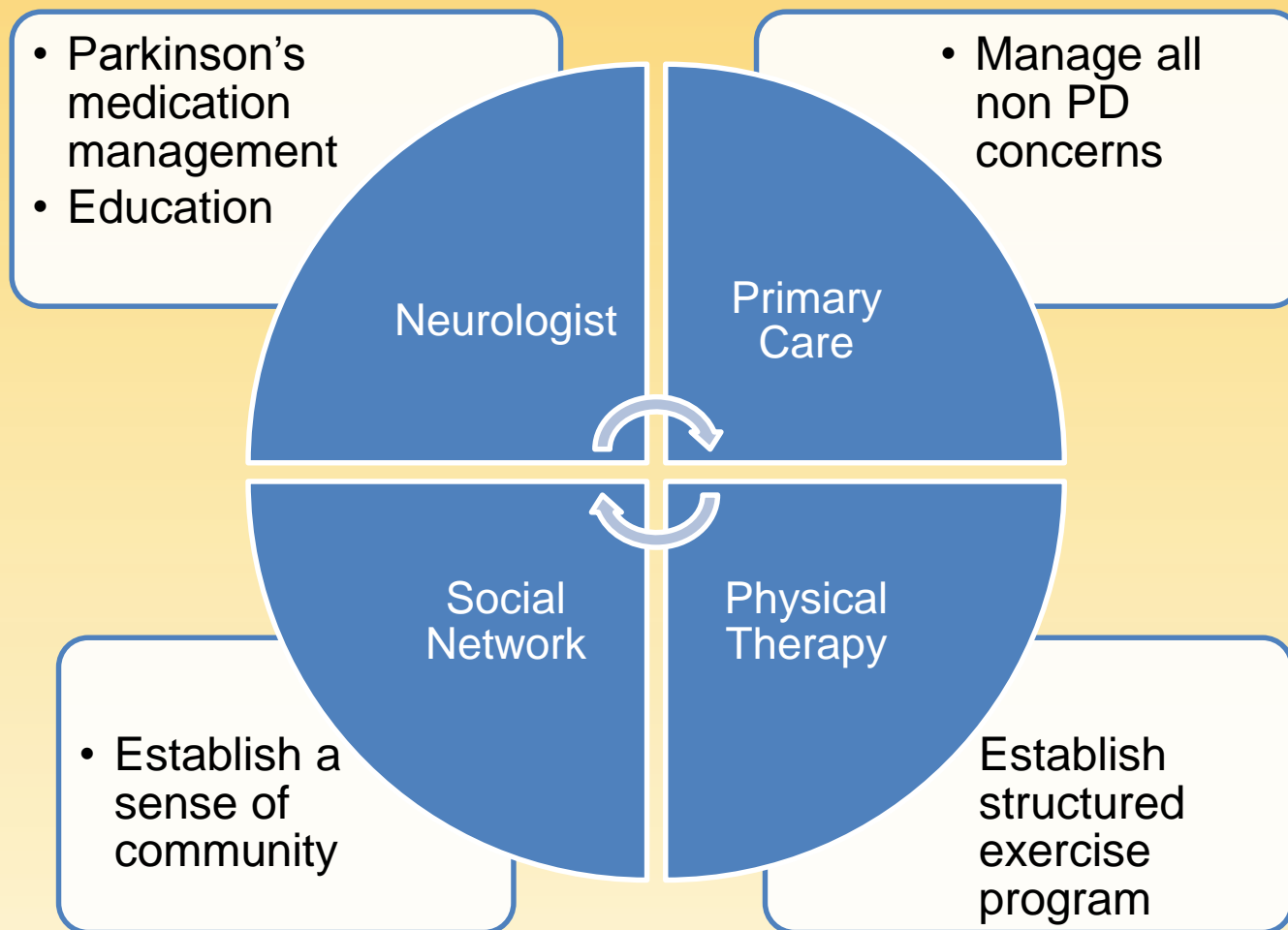


Developing a Care Team

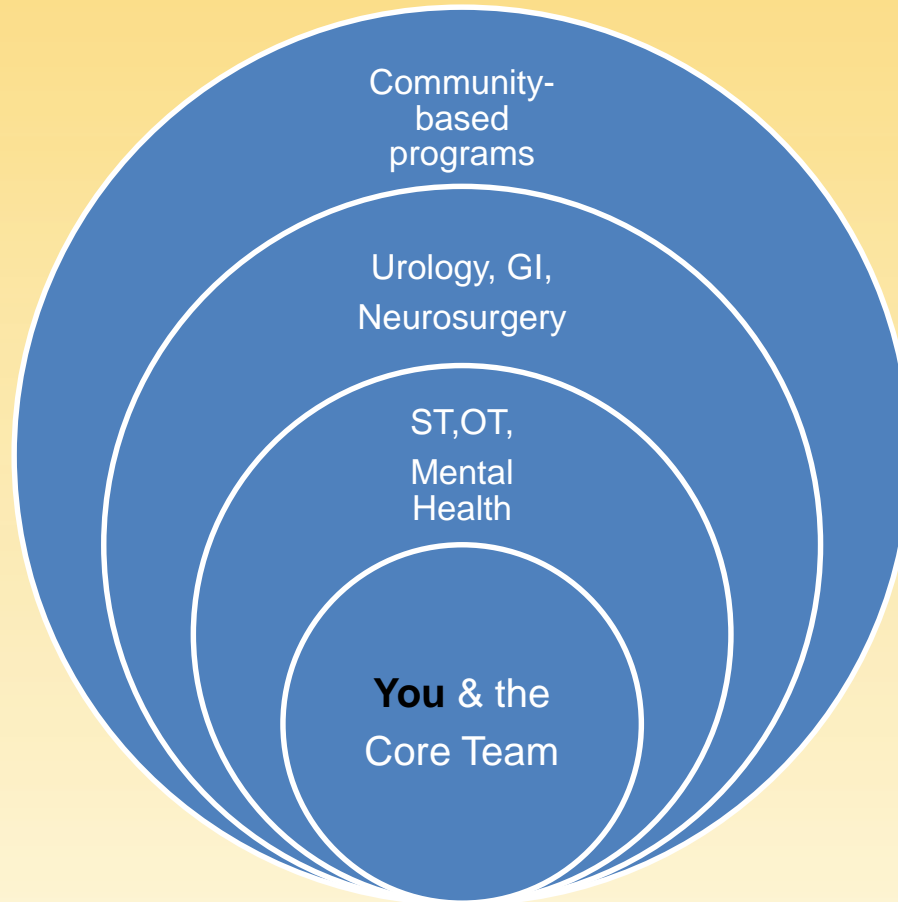


Care Team Requirements

- Expertise
- Experience
- Passion
- Network



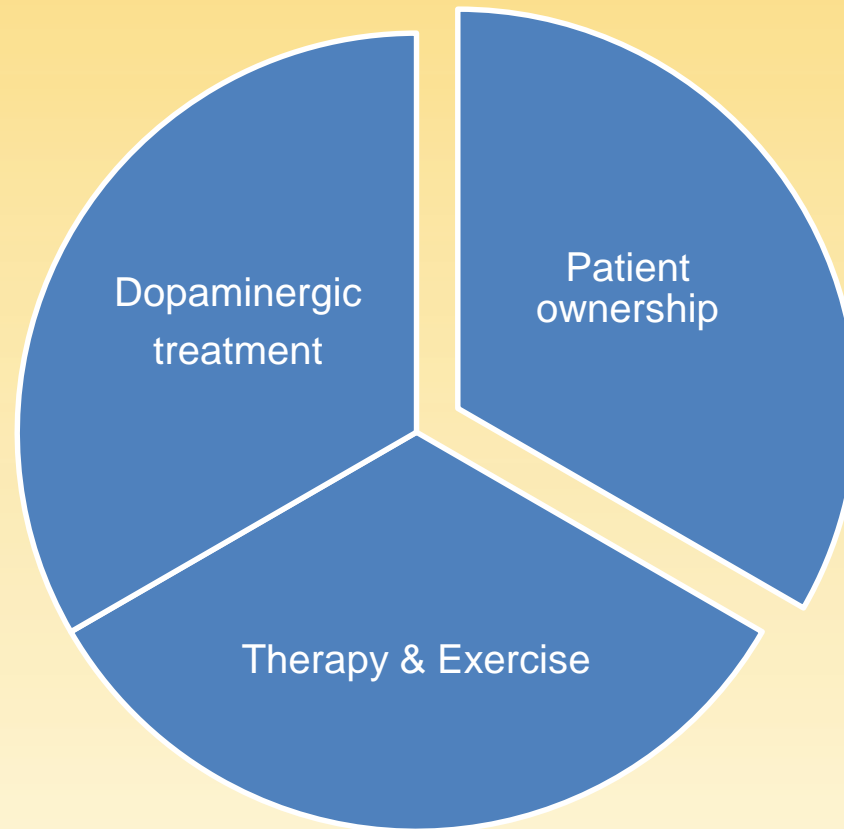
Larger Care Team



Effectively Working Together

- Dissolve traditional medical hierarchy
- Educate yourself
- Partnering with your care team
- Leveraging telemedicine
 - Email, telephone, video visits

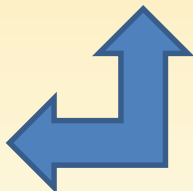
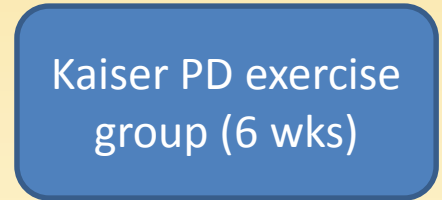
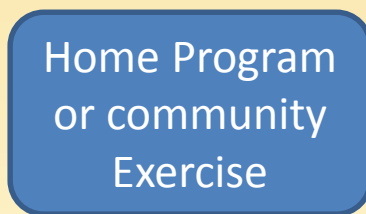
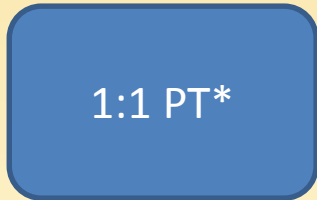
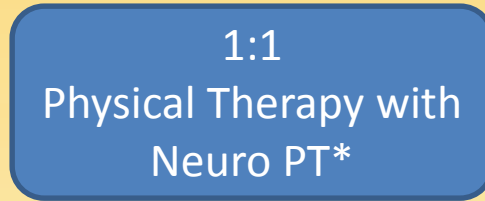
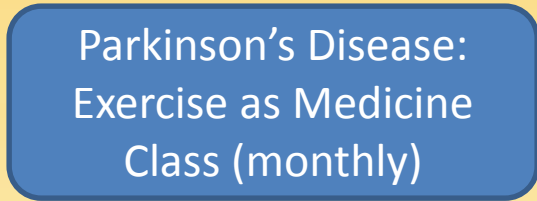
Successful Treatment Strategy



EARLY referral from Neurology
HIGHLY encouraged



Annual Neurology follow-up
with re-referral to PT for annual
re-assessment



*Time with 1:1 PT
Dependent upon a person with PD's needs

E.Vestal, PT, DPT, NCS

When to Start Medications

- Time of diagnosis?
- Delaying possible side effects
 - Motor fluctuations
 - Dyskinesia
 - Behavioral complications
- Assessing motor disability
 - School or job performance
 - Activities of daily living

Informed Patient

- An informed and empowered patient is more likely seek appropriate care
- Most people with Parkinson's on the webinar today are informed patients
- Informed patients are usually followed by a Neurologist
- This reflects the **minority** of the PD population
- Could reflect uneven health care coverage with financial limitations
- Could also reflect uneven and limited spread of specialists

Creating a Sense of Community

- Patient ownership and empowerment
- Disclosure of diagnosis
- Involving loved ones
- Connecting with local support organizations
- Where to find resources

Thank You!



“Since my Parkinson’s diagnosis in 2013, I have learned to doodle. Creativity keeps my mind and body focused on something besides Parkinson’s and my tremors make my art more interesting. Doodling has become a thirst that must be quenched.”

*March Texas Spring Color, Sharon Skindell
Creativity and Parkinson’s Project*

Questions and Discussion



Resources



Parkinson's HelpLine

- Available at **(800) 457-6676** or info@pdf.org
- Monday through Friday
- 9:00 AM – 5:00 PM ET



Centers of Excellence

- Worldwide network of 42 leading academic medical centers
- Search for one near you at www.parkinson.org/search



Fact Sheets and Brochures

- Parkinson's Q&A
- Seeking Out a PD Specialist
- Secrets, Myths & Misconceptions



Video

- Diagnosis Parkinson's Disease: You are Not Alone